

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Health and social care directorate

Quality standards and indicators

Briefing paper

Quality standard topic: Dementia

Output: Prioritised quality improvement areas for development.

Date of Quality Standards Advisory Committee meeting: 21 November 2018

Contents

1	Introduction	2
2	Overview	2
3	Summary of suggestions	5
4	Suggested improvement areas	8
	Appendix 1: Review flowchart	57
	Appendix 2: Suggestions from stakeholder engagement exercise – registered stakeholders.....	58

1 Introduction

This briefing paper presents a structured overview of potential quality improvement areas for dementia. It provides the committee with a basis for discussing and prioritising quality improvement areas for development into draft quality statements and measures for public consultation.

1.1 Structure

This briefing paper includes a brief description of the topic, a summary of each of the suggested quality improvement areas and supporting information.

If relevant, recommendations selected from the key development source below are included to help the committee in considering potential statements and measures.

1.2 Development sources

The key development sources referenced in this briefing paper are:

- [Dementia: assessment, management and support for people living with dementia and their carers](#) (2018) NICE guideline NG97.

This guideline is an update of the NICE guideline on dementia (CG42, published November 2006) and replaces it. It also replaces recommendation 1.3 in the NICE technology appraisal guidance on donepezil, galantamine, rivastigmine and memantine for the treatment of Alzheimer's disease (TA217).

- [Dementia, disability and frailty in later life – mid-life approaches to delay or prevent onset](#) (2015) NICE guideline NG16.

2 Overview

2.1 Focus of quality standard

This quality standard will cover prevention of dementia, and assessment, management and health and social care support for adults with dementia.

It will replace the existing NICE quality standards for dementia ([Dementia: support in health and social care](#) and [Dementia: independence and wellbeing](#)). The topic was identified for update following an annual review of quality standards. The review identified that there had been changes in the areas for improvement, and an updated guideline on [Dementia: assessment, management and support for people living with dementia and their carers](#) has also been published. This is also an opportunity to combine the health care and social care quality standards.

2.2 Definition

Dementia is a term used to describe a range of cognitive and behavioural symptoms that can include:

- memory loss
- problems with reasoning and communication
- changes in personality
- reduction in ability to carry out daily activities.

The most common types of dementia are:

- Alzheimer's disease
- vascular dementia
- mixed dementia
- dementia with Lewy bodies
- frontotemporal dementia.

Dementia is a progressive condition, which means that the symptoms will gradually get worse. This progression will vary from person to person and each will experience dementia in a different way – people may often have some of the same general symptoms, but the degree to which these affect each person will vary¹.

2.3 Incidence and prevalence

NHS Digital August 2018 data² show that in England:

- 458,562 people have a coded dementia diagnosis
- The estimated diagnosis rate for people 65 years or older is 67.8%.

Alzheimer's Research UK³ report that in the UK:

- 850,000 people are estimated to be living with dementia
- 537,097 people have a coded dementia diagnosis
- 42,000 people with dementia are under 65
- The estimated diagnosis rate for people 65 years or older is 66%
- The current cost of dementia is £26bn

1 million people will have dementia by 2025.

¹ Social Care Institute for Excellence, [Dementia Gateway](#) (Accessed October 2018)

² NHS Digital, [Recorded dementia diagnoses – August 2018](#) (Accessed November 2018)

³ Alzheimer's Research UK, [Dementia statistics hub](#) (Accessed November 2018)

2.4 *Management*

Dementia is a progressive condition, which means that the symptoms become more severe over time. People with dementia and their families have to cope with changing abilities such as the capacity to make decisions about major life events as well as day-to-day situations. No two people with dementia are affected in the same way and so the right care and support is unique to each person.

Many people with dementia will have complex needs compounded by a range of co-morbidities. Alzheimer's Research UK⁴ report that:

- 91.8% of people living with dementia have another health condition
- 78.5% have 2 or more additional health conditions
- 44.7% have 4 or more additional health conditions.

The UK Government's strategy⁵ for transforming dementia care aims to:

- improve diagnosis, assessment and care for people living with dementia
- ensure that all people living with dementia have equal access to diagnosis
- provide all NHS staff with training on dementia appropriate to their role
- ensure that every person diagnosed with dementia receives meaningful care.

Initial assessment of people with suspected dementia can take place in non-specialist settings (such as general practices). Before referral to specialist diagnostic services (such as memory clinics), reversible causes of cognitive decline are ruled out. Dementia is not yet curable, however medicines and other interventions can help lessen symptoms and support people with dementia to live well.

Key components of supporting people with dementia include:

- involving people in decision about their care
- advance care planning
- care co-ordination
- managing transitions
- supporting carers.

⁴ Alzheimer's Research UK, [Dementia statistics hub](#) (Accessed November 2018)

⁵ Department of Health and Social Care, [Prime Minister's challenge on dementia](#) 2020.

3 Summary of suggestions

3.1 Responses

In total 43 stakeholders responded to the 2-week engagement exercise 26/07/18-23/08/18.

Stakeholders were asked to suggest up to 5 areas for quality improvement. Specialist committee members were also invited to provide suggestions. The responses have been merged and summarised in table 1 for further consideration by the Committee.

NHS Improvement's patient safety division submitted comments during stakeholder engagement, which are summarised in this paper and can be found in full in appendix 2.

Full details of all the suggestions provided are given in appendix 2 for information.

Table 1 Summary of suggested quality improvement areas

Suggested area for improvement	Stakeholders
Approaches to prevent or delay onset of dementia <ul style="list-style-type: none"> • Raising awareness • Prevention 	<ul style="list-style-type: none"> • DIG, RCPsych, RP Ltd., SCM 1 • ARUK, BIHS, NCCPH, NWBNHSFT, RCN, SCM 1, SCM 2
Diagnosis <ul style="list-style-type: none"> • Earlier diagnosis • Diagnosis 	<ul style="list-style-type: none"> • ARUK, AS, DIG, NHSEDPT, RP Ltd., SCM 3 • ABN, Biogen, ICHNHST, LDCN, Mencap, NCD, NHSEDPT, PUK, RP Ltd., RCGP, RLBUNHST, SCM 4
Care coordination <ul style="list-style-type: none"> • Coordinated care • Care planning • Making services accessible 	<ul style="list-style-type: none"> • ADASS, AS, DSA, LDCN, RCN, RCSLT, SCM 5, SCM 6, SCM 7 • AS, CRE, LDCN, NA Ltd., NHSEDPT, SCM 1, SCM 5, SCM 8 • AHL
Management <ul style="list-style-type: none"> • Interventions to promote cognition, independence and wellbeing • Pharmacological interventions • Managing non-cognitive symptoms • Personalised interventions 	<ul style="list-style-type: none"> • PUK, SCM 3, SCM 8, SSL, • RCN, SCM 4, SCM 6 • LDCN, NHSEDPT, RCOT, SCM 5 • Mencap, NAL, RCPsych, SCM 5
Assessing and managing other long-term conditions in people living with dementia	AHL, ARUK, BAAP, CO, OC, RCN, SCM 8
Risks during hospital admission	ADASS, SCM 4, SCM 8

Suggested area for improvement	Stakeholders
Involving people living with dementia in decisions about their care <ul style="list-style-type: none"> • Involving people in decision making • Providing information 	<ul style="list-style-type: none"> • AFT-UK, RCN, RCSLT, RLBUNHST, SPRUUY, SCM 3 • ARUK, AS, ABN, DSA, NCD, NIHR, NA Ltd., NHSEDPT, ONDDR, RCPsych, SCOR, SCM 2, SCM 3, SCM 4, SCM 5, SCM 6, SCM 7
Palliative care <ul style="list-style-type: none"> • Advance care planning • Palliative care 	<ul style="list-style-type: none"> • CID, Mencap, NCD, NHSEDPT, RCGP, RCPsych, SCM 4, SCM 5, SCM 7 • NA Ltd., NWBNHSFT, RCPsych, RCSLT, SCM 8
Supporting carers	ADASS, CT, LDCN, NWBNHSFT, PUK, RCGP, RCN, RCPsych, SCM 2, SCM 7, SCM 8
Additional areas <ul style="list-style-type: none"> • Staff training • Nutrition • Equality • Learning disabilities • Use of superabsorbent polymer gel granules 	<ul style="list-style-type: none"> • ARUK, AS, ADASS, DIG, DSA, Mencap, NLGBTP, RCPsych, RCSLT, RLBUNHST, Sfc, SSL • BDA, NHSIPS • NLGBTP, NA Ltd. • DSA, Mencap, SCM 6 • NHSIPS

Stakeholders
ABN, Association of British Neurologists ADASS, Association of Directors of Adult Social Services AFT-UK, Association for Family Therapy and Systemic Practice AHL, Action on Hearing Loss ARUK, Alzheimer's Research UK AS, Alzheimer's Society Biogen BAAP, British Association of Audiovestibular Physicians BDA, British Dietetic Association BIHS, British and Irish Hypertension Society CID, Compassion in Dying CO, College of Optometrists CRE, Care and Repair England CT, Carer's Trust DIG, Dementia Industry Group DSA, The Down's Syndrome Association ICHNHST, Imperial College Healthcare NHS Trust LDCN, London Dementia Clinical Network Mencap NA Ltd., Neurology Academy Limited NCCPH, Nottinghamshire County Council Public Health NCD, National Clinical Director NIHR, National Institute for Health Research NLGBTP, The National LGB&T Partnership NHSEDPT, NHS England Dementia Policy Team NHSIPS, NHS Improvement Patient Safety

NWBNHSFT, North West Boroughs NHS Foundation Trust
OC, Optical Confederation
ONDDR, Office of the National Director for Dementia Research
PUK, Parkinson's UK
RCGP, Royal College of General Practitioners
RCN, Royal College of Nursing
RCOT, Royal College of Occupational Therapists
RCPsych, Royal College of Psychiatrists
RCSLT, Royal College Of Speech & Language Therapists
RLBUHNSHT, Royal Liverpool & Broadgreen University Hospitals NHS Trust
RP Ltd., Roche Products Limited
SCOR, The Society and College of Radiographers
SCM, Specialist Committee Member
SfC, Skills for Care
SPRUUY, Social Policy Research Unit, University of York
SSL, Sunrise Senior Living

3.2 *Identification of current practice evidence*

Bibliographic databases were searched to identify examples of current practice in UK health and social care settings; 1434 papers were identified for dementia. In addition, 149 papers were suggested by stakeholders at topic engagement and 11 papers internally at project scoping.

Of these papers, 30 have been included in this report and are included in the current practice sections where relevant. Appendix 1 outlines the search process.

4 Suggested improvement areas

4.1 Approaches to prevent or delay onset of dementia

4.1.1 Summary of suggestions

Raising awareness

Stakeholders highlighted the importance of raising public awareness of how to prevent dementia through healthy lifestyles, and how to detect dementia. They stated that the early signs of dementia are not well known, but by making the public and health professionals aware of them, it could lead to earlier detection and improved outcomes. Aligning with the NHS Health Check programme was also suggested.

Prevention

Stakeholders highlighted that dementia prevention and risk reduction could be achieved through modifying lifestyle and health factors, such as blood pressure control, alcohol, stress, weight, smoking and physical activity. Stakeholders suggested that lifestyle changes could be included in health promotion programmes and Making Every Contact Count. Stakeholders felt that more funding goes to managing dementia rather than prevention, and the cost savings from prevention work are not considered.

4.1.2 Selected recommendations from development source

Table 2 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 2 to help inform the committee's discussion.

Table 2 Specific areas for quality improvement

Suggested quality improvement area	Suggested source guidance recommendations
Raising awareness	Raising awareness of risk of dementia, disability and frailty NICE NG16 Recommendation 3 Delivering services to promote behaviour change NICE NG16 Recommendation 9
Prevention	Providing advice on reducing the risks of dementia, disability and frailty at every appropriate opportunity NICE NG16 Recommendation 11

Raising awareness

Raising awareness of risk of dementia, disability and frailty

NICE NG16 – Recommendation 3

Public Health England, Health Education England and NHS England should:

- Commission national, regional and local campaigns aimed at the public and health and social care professionals to show how the risk of dementia, disability and frailty can be reduced and to promote the concept of keeping mentally and physically healthy. Campaigns should use a range of media and formats to reach as many people as possible. See NICE's pathway on [preventing type 2 diabetes: population and community interventions](#).
- Use the campaigns to provide messages such as:
 - Sustained ill health in old age is not inevitable. The risk of developing dementia, disability and frailty may be reduced and, for some, onset can be delayed and the severity of the conditions reduced.
 - Smoking, lack of physical activity, alcohol consumption, poor diet, being overweight or obese and loneliness are all avoidable risk factors for dementia, disability and frailty.
 - The earlier in life that healthy changes are made, the greater the likelihood of reducing the risk of dementia, disability and frailty.
 - There are health gains that can be made by changing behaviours even in mid-life.
 - Healthy behaviours are more likely to be maintained if they are built into everyday life.
- Ensure messages do not stigmatise people by suggesting that people who develop dementia, disability or frailty are at fault. Tell people that although some important risks can be reduced, there may be others such as genetic susceptibility that cannot be changed. It is still worth reducing risks where possible, even if there are unmodifiable risks, as this can increase the years spent in good health.

Delivering services to promote behaviour change

NICE NG16 – Recommendation 9

Public Health England, commissioners, local authorities, providers of NHS services, NHS Health Checks and other providers of [behaviour change programmes](#) should:

- Ensure programmes to prevent non-communicable chronic diseases share resources and expertise nationally and locally to maximise coverage and impact

(see NICE's pathways on [preventing type 2 diabetes: population and community interventions](#) and [behaviour change: individual approaches](#)).

- Work together to deliver services that address the needs of people with multiple risk factors as well as for those with single risk factors.
- Emphasise the need for, and help people to maintain, healthy behaviours throughout life (such as stopping smoking, being physically active, drinking less alcohol, eating healthily and being a healthy weight).
- Help people identify and address their personal barriers that prevent them from making changes to improve their health.
- Make information and services available to all (see the [Equality Act 2010](#)). Additionally, target these towards those with the greatest need whenever possible.
- Develop the NHS Health Check programme to promote opportunities in mid-life to reduce the behavioural risk factors for dementia, disability and frailty by:
 - tailoring the advice component of the NHS Health Check programme for different age groups
 - adding dementia prevention advice to all health checks.
- Use audit to help improve the effectiveness of services.

Prevention

Providing advice on reducing the risks of dementia, disability and frailty at every appropriate opportunity

NICE NG16 – Recommendation 11

Public and third sector providers (such as local authorities, leisure services, emergency services and health and social care providers) should:

- Use routine appointments and contacts to identify people at risk of dementia, disability and frailty (for example, appointments with a GP or practice nurse, when attending leisure centre classes, or visiting a community pharmacy).
- Take advantage of times in people's lives when substantial change occurs. (Examples include: retirement, when children leave home, when starting to care for older relatives or grandchildren, or during the menopause.) These are times when people may consider adopting new healthy behaviours, or may be at risk of adopting unhealthy ones.
- Whenever the opportunity arises give people advice on how to reduce the risk factors for dementia, disability and frailty or refer them to specialist services when necessary (see [recommendation 9](#) in NICE's guideline on behaviour change: individual approaches).

4.1.3 Current UK practice

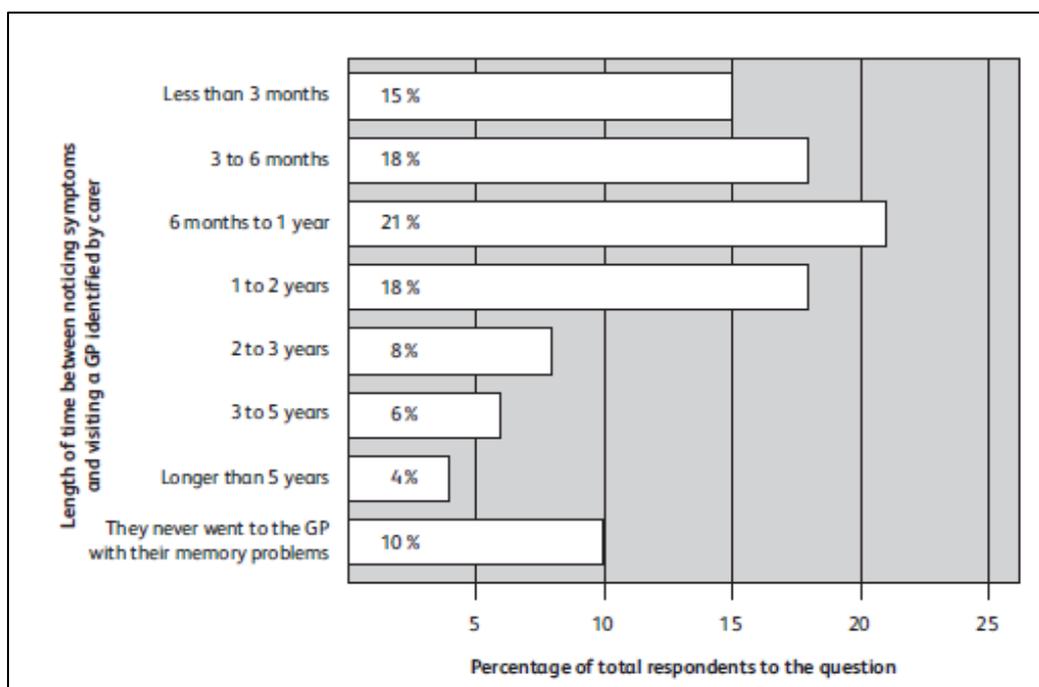
Raising awareness

YouGov surveys commissioned by Alzheimer’s Research UK in 2015 and 2016⁶ revealed that:

- 23% identified dementia as caused by brain disease or degeneration
- 46% identified dementia as loss of memory
- 3/4 people are unaware that they can affect their risk of developing dementia
- 3/4 people didn’t think giving up smoking could reduce their risk
- 40% of people would adopt a healthier lifestyle to reduce their risk
- 48% of 45-54 year olds would be more likely to adopt a healthy lifestyle.

The House of Commons All-Party Parliamentary Group on Dementia report from 2012⁷ includes findings from 43 pieces of written evidence, 1,075 completed questionnaires from people with dementia, carers, professionals, organisations and interested parties, and oral evidence from witnesses. The report highlights poor public understanding of dementia in particular, the symptoms of dementia and the benefits of an early diagnosis. This was partly responsible for delays between symptoms of dementia arising and people going to see a professional for advice.

Figure 1: Length of time between noticing symptoms of dementia and going to the GP, as identified by carers, family or friends from questionnaire (Source: House of Commons All-Party Parliamentary Group on Dementia report)



⁶ Alzheimer’s Research UK, [Dementia statistics hub](#) (Accessed November 2018)

⁷ House of Commons All-Party Parliamentary Group on Dementia (2012) [Unlocking diagnosis - The key to improving the lives of people with dementia](#)

Figure 1 shows fewer than 15% of carers, family members or friends said the person saw a GP within 3 months of noticing symptoms, 36% waited more than a year before going to the GP, and 10% never went to the GP.

52% of respondents with dementia, and 28% of carers, thought that memory problems are normal as you get older.

Health professionals cited people not seeking professional help as the main reason for under diagnosis. More than 76% of GPs and 70% of memory specialists agreed that people do not come forward to professionals with problems with their memory.

Prevention

Public Health England's Dementia Profile⁸ includes a section on 'preventing well', with data relating to lifestyle factors for people in England:

- Smoking prevalence (current smokers) in adults (2016) – 15.5%
- Physically inactive adults (2016/17) – 28.7%
- Overweight or obese adults (2015/16) – 61.3%
- Hypertension prevalence (2016/17) all ages – 13.8%
- Hospital admissions for alcohol-related conditions in 40-64 year olds (2016/17) – 887 (Directly standardised rate per 100,000)

4.1.4 Resource impact

The resource impact report for NG16 did not identify any recommendations with a significant resource impact (>£1m in England each year).

The resource impact report for NG16 estimated savings from preventing or delaying dementia for 1 year for the public sector would be £15,050 per person with dementia.

It was estimated that around 56% of people develop dementia due to modifiable risk factors, so based on a recorded prevalence of dementia of approximately 451,700 (NHS Digital February 2018), up to 253,000 people could have their dementia delayed.

For every 1% (2,530) of the population for whom dementia is delayed for a year, a saving of approximately £38 million per annum could be achieved, based on the estimated savings above.

⁸ Public Health England (2018) [Dementia Profile](#)

4.2 *Diagnosis*

4.2.1 Summary of suggestions

Earlier diagnosis

Stakeholders highlighted the benefits of earlier diagnosis of dementia, in particular diagnosing Alzheimer’s disease before clinical symptoms are present. Examples given of the benefits include earlier access to care, earlier treatment and receiving information sooner, which can lead to better outcomes and delayed progression. Stakeholders discussed diagnosis rates, including the importance of reaching targets and improving diagnosis rates to ensure that people are receiving a diagnosis so that they can access information and support.

Diagnosis

Stakeholders raised the importance of accurate and timely diagnosis, referencing the 6 week timeframe from referral to starting treatment in the [NHS Operational Planning and Contracting Guidance 2017-19](#). Access to cerebrospinal fluid biomarkers and PET scanning was suggested as a way of ensuring accurate and earlier diagnosis. Interpretation of brain imaging by radiologists with appropriate training to ensure the quality of the scan report was also raised. Stakeholders felt that identifying a dementia subtype in a specialist diagnostic service is a quality improvement area, as knowing the subtype will determine how dementia is managed. Getting a diagnosis in the right setting also allows for planning services and coordinating care.

4.2.2 Selected recommendations from development source

Table 3 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 3 to help inform the committee’s discussion.

Table 3 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Earlier diagnosis	Not directly covered in NICE NG16 or NG97 and no recommendations are presented
Diagnosis	Initial assessment in non-specialist settings NICE NG97 Recommendations 1.2.6 and 1.2.7 Diagnosis in specialist dementia diagnostic services NICE NG97 Recommendations 1.2.9, 1.2.14, 1.2.15, 1.2.20, 1.2.23, 1.2.26

Diagnosis

Initial assessment in non-specialist settings

NICE NG97 – Recommendation 1.2.6

Refer the person to a specialist dementia diagnostic service (such as a memory clinic or community old age psychiatry service) if:

- reversible causes of cognitive decline (including delirium, depression, sensory impairment [such as sight or hearing loss] or cognitive impairment from medicines associated with increased anticholinergic burden) have been investigated **and**
- dementia is still suspected.

NICE NG97 – Recommendation 1.2.7

If the person has suspected rapidly-progressive dementia, refer them to a neurological service with access to tests (including cerebrospinal fluid examination) for Creutzfeldt–Jakob disease and similar conditions.

Diagnosis in specialist dementia diagnostic services

NICE NG97 – Recommendation 1.2.9

Diagnose a dementia subtype (if possible) if initial specialist assessment (including an appropriate neurological examination and cognitive testing) confirms cognitive decline and reversible causes have been ruled out.

NICE NG97 – Recommendation 1.2.14

Only consider further tests (recommendations 1.2.15–28) if:

- it would help to diagnose a dementia subtype **and**
- knowing more about the dementia subtype would change management.

NICE NG97 – Recommendation 1.2.15

If the diagnosis is uncertain (see recommendation 1.2.14) and Alzheimer's disease is suspected, consider either:

- FDG-PET (fluorodeoxyglucose-positron emission tomography-CT), or perfusion SPECT (single-photon emission CT) if FDG-PET is unavailable
- or**
examining cerebrospinal fluid for:

- either total tau or total tau and phosphorylated-tau 181 and
- either amyloid beta 1–42 or amyloid beta 1–42 and amyloid beta 1–40.

If a diagnosis cannot be made after one of these tests, consider using the other one.

NICE NG97 – Recommendation 1.2.20

If the diagnosis is uncertain (see recommendation 1.2.14) and dementia with Lewy bodies is suspected, use ¹²³I-FP-CIT SPECT.

NICE NG97 – Recommendation 1.2.23

If the diagnosis is uncertain (see recommendation 1.2.14) and frontotemporal dementia is suspected, use either:

- FDG-PET **or**
- perfusion SPECT.

NICE NG97 – Recommendation 1.2.26

If the dementia subtype is uncertain and vascular dementia is suspected, use MRI. If MRI is unavailable or contraindicated, use CT.

4.2.3 Current UK practice

Earlier diagnosis

NHS Digital data⁹ shows that in August 2018, 67.8% of the 653,817 people aged over 65 estimated to have dementia in England have a coded diagnosis, ranging from 61.7% in the South West of England, to 72.7% in the North of England.

The Royal College of Psychiatrists conducted an audit of memory clinics in England¹⁰ between 15 September and 31 October 2014 with a response rate of 82% (182 out of 222 memory clinics). It reported that the percentage of people being diagnosed in the early stages of dementia increased from 49% in 2013 to 52% in 2014. However, it also states that some clinics are seeing the majority of people presenting with moderate to severe stages of dementia.

NHS England data on Dementia Assessment and Referral¹¹ reports the proportion of patients aged 75 and over admitted as an emergency for more than 72 hours in England who have been identified as potentially having dementia, who are appropriately assessed and, where appropriate, referred on to specialist services. Data for quarter 1 of 2018/19 shows that 86.8% of patients had case finding applied

⁹ NHS Digital (2018) [Recorded Dementia Diagnoses - August 2018](#)

¹⁰ Royal College of Psychiatrists (2015) [Second English National Memory Clinics Audit Report](#)

¹¹ NHS England (2018) [Dementia Assessment and Referral](#)

(range 1% to 100%), 92.5% had a diagnostic assessment (range 8% to 100%) and 94.3% of cases were referred (range 0% to 100%).

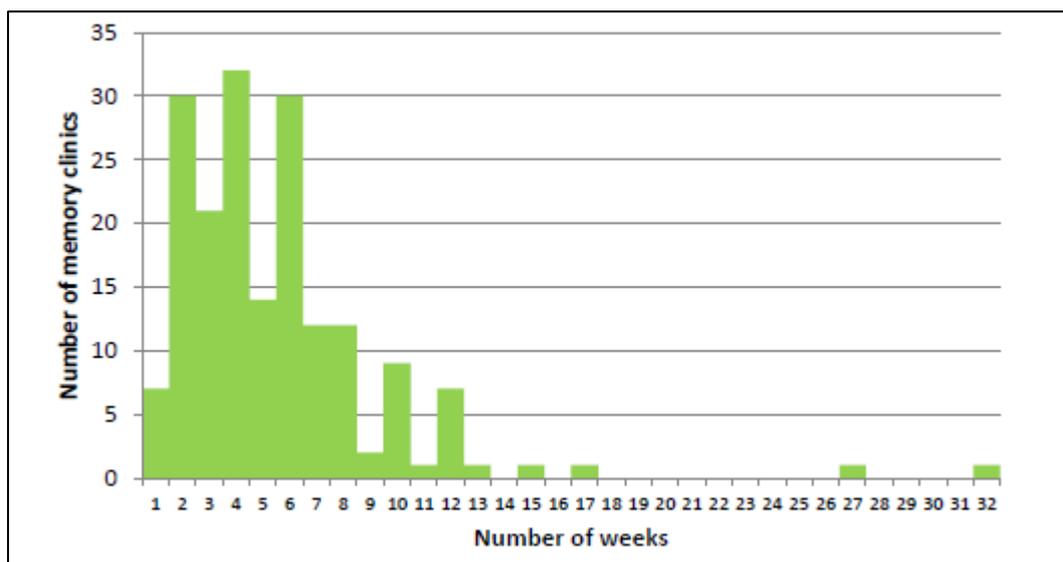
Diagnosis

The Royal College of Psychiatrists' audit of memory clinics¹² reports that between 2013 and 2014:

- the number of patients seen by memory clinics increased by 31% on average, although available capacity did not increase significantly
- average waiting time from referral to assessment increased from 5.2 to 5.4 weeks
- waiting time from assessment to diagnosis increased from 8.4 to 8.6 weeks
- receipt of referral and first assessment varied between 1 week to 32 weeks
- services meeting the 6 weeks target between referral and first assessment fell from 75.7% to 73.6%
- average waiting time between the first appointment and receiving a diagnosis also increased slightly varying from 0 weeks (delivering a 'one-stop shop' where the diagnosis is given the same day as the assessment) to 40 weeks' wait, with the average at 8.6 weeks
- average total wait between referral and diagnosis increased slightly from 13.48 to 13.9 weeks, with the wait for diagnosis accounting for approximately two-thirds of that time and varied from 2 to 56 weeks.

Figure 2 shows that most clinics fall between 2-24 weeks' wait from referral to diagnosis. Furthermore, 80.2% clinics deliver a diagnosis within 18 weeks of referral.

Figure 2: Number of weeks' wait between memory clinic receipt of referral and first assessment (Source: Royal College of Psychiatrists memory service audit)



¹² Royal College of Psychiatrists (2015) [Second English National Memory Clinics Audit Report](#)

Alzheimer's Society commissioned a poll of 1,013 GPs through MedeConnect Healthcare Insight to seek their views on access to post-diagnosis support¹³. The results included:

- 27% of GPs said they would be less likely to refer people with suspected dementia for a diagnosis if there isn't enough local support in place
- 23% of GPs would be less likely to diagnose/refer for a diagnosis where it is not clear what treatment or support they will get after the diagnosis
- 33% of GPs would be less likely to diagnose/refer for a diagnosis someone who lives in a care home
- 25% of GPs would be less likely to diagnose/refer for a diagnosis where the person's dementia is already very advanced
- 16% would be less likely to diagnose/refer for a diagnosis where the person has other complex health conditions.

4.2.4 Resource impact

This area was not included in the resource impact report for NG97. No changes were made to the original guideline that would have a significant resource impact (>£1m in England each year).

¹³ Alzheimer's Society (2015) [Dementia 2015: Aiming higher to transform lives](#)

4.3 Care coordination

4.3.1 Summary of suggestions

Coordinated care

Stakeholders raised the importance of a person with dementia having a single named person to coordinate care so that they have access to personalised support and information, and their changing needs are met. Stakeholders highlighted that various professionals will be involved in the care of a person with dementia, so it is valuable to have someone to coordinate this. Improving partnership working between health and social care to ensure joined up working and better communication was also raised. Stakeholders also felt that community-based models of care providing integrated health and social care closer to home would help people to stay at home, and out of hospital or long-term care.

Care planning

Stakeholders stated that people with dementia should have a care plan that is reviewed annually, and developed in partnership with them, as their needs are complex and will change over time. Stakeholders felt that identifying and planning actions around the person's home environment, such as repairs, home adaptations, available technology and moving options, should be included in the care plan. Having systems in place to share care plans and transfer information about the person with dementia between settings, such as from home to care home, was also raised as a way of ensuring that care is person-centred and crises are prevented.

Making services accessible

Improving the accessibility of dementia services for people with hearing loss who may have different communication needs was raised. Stakeholders suggested ways that services could be adapted to support people with hearing loss, such as offering text and email as alternative methods of contacting people to telephone calls, or offering support from a British Sign Language interpreter at face-to-face meetings.

4.3.2 Selected recommendations from development source

Table 4 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 4 to help inform the committee's discussion.

Table 4 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Coordinated care	Care coordination NICE NG97 Recommendations 1.3.1 and 1.3.2
Care planning	Care coordination NICE NG97 Recommendation 1.3.2 Transferring information between services and care settings NICE NG97 Recommendations 1.3.3 to 1.3.5
Making services accessible	Making services accessible NICE NG97 Recommendation 1.3.6

Coordinated care

Care coordination

NICE NG97 – Recommendation 1.3.1

Provide people living with dementia with a single named health or social care professional who is responsible for coordinating their care.

NICE NG97 – Recommendation 1.3.2

Named professionals should:

- arrange an initial assessment of the person's needs, which should be face to face if possible
- provide information about available services and how to access them
- involve the person's family members or carers (as appropriate) in support and decision-making
- give special consideration to the views of people who do not have capacity to make decisions about their care, in line with the principles of the [Mental Capacity Act 2005](#)
- ensure that people are aware of their rights to and the availability of local advocacy services, and if appropriate to the immediate situation an independent mental capacity advocate
- develop a care and support plan, and:
 - agree and review it with the involvement of the person, their family members or carers (as appropriate) and relevant professionals
 - specify in the plan when and how often it will be reviewed
 - evaluate and record progress towards the objectives at each review
 - ensure it covers the management of any comorbidities

- provide a copy of the plan to the person and their family members or carers (as appropriate).

Care planning

NICE NG97 – Recommendation 1.3.2 (please see above)

Transferring information between services and care settings

NICE NG97 – Recommendation 1.3.3

When developing care and support plans and advance care and support plans, request consent to transfer these to different care settings as needed.

NICE NG97 – Recommendation 1.3.4

Service providers should ensure that information (such as care and support plans and advance care and support plans) can be easily transferred between different care settings (for example home, inpatient, community and residential care).

NICE NG97 – Recommendation 1.3.5

Staff delivering care and support should maximise continuity and consistency of care. Ensure that relevant information is shared and recorded in the person's care and support plan.

Making services accessible

NICE NG97 – Recommendation 1.3.6

Service providers should design services to be accessible to as many people living with dementia as possible, including:

- people who do not have a carer or whose carer cannot support them on their own
- people who do not have access to affordable transport, or find transport difficult to use
- people who have other responsibilities (such as work, children or being a carer themselves)
- people with learning disabilities, sensory impairment (such as sight or hearing loss) or physical disabilities
- people who may be less likely to access health and social care services, such as people from black, Asian and minority ethnic groups.

4.3.3 Current UK practice

Coordinated care

The National Audit of Dementia Care in General Hospitals 2016-2017¹⁴ received data from 199 hospitals (98% of eligible hospitals), which included organisational checklists, staff questionnaires, casenote audits and carer questionnaires. The audit reported that:

- 91% of hospitals (180/199) have a system in place to ensure all staff in the ward are aware of the person's dementia
- 70% of hospitals (140/199) have a system to ensure staff from other areas are aware of the person's dementia
- 50% of staff (6203/12457) frequently spoke as a team about the care/support given to people with complex needs, 37% (4636/12457) said they occasionally spoke and 13% (1618/12457) reported they almost never or never did
- a named person or team was identified to coordinate the discharge plan in 82% (5807/7083) of casenotes
- 16% (178/1112) of staff suggestions about communication of dementia wanted better communication of patients' dementia between hospital departments

The All-Party Parliamentary Group (APPG) on Dementia report from 2016¹⁵ received around 30 evidence submissions around the barriers and solutions to supporting people with dementia living with multiple long-term conditions from voluntary organisations, the Royal Colleges, academics, practitioners, service providers, commissioners and people affected by dementia. They also heard from expert witnesses over 2 oral evidence sessions.

Some people told the APPG that:

- they were expected to attend over 20 different agencies, bodies and organisations to access the care and support they needed
- people routinely lost track of appointments or had to prioritise between them because they didn't have the capacity to attend each one
- many felt that healthcare professionals were not helping them to plan or co-ordinate their care properly. Moreover, they felt that they had to repeat their story to each professional as no one had overall oversight of their health or care.

Alzheimer's Society's poll of 1,013 GPs¹⁶ reported that:

¹⁴ Royal College of Psychiatrists (2017). [National Audit of Dementia care in general hospitals 2016-2017: Third round of audit report](#)

¹⁵ All-Party Parliamentary Group on Dementia (2016) [Dementia rarely travels alone: Living with dementia and other conditions](#)

¹⁶ Alzheimer's Society (2015) [Dementia 2015: Aiming higher to transform lives](#)

- 73% of GPs agree that it is confusing for people with dementia and carers to navigate the health and social care system
- 1 in 5 (20%) said that there are integrated services for people with dementia in their area that deliver effective person-centred care, 46 % said that there were not.

The Alzheimer's Society report on the cost of dementia¹⁷ was based on qualitative research from 5 listening events with people affected by dementia, social care professionals and dementia lead nurses. They gathered evidence and testimony from over 70 people to get an in-depth understanding of the challenges they face day-in and day-out to get the care they need. The report found that lack of communication between staff and disjointed care pathways meant carers did not always know about the person's situation. For example, they weren't aware someone had fallen during the night and bruised themselves.

Care planning

NHS Digital's Quality and Outcomes Framework data 2017/18¹⁸ includes an indicator on the percentage of patients diagnosed with dementia whose care plan has been reviewed in a face-to-face review in the preceding 12 months. 83% of practices in England achieved this indicator (down from 83.7% in 2016/17) ranging from 81% in the South West to 84.3% in the North of England

Analysis by Age UK¹⁹ of data from 7,185 GP practices in England found that 1 in 3 people with dementia don't have a care plan:

- 458,461 people had a recorded diagnosis of dementia in November 2017. However, only 282,573 had a new care plan, or at least 1 care plan review on record in the last year
- at 24.7% of practices, only 50% or fewer people with a dementia diagnosis had received a new care plan, or had their existing care plan reviewed in the last 12 months.

Making services accessible

No current practice information identified.

¹⁷ Alzheimer's Society (2018) [Dementia – the true cost: Fixing the care crisis.](#)

¹⁸ NHS Digital (2018) [Quality and Outcomes Framework, Achievement, prevalence and exceptions data - 2017-18](#)

¹⁹ Age UK (2018) [1 in 3 with dementia diagnosis don't get NHS follow up support they're supposed to](#)

4.3.4 Resource impact

The resource impact assessment work for NG97 identified recommendation 1.3.1 as a recommendation which may have a resource impact. Feedback suggests that this recommendation has not been well implemented and there is wide variation in practice.

The key cost driver is the staff cost of appointing care coordinators. This may be achieved either using existing staff differently or appointing additional staff. The cost of each additional named health or social care professional could be around £38,200 (for a band 6 nurse, mid-point plus on-costs, [Agenda for Change 2017-18](#)).

The potential benefits of implementing this recommendation may include:

- reduced hospital admissions
- reduced contact with healthcare professionals including GPs, psychiatrists, specialist mental health services and social workers
- delayed admission to care homes
- help to access services and support available
- improved wellbeing of carer's for people with dementia

Placements in a residential home are estimated to cost £28,860-£39,520 per annum depending on whether the provider is for- or not-for profit, whether it is a dementia residential home and whether the room is single or shared (PSSRU, Unit Costs of Health and Social Care 2017).

4.4 Management

4.4.1 Summary of suggestions

Interventions to promote cognition, independence and wellbeing

Stakeholders highlighted the importance of cognitive assessment so that activities to promote wellbeing are tailored to the individual's abilities and enable them to engage in them. Stakeholders also felt that Cognitive Rehabilitation Therapy supports the emotional wellbeing of individuals with dementia. Stakeholders felt that enabling people with dementia to maintain daily activities can improve function for longer and reduce the need for medication or support from carers.

Pharmacological interventions

Ensuring that systems are in place so that people with Alzheimer's disease prescribed an AChE inhibitor can be identified, and have access to memantine if needed, was raised as an area for quality improvement. Stakeholders also raised the importance of regular medication reviews to consider discontinuing or minimising the use of medications that can cause cognitive impairment.

Managing non-cognitive symptoms

Stakeholders highlighted that psychosocial and environmental interventions should be offered to support people with behavioural and psychological symptoms of dementia, and to prevent unnecessary admissions to hospital and use of antipsychotic medication. Stakeholders suggested that training care staff to understand and respond to challenging behaviour would enable this.

Personalised interventions

Stakeholders suggested that providing subtype-specific interventions, and need and age-appropriate services, as well as personalising psychological interventions for people with dementia, would improve the uptake of interventions, make treatment more appropriate and improve outcomes.

4.4.2 Selected recommendations from development source

Table 5 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 5 to help inform the committee's discussion.

Table 5 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Interventions to promote cognition, independence and wellbeing	Interventions to promote cognition, independence and wellbeing NICE NG97 Recommendations 1.4.1 to 1.4.4
Pharmacological interventions	Pharmacological interventions for dementia NICE NG97 Recommendations 1.5.4 and 1.5.5 Medicines that may cause cognitive impairment NICE NG97 Recommendations 1.6.2 and 1.6.4
Managing non-cognitive symptoms	Managing non-cognitive symptoms NICE NG97 Recommendations 1.7.1, 1.7.2, 1.7.3, 1.7.8 and 1.7.9
Personalised interventions	Depression and anxiety NICE NG97 Recommendations 1.7.11 and 1.7.12

Interventions to promote cognition, independence and wellbeing

NICE NG97 – Recommendation 1.4.1

Offer a range of activities to promote wellbeing that are tailored to the person's preferences.

NICE NG97 – Recommendation 1.4.2

Offer group cognitive stimulation therapy to people living with mild to moderate dementia.

NICE NG97 – Recommendation 1.4.3

Consider group reminiscence therapy for people living with mild to moderate dementia.

NICE NG97 – Recommendation 1.4.4

Consider cognitive rehabilitation or occupational therapy to support functional ability in people living with mild to moderate dementia.

Pharmacological interventions

Pharmacological management of Alzheimer's disease

NICE NG97 – Recommendation 1.5.4

For people with an established diagnosis of Alzheimer's disease who are already taking an AChE inhibitor:

- consider memantine in addition to an AChE inhibitor if they have moderate disease
- offer memantine in addition to an AChE inhibitor if they have severe disease.

NICE NG97 – Recommendation 1.5.5

Treatment should be under the following conditions:

- For people who are not taking an AChE inhibitor or memantine, prescribers should only start treatment with these on the advice of a clinician who has the necessary knowledge and skills. This could include:
 - secondary care medical specialists such as psychiatrists, geriatricians and neurologists
 - other healthcare professionals (such as GPs, nurse consultants and advanced nurse practitioners), if they have specialist expertise in diagnosing and treating Alzheimer's disease.
- Once a decision has been made to start an AChE inhibitor or memantine, the first prescription may be made in primary care.
- For people with an established diagnosis of Alzheimer's disease who are already taking an AChE inhibitor, primary care prescribers may start treatment with memantine (see recommendation 1.5.4) without taking advice from a specialist clinician.
- Ensure that local arrangements for prescribing, supply and treatment review follow the NICE guideline on [medicines optimisation](#).
- Do not stop AChE inhibitors in people with Alzheimer's disease because of disease severity alone.

Medicines that may cause cognitive impairment

NICE NG97 – Recommendation 1.6.2

Consider minimising the use of medicines associated with increased anticholinergic burden, and if possible look for alternatives:

- when assessing whether to refer a person with suspected dementia for diagnosis
- during medication reviews with people living with dementia.

NICE NG97 – Recommendation 1.6.4

For guidance on carrying out medication reviews, see medication review in the NICE guideline on medicines optimisation

Managing non-cognitive symptoms

Agitation, aggression, distress and psychosis

NICE NG97 – Recommendation 1.7.1

Before starting non-pharmacological or pharmacological treatment for distress in people living with dementia, conduct a structured assessment to:

- explore possible reasons for their distress **and**
- check for and address clinical or environmental causes (for example pain, delirium or inappropriate care).

NICE NG97 – Recommendation 1.7.2

As initial and ongoing management, offer psychosocial and environmental interventions to reduce distress in people living with dementia.

NICE NG97 – Recommendation 1.7.3

Only offer antipsychotics^{6, 7} for people living with dementia who are either:

- at risk of harming themselves or others **or**
- experiencing agitation, hallucinations or delusions that are causing them severe distress.

NICE NG97 – Recommendation 1.7.8

Ensure that people living with dementia can continue to access psychosocial and environmental interventions for distress while they are taking antipsychotics and after they have stopped taking them.

NICE NG97 – Recommendation 1.7.9

For people living with dementia who experience agitation or aggression, offer personalised activities to promote engagement, pleasure and interest.

Personalised interventions

Depression and anxiety

NICE NG97 – Recommendation 1.7.11

For people living with mild to moderate dementia who have mild to moderate depression and/or anxiety, consider psychological treatments.

NICE NG97 – Recommendation 1.7.12

Do not routinely offer antidepressants to manage mild to moderate depression in people living with mild to moderate dementia, unless they are indicated for a pre-existing severe mental health problem.

4.4.3 Current UK practice

Interventions to promote cognition, independence and wellbeing

The Royal College of Psychiatrists audit of memory clinics²⁰ reports that Cognitive Stimulation Therapy (CST) and life story work are available to people with dementia in around two-thirds of memory clinics: 68% of clinics have access to CST, and 63% of clinics have access to life story work.

Alzheimer's Society's poll of 1,013 GPs²¹ reported that 16% of GPs think their patients get enough day-to-day support to remain independent from the NHS and social services.

A survey of provision of dementia adviser services²² invited those responsible for commissioning dementia adviser services within Clinical Commissioning Groups (CCGs) and Local Authorities (LAs), to complete an online survey in October/November 2015. 89 CCGs and LAs responded to the voluntary survey out of 359. Respondents reported services available for older people in their area include 'singing for the brain' (8%), dementia/memory cafes (6%), befriending services (4%) and other memory services (2%).

An Alzheimer's Society survey that received responses from over 500 people with dementia in England in January to March 2015²³ found that 65% of people said they were able to get out of the house every day, 18% got out once a week or more and only 4% went out less frequently than this.

Pharmacological interventions

The Alzheimer's Research UK Dementia Statistics Hub²⁴ reports that 13.2% of all people with severe Alzheimer's disease are receiving memantine.

The Royal College of Psychiatrists' audit of memory clinics in England²⁵ found that almost all clinics prescribed and monitored anti-dementia medication in 2014.

²⁰ Royal College of Psychiatrists (2015) [Second English National Memory Clinics Audit Report](#)

²¹ Alzheimer's Society (2015) [Dementia 2015: Aiming higher to transform lives](#)

²² Ipsos MORI (2016) [Dementia Advisers Survey: Survey of provision of dementia adviser services](#)

²³ Alzheimer's Society (2015) [Dementia 2015: Aiming higher to transform lives](#)

²⁴ Alzheimer's Research UK (2018) [Dementia Statistics Hub – current treatments](#). (Accessed November 2018)

²⁵ Royal College of Psychiatrists (2015) [Second English National Memory Clinics Audit Report](#)

Managing non-cognitive symptoms

NHS Digital data²⁶ shows that 9.2% of patients with a record of dementia diagnosis were prescribed antipsychotic medication in the 6 weeks prior to 31 August 2018.

A Care Quality Commission (CQC) report on people's experiences of dementia care as they move between care homes and hospitals²⁷ includes results from inspections of 129 care homes and 20 hospitals from 22 local authority areas. They reported seeing:

- good care, including any changes in behaviours, or out-of-character behaviours, being noted and steps taken to identify the cause such as ruling out physical causes such as infection, constipation or low blood sugar levels
- examples when not responding to changes in behaviour led to avoidable situations that adversely affected the person living with dementia and others. For example, staff called security to handle situations where people were exhibiting behaviour that challenges causing additional stress and anxiety to the person
- hospitals and care homes considering the environment for people with dementia and making improvements to support good care including pictorial signage and photographs to identify bedrooms and bathrooms, and lighting and colours to help people orientate.

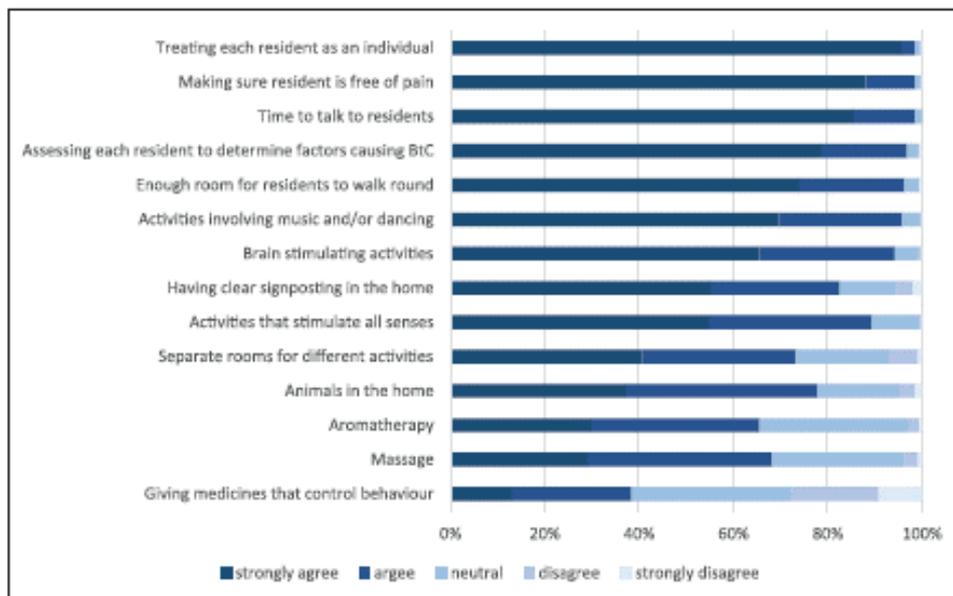
A survey conducted on the views and experiences of care home staff on managing behaviour that challenges (BtC) in dementia²⁸ received responses from 352 care staff (25%), representing 5% of all dementia-specialist care homes in England. As seen in figure 3 below, approaches such as assessing residents, knowing them and treating them as individuals, identifying triggers, having time for them and using an appropriate style of communication, were viewed as key to managing BtC. Only 38% agreed/strongly agreed medicines were useful to control BtC.

²⁶ NHS Digital (2018) [Recorded Dementia Diagnoses - August 2018](#)

²⁷ Care Quality Commission (2014) [Cracks in the Pathway: people's experiences of dementia care as they move between care homes and hospitals](#)

²⁸ Mallon C, Krska J, Gammie S (2018) Views and experiences of care home staff on managing behaviours that challenge in dementia: a national survey in England. *Aging and Mental Health* 2018 p1-8

Figure 3: Staff views on potential ways to manage Behaviour that Challenges (Source: Views and experiences of care home staff on managing behaviours that challenge in dementia: a national survey in England)



Personalised interventions

No current practice information identified.

4.4.4 Resource impact

The resource impact assessment work for NG97 identified recommendation 1.4.2 as a recommendation that has still not been fully implemented meaning there could be a resource impact locally.

The key cost driver is staff time to deliver cognitive stimulation therapy. The staff cost per session of cognitive stimulation therapy based on the assumptions used in the health economics that support the guideline recommendation is £80.41 for a band 6 (e.g. OT specialist; clinical psychology trainee) and £52.36 for a band 4 (e.g. OT technician; clinical psychology assistant).

Cognitive stimulation therapy has been shown to improve cognition, which would be expected to then improve quality of life. This may delay admission into residential care. Placements in a residential home are estimated to cost £28,860-£39,520 per annum depending on whether the provider is for- or not-for profit, whether it is a dementia residential home and whether the room is single or shared (PSSRU, Unit Costs of Health and Social Care 2017).

4.5 *Assessing and managing other long-term conditions in people living with dementia*

4.5.1 Summary of suggestions

Stakeholders suggested that hearing tests should be included as part of the assessment for dementia, so that hearing aids can be fitted before dementia progresses, and to improve communication and reduce confusion. It was also suggested that hearing aids can slow down cognitive decline and improve quality of life. Ensuring that people with dementia receive regular eye tests, and that optometrists are aware of their dementia so that they can adapt the examination, was also raised as a way to improve quality of life for people with dementia.

Stakeholders felt that dementia should be considered as a multimorbidity to ensure that all aspects of care are considered, and no other conditions that need management are overlooked. Stakeholders also stated that structured observational pain assessment tools should be used, as there is variation in pain assessment nationally.

4.5.2 Selected recommendations from development source

Table 6 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 6 to help inform the committee's discussion.

Table 6 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Assessing and managing other long-term conditions in people living with dementia	Assessing and managing other long-term conditions in people living with dementia NICE NG97 Recommendation 1.8.1 Pain NICE NG97 Recommendation 1.8.3 Sensory impairment NICE NG97 Recommendations 1.8.10 and 1.8.11

Assessing and managing other long-term conditions in people living with dementia

NICE NG97 – Recommendation 1.8.1

Ensure that people living with dementia have equivalent access to diagnosis, treatment and care services for comorbidities to people who do not have dementia. For more guidance on assessing and managing multimorbidity, see the NICE

guidelines on [multimorbidity](#) and [older people with social care needs and multiple long-term conditions](#).

Pain

NICE NG97 – Recommendation 1.8.3

Consider using a structured observational pain assessment tool:

- alongside self-reported pain and standard clinical assessment for people living with moderate to severe dementia
- alongside standard clinical assessment for people living with dementia who are unable to self-report pain.

Sensory impairment

NICE NG97 – Recommendation 1.8.10

For guidance on hearing assessments for people with suspected or diagnosed dementia, see [adults with suspected dementia](#) in the NICE guideline on hearing loss.

NICE NG97 – Recommendation 1.8.11

Encourage people living with dementia to have eye tests every 2 years. Consider referring people who cannot organise appointments themselves.

4.5.3 Current UK practice

An Alzheimer's Society report on the unheard voices of people with dementia²⁹ used information from 966 survey responses from people living with dementia, in-depth interviews with 32 people with dementia and 5 carers, 500 surveys with people who look after or support someone with dementia and 2,356 surveys of people aged 16-75 in the UK from the general public on their attitudes towards dementia and dementia care. This report states that 49% of the UK adults surveyed agree that people with dementia experience worse care and support than people with other long-term conditions such as cancer or heart disease.

A review of evidence on the equity of palliative care provision in the UK³⁰ that did a rapid review of evidence on palliative and end of life care published within the last 5 years, reported that identifying pain in people with dementia is particularly challenging, even with clinical assessment tools. It found that people with dementia were more likely to experience persistent, untreated pain, when compared to other

²⁹ Alzheimer's Society (2017) [Turning Up the Volume: unheard voices of people with dementia](#)

³⁰ Personal Social Services Research Unit, London School of Economics and Political Science (2015) [Equity in the Provision of Palliative Care in the UK: Review of Evidence](#)

patient groups. It also found that even when pain is identified, people with dementia can receive less pain relief than those with other conditions.

The National Audit of Dementia³¹ casenote review found that 83% of patients are receiving an assessment of pain in hospital, which is a slight decrease from the previous round of the audit (87%).

4.5.4 Resource impact

This area was not included in the resource impact report for NG97. No changes were made to the original guideline that would have a significant resource impact (>£1m in England each year).

³¹ Royal College of Psychiatrists 2017). [National Audit of Dementia care in general hospitals 2016-2017: Third round of audit report](#)

4.6 Risks during hospital admission

4.6.1 Summary of suggestions

Stakeholders suggested that a hospital stay for people with dementia should include consideration of their wellbeing and ensuring no harm is done due to a lack of understanding of dementia in hospital settings. Reducing inappropriate admissions, longer length of stay and deterioration in hospital were also raised as areas for quality improvement. Suggestions of how to improve these included reviewing a person's needs and wishes after every transition of care, and joined up working between hospital and social care settings.

4.6.2 Selected recommendations from development source

Table 7 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 7 to help inform the committee's discussion.

Table 7 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Risks during hospital admission	Risks during hospital admission NICE NG97 Recommendations 1.9.2 and 1.9.3 Moving to different care settings NICE NG97 Recommendations 1.12.1 and 1.12.2

Risks during hospital admission

NICE NG97 – Recommendation 1.9.2

When thinking about admission to hospital for a person living with severe dementia, carry out an assessment that balances their current medical needs with the additional harms they may face in hospital, for example:

- disorientation
- a longer length of stay
- increased mortality
- increased morbidity on discharge
- delirium
- the effects of being in an impersonal or institutional environment.

NICE NG97 – Recommendation 1.9.3

When thinking about admission to hospital for a person living with dementia, take into account:

- any advance care and support plans
- the value of keeping them in a familiar environment.

Moving to different care settings

NICE NG97 – Recommendation 1.12.1

For guidance on managing transition between care settings for people living with dementia, see:

- the NICE guideline on [transition between inpatient hospital settings and community or care home settings for adults with social care needs](#)
- the NICE guideline on [transition between inpatient mental health settings and community or care home settings](#)
- [section 1.2](#) of the NICE guideline on medicines optimisation.

Follow the principles in these guidelines for transitions between other settings (for example from home to a care home or respite care).

NICE NG97 – Recommendation 1.12.2

Review the person's needs and wishes (including any care and support plans and advance care and support plans) after every transition.

4.6.3 Current UK practice

An Alzheimer's Society report on dementia care in hospitals³² includes results from a Facebook survey in 2015 of 570 carers, families and friends of people with dementia:

- 2% felt that all hospital staff understood their specific needs
- 57% felt the person with dementia wasn't treated with dignity or understanding while in hospital
- 92% said hospital environments are frightening for the person with dementia
- 90% said the person with dementia became more confused while in hospital

Other findings in the report based on Freedom of Information (FOI) requests from NHS hospital trusts in England include:

- people with dementia stay 5 to 7 times longer than other patients over the age of 65 in the worst-performing hospitals, and on average stay more than twice as

³² Alzheimer's Society (2016) [Fix Dementia Care: Hospitals](#)

long. In the best-performing hospitals the length of stay was similar for people aged over 65 with and without dementia (response from 73 trusts)

- £264.2 million was wasted due to poor dementia care in hospitals in 2013/14
- in the previous year, 4,926 people with dementia were discharged from hospital between the hours of 11pm and 6am (68 trusts)
- 6,834 incidents of people with dementia falling in hospital in the previous year. 28.3% of people aged over 65 who had a fall were people with dementia, reaching 52.2% to 70.6% in the 3 worst-performing hospitals (38 trusts).

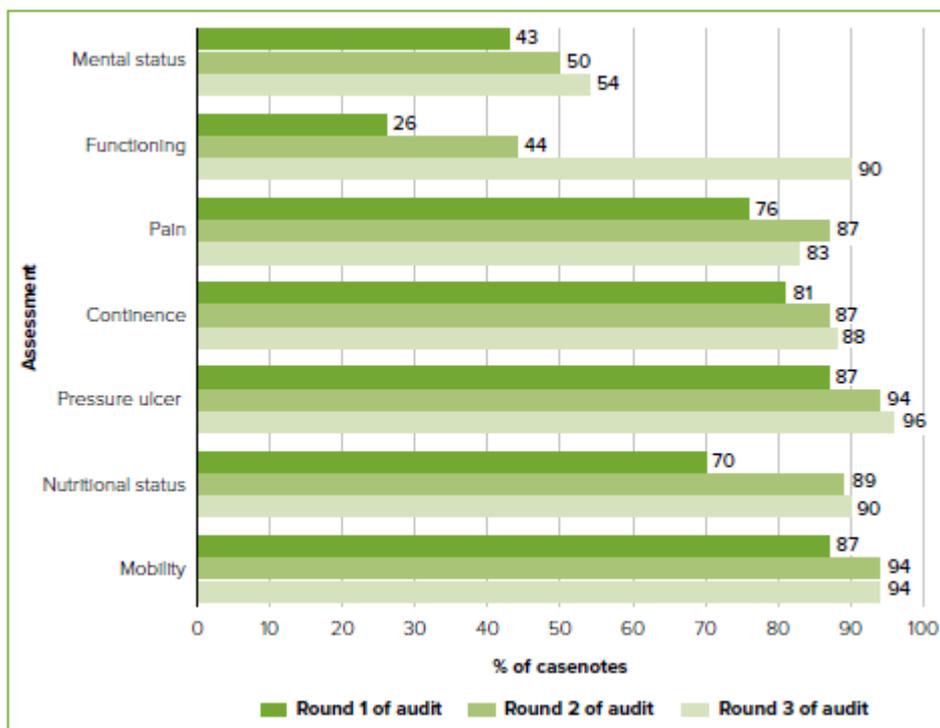
The National Audit of Dementia Care in General Hospitals 2016-2017³³ reviewed the proformas that collect information about the person with dementia and found:

- all 196 hospitals record information about factors which may cause distress
- 99% of hospitals record information about support/actions that can calm the patient if agitated

The National Audit of Dementia casenote review found:

- 33% (1818/5583) had patient information about factors that may cause distress
- 28% (1564/5539) included support/actions that can calm the patient if agitated
- symptoms of delirium and behavioural and psychiatric symptoms of dementia remain unrecorded in more than half of casenotes

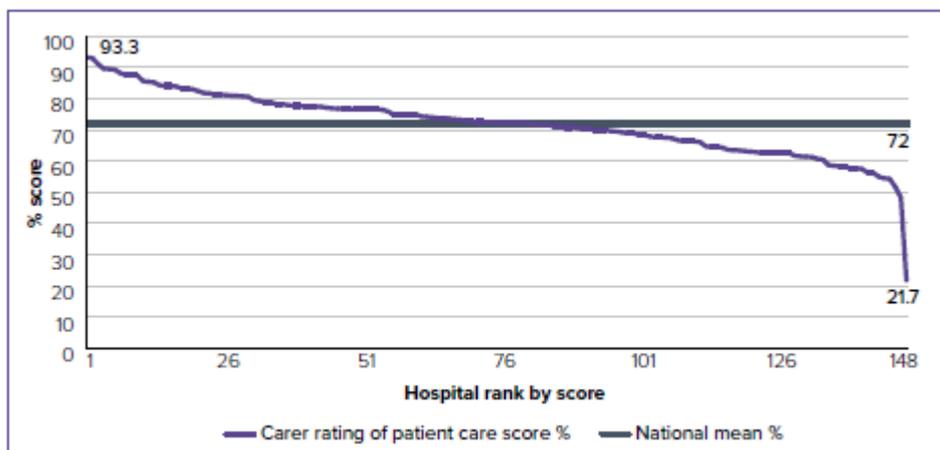
Figure 4: Assessments for older people in hospital completed in national sample of casenotes for all three rounds of the audit (Source: National Audit of Dementia Care in General Hospitals)



³³ Royal College of Psychiatrists 2017). [National Audit of Dementia care in general hospitals 2016-2017: Third round of audit report](#)

The audit also reported on carer rating of patient care scores for 148 hospitals in England and Wales. Only 1 hospital scored less than 25% and only 2 less than 50%. Sixty hospitals scored 75% or above with 3 hospitals scoring over 90%. The range of hospital scores can be seen in figure 5 below.

Figure 5: Range, ranking and national mean of ‘carer rating of patient care’ scores (Source: National Audit of Dementia care in general hospitals 2016-2017: Third round of audit report)



465 out of 10370 (4%) carer comments made using the free text comments box on questionnaires for the audit were negative comments about discharge or care transfer. 9% of these comments said communication was poor between the hospital and other services/places of care.

The Alzheimer’s Society report on the cost of dementia³⁴ says that there were more than 50,000 avoidable emergency admissions for people with dementia in 2016/17, and that people with dementia in care homes are more likely to experience inappropriate admissions to hospital.

NHS Digital’s Focus on dementia³⁵ reports that recording inconsistencies are found in nearly half of inpatient admissions for people previously recorded as having dementia.

The CQC report on people’s experiences of dementia care as they move between care homes and hospitals³⁶ found that the importance of professionals and other agencies working together to make sure that discharges from hospitals were well managed was highlighted on their inspections. Many hospitals had dedicated discharge teams and started to plan for discharge from the time of admission, ensuring that the individual’s needs were met.

³⁴ Alzheimer’s Society (2018) [Dementia – the true cost: Fixing the care crisis.](#)

³⁵ NHS Digital (2016) [Focus on dementia – January 2016](#)

³⁶ Care Quality Commission (2014) [Cracks in the Pathway: people’s experiences of dementia care as they move between care homes and hospitals](#)

They found aspects of variable or poor care with the arrangements for sharing information in 27% of the care homes, and 22% of the hospitals they visited.

4.6.4 Resource impact

This area was not included in the resource impact report for NG97. No changes were made to the original guideline that would have a significant resource impact (>£1m in England each year).

4.7 *Involving people living with dementia in decisions about their care*

4.7.1 Summary of suggestions

Involving people in decision-making

Stakeholders highlighted that person-centred care results in better outcomes for people with dementia, and tools such as ‘This is Me’ can help to achieve this. Stakeholders stated that providers should evaluate or monitor the person-centred quality of their support to identify problems and improve their offer. The importance of involving people living with dementia in decisions about their care was also raised. Stakeholders felt that this is a way of ensuring the needs of people with dementia are met and people are more likely to consent to treatment.

Providing information

Stakeholders suggested providing people with dementia with information about opportunities to be involved in research studies is a quality improvement area, as people report wanting to be involved, but not knowing how to do this. This was felt to be important as there are benefits in taking part in research for people with dementia, such as feeling in control of the condition, receiving higher quality care and having better outcomes. A stakeholder also felt that when research results in effective new treatments, they should be made available to people living with dementia as quickly as possible.

Improving post-diagnostic support and information provision in all settings, signposting to local support groups, follow-up, and asking for consent to share information with services and family members were also raised as areas for quality improvement.

4.7.2 Selected recommendations from development source

Table 8 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 8 to help inform the committee’s discussion.

Table 8 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Involving people in decision-making	Involving people in decision-making NICE NG97 Recommendations 1.1.1 to 1.1.3
Providing information	Providing information NICE NG97 Recommendations 1.1.4, 1.1.6, 1.1.7, 1.1.8, 1.1.10 and 1.1.11

Involving people in decision-making

NICE NG97 – Recommendation 1.1.1

Encourage and enable people living with dementia to give their own views and opinions about their care.

NICE NG97 – Recommendation 1.1.2

If needed, use additional or modified ways of communicating (for example visual aids or simplified text).

NICE NG97 – Recommendation 1.1.3

Consider using a structured tool to assess the likes and dislikes, routines and personal history of a person living with dementia.

Providing information

NICE NG97 – Recommendation 1.1.4

Provide people living with dementia and their family members or carers (as appropriate) with information that is relevant to their circumstances and the stage of their condition.

NICE NG97 – Recommendation 1.1.6

At diagnosis, offer the person and their family members or carers (as appropriate) oral and written information that explains:

- what their dementia subtype is and the changes to expect as the condition progresses
- which healthcare professionals and social care teams will be involved in their care and how to contact them

- if appropriate, how dementia affects driving, and that they need to tell the Driver and Vehicle Licensing Agency (DVLA) and their car insurer about their dementia diagnosis
- their legal rights and responsibilities
- their right to reasonable adjustments (in line with the [Equality Act 2010](#)) if they are working or looking for work
- how the following groups can help and how to contact them:
 - local support groups, online forums and national charities
 - financial and legal advice services
 - advocacy services.

NICE NG97 – Recommendation 1.1.7

If it has not been documented earlier, ask the person at diagnosis:

- for their consent for services to share information
- which people they would like services to share information with (for example family members or carers)
- what information they would like services to share.

Document these decisions in the person's records.

NICE NG97 – Recommendation 1.1.8

After diagnosis, direct people and their family members or carers (as appropriate) to relevant services for information and support (see [recommendations 1.3.1 and 1.3.2](#) on care coordination).

NICE NG97 – Recommendation 1.1.10

Ensure that people living with dementia and their carers know how to get more information and who from if their needs change.

NICE NG97 – Recommendation 1.1.11

Tell people living with dementia (at all stages of the condition) about research studies they could participate in.

4.7.3 Current UK practice

Involving people in decision making

The National Audit of Dementia Care in General Hospitals 2016-2017³⁷ reported that:

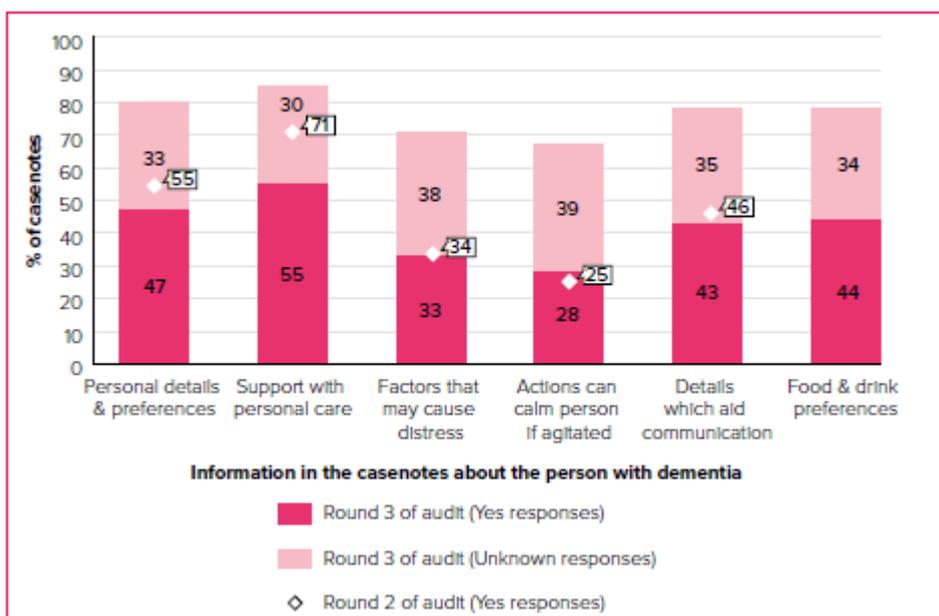
- 99% of hospitals reported a system in place, such as 'This is Me', for documenting and transmitting details about the person with dementia's preferences and needs to aid care provision
- 196/199 hospitals have a formal system for gathering information about the person with dementia, such as food and drink preferences and life history, an increase from 74% in Round 2
- 195/196 hospitals collect details about the patient that aid communication, and details on how the patient communicates and understands information.

The National Audit of Dementia casenote review found:

- 57% (5727/10010) of patients' notes contained a section dedicated to collecting information about the patient from the carer, next of kin or a person who knows the patient well.

Figure 6 (below) shows that there is inconsistent recording of information about the person with dementia in casenotes.

Figure 6: Comparison of casenote information about the person with dementia in Rounds 2 and 3 of audit (Source: National Audit of Dementia care in general hospitals 2016-2017: Third round of audit report)

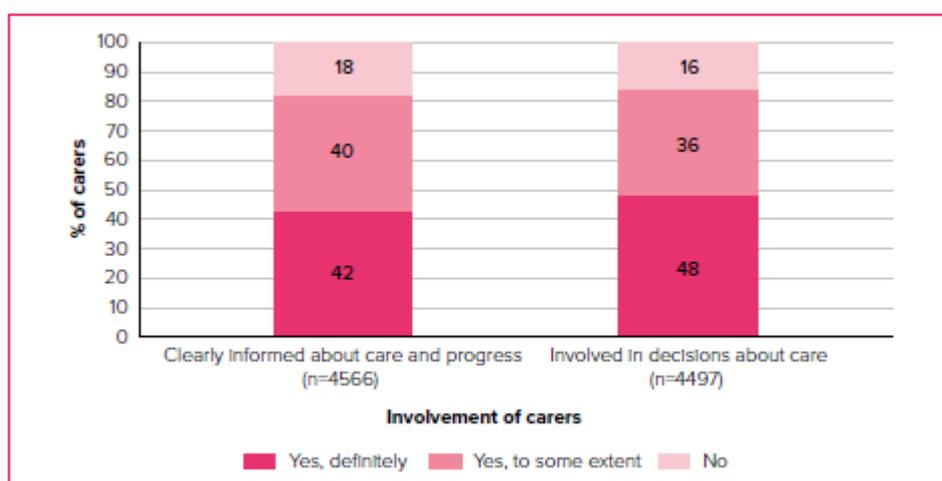


³⁷ Royal College of Psychiatrists 2017). [National Audit of Dementia care in general hospitals 2016-2017: Third round of audit report](#)

The audit also reported on carers' opinions on care received:

- 45% (2053/4524) of carers said 'yes, definitely' staff asked them about the care needs of the person they look after, and 35% (1563/4524) responded 'yes, to some extent'. Under half of carers (47%, 2130/4578) said definitely, staff were well informed and understood the needs of the person they looked after, and 43% (1980/4578) said that this was true to some extent
- when carers were asked if staff delivered high quality care appropriate to the patients' needs, 54% (2489/4592) answered 'yes, definitely' and 36% (1672/4592) 'yes, to some extent'
- figure 7 below shows carer responses to how informed and involved they were in care decisions for the person with dementia.

Figure 7: Carer questionnaire responses about being kept informed and involved in care decisions of the person with dementia



The Alzheimer's Society report on the cost of dementia³⁸ reports that some of the people who gave evidence and testimony shared that care staff were not aware of the person's history or relevant information.

The following two reports both identified that not everyone with dementia was involved in their care:

- A National Voices review of evidence on person-centred care in 2017³⁹ found that 62% of care homes the CQC inspected did not involve people with dementia, or their families, in care or choices about how to spend their time.
- An Alzheimer's Society survey that received responses from over 500 people with dementia in England in January to March 2015⁴⁰ found that 26% of people

³⁸ Alzheimer's Society (2018) [Dementia – the true cost: Fixing the care crisis.](#)

³⁹ National Voices (2017) [Person-centred care in 2017 – Evidence from services users](#)

⁴⁰ Alzheimer's Society (2015) [Dementia 2015: Aiming higher to transform lives](#)

said they were not involved in decisions about their care and support, 61% said they were and 13% said they did not know.

A CQC review of inequalities in end of life care⁴¹ asked for the views of people from different population groups, including people with dementia and conditions other than cancer, on their experiences, and barriers that may prevent them from experiencing good, personalised care at the end of life. CQC also visited local areas to talk to commissioners, providers and staff about how they address the needs of different groups. The review found that communication with people with dementia, their carers and families, can be poor or non-existent. In their case note review, 53 out of 70 (76%) of the overall sample showed that health and care professionals had considered the individual's communication needs. However, this dropped to only 5 out of 11 (45%) people with dementia whose individual communication needs had been considered.

Providing information

Providing information about research

The [Prime Minister's Challenge on Dementia 2020](#)⁴² sets the challenge to increase numbers of people with dementia participating in research, so that 25% of people diagnosed with dementia will be registered on [Join Dementia Research](#) (JDR), and 10% participating in research. There are currently 38,022 volunteers for JDR, and 28% have participated in a study⁴³. However, the proportion of people in England with a dementia diagnosis who have joined JDR is currently only at 1%⁴⁴.

The Alzheimer's Research UK Dementia Statistics Hub⁴⁵ reports that, based on a YouGov poll commissioned by Alzheimer's Research UK in 2015, whilst 62% of the general public would be willing to take part in dementia research, 81% would not know how to volunteer.

The Royal College of Psychiatrists audit of memory clinics⁴⁶ reports that 85% of clinics ask people with dementia if they would like to register their interest in participating in research and 83% of clinics recruited people with dementia to at least 1 research study in 2014.

⁴¹ Care Quality Commission (2016) [A different ending – Addressing inequalities in end of life care: overview report](#)

⁴² Cabinet Office, Department of Health and Social Care, and Prime Minister's Office, 10 Downing Street (2015) [Prime Minister's challenge on dementia 2020](#)

⁴³ [Join Dementia Research](#) (Accessed November 2018)

⁴⁴ [Join Dementia Research October Volunteer Statistics](#) (Accessed November 2018)

⁴⁵ Alzheimer's Research UK (2018) [Dementia Statistics Hub – attitudes to research](#). (Accessed November 2018)

⁴⁶ Royal College of Psychiatrists (2015) [Second English National Memory Clinics Audit Report](#)

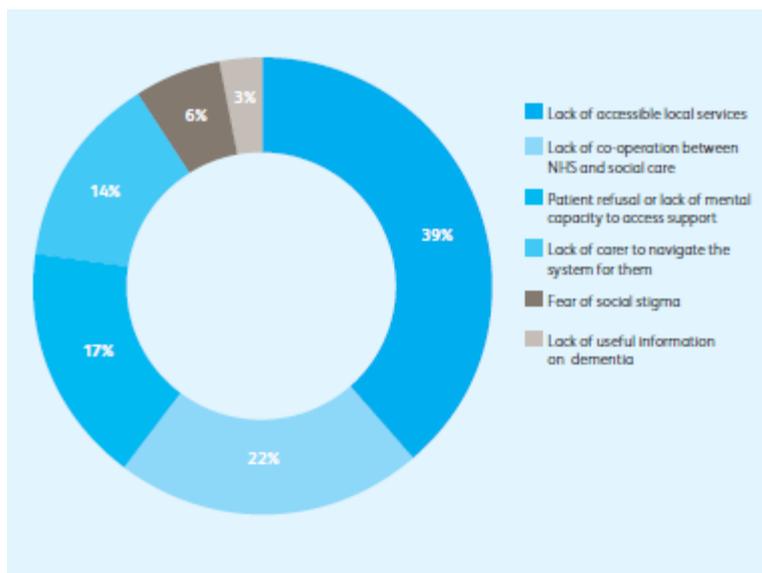
Support after diagnosis

An Alzheimer's Society report on the unheard voices of people with dementia⁴⁷, that carried out in-depth interviews with 32 people with dementia and 5 carers, found that a number of people they spoke to shared how desperate and alone they felt following a diagnosis. Rather than being given a range of options and advice and being placed on a pathway of support, they felt discharged by the health service and left to fend for themselves.

The Alzheimer's Research UK Dementia Statistics Hub⁴⁸ reports that 68% of people feel isolated following a diagnosis of dementia.

The Alzheimer's Society⁴⁹ poll of 1,013 GPs asked about their thoughts on the main barriers to people with dementia getting support following a diagnosis. Figure 8 shows the views reported.

Figure 8: GP views on main barriers for people with dementia getting the support they need following a diagnosis (Source: Alzheimer's Society (2015) Dementia 2015: Aiming higher to transform lives)



4.7.4 Resource impact

This area was not included in the resource impact report for NG97. No changes were made to the original guideline that would have a significant resource impact (>£1m in England each year).

⁴⁷ Alzheimer's Society (2017) [Turning Up the Volume: unheard voices of people with dementia](#)

⁴⁸ Alzheimer's Research UK (2018) [Dementia Statistics Hub – attitudes to diagnosis](#). (Accessed November 2018)

⁴⁹ Alzheimer's Society (2015) [Dementia 2015: Aiming higher to transform lives](#)

4.8 *Palliative care*

4.8.1 Summary of suggestions

Advance care planning

Stakeholders highlighted the benefits of advance care planning, including satisfaction with overall care, receiving fewer aggressive medical interventions, fewer hospital admissions and increased use of palliative care services. Stakeholders stated that people with dementia have less opportunities for advance care planning and poorer end of life care than people with other life-limiting conditions. Stakeholders therefore thought that people with dementia must be given opportunities to discuss advance care planning in a timely manner, and make updates if their preferences change, to ensure their future care and treatment is aligned with their preferences and values, before they have lost the capacity to make decisions. Making sure that people with dementia and their families are informed about having a lasting power of attorney was also raised as a quality improvement area.

Palliative care

Stakeholders highlighted that people with dementia should have access to palliative care that considers their needs and preferences, supports carers and prevents admission to hospital and over-medicalisation. Lack of awareness of the end stages of dementia among professionals and establishing safe eating and drinking practices were also raised.

4.8.2 Selected recommendations from development source

Table 9 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 9 to help inform the committee's discussion.

Table 9 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Advance care planning	Advance care planning NICE NG97 Recommendations 1.1.12 and 1.1.13
Palliative care	Palliative care NICE NG97 Recommendations 1.10.1, 1.10.2, 1.10.6, 1.10.7 and 1.10.8

Advance care planning

NICE NG97 – Recommendation 1.1.12

Offer early and ongoing opportunities for people living with dementia and people involved in their care (see recommendation 1.1.7) to discuss:

- the benefits of planning ahead
- lasting power of attorney (for health and welfare decisions and property and financial affairs decisions)
- an advance statement about their wishes, preferences, beliefs and values regarding their future care
- advance decisions to refuse treatment
- their preferences for place of care and place of death.

Explain that they will be given chances to review and change any advance statements and decisions they have made.

NICE NG97 – Recommendation 1.1.13

At each care review, offer people the chance to review and change any advance statements and decisions they have made.

Palliative care

NICE NG97 – Recommendation 1.10.1

From diagnosis, offer people living with dementia flexible, needs-based palliative care that takes into account how unpredictable dementia progression can be.

NICE NG97 – Recommendation 1.10.2

For people living with dementia who are approaching the end of life, use an anticipatory healthcare planning process (see [recommendation 1.1.12](#) on advance care planning). Involve the person and their family members or carers (as appropriate) as far as possible, and use the principles of best-interest decision-making if the person does not have capacity to make decisions about their care.

NICE NG97 – Recommendation 1.10.6

Encourage and support people living with dementia to eat and drink, taking into account their nutritional needs.

NICE NG97 – Recommendation 1.10.7

Consider involving a speech and language therapist if there are concerns about a person's safety when eating and drinking.

NICE NG97 – Recommendation 1.10.8

Do not routinely use enteral feeding in people living with severe dementia, unless indicated for a potentially reversible comorbidity.

4.8.3 Current UK practice

Advanced care planning

The Carers Trust report on supporting older carers⁵⁰ includes results from 6 focus groups with older carers in England, and interviews with 7 carers and 1 former carer. 92 people attended the focus groups, with the majority of carers aged 60–80. Carers of people with dementia, mental health conditions and learning disabilities found it difficult to have conversations about planning for the future with the person who was being cared for, as it made the person anxious or distressed. They consequently avoided conversations, even though they knew they were important.

A Marie Curie and Alzheimer's Society report on quality of end of life care⁵¹ that looked at developments and research from across the UK states that the evidence shows that people with dementia were less likely to have advance care directives than people with other conditions.

Palliative care

A CQC review of inequalities in end of life care⁵² found that:

- families and carers of people with dementia were unsure about when the end of life phase began, suggesting that people were not clearly identified as approaching the end of life
- health professionals said that they sometimes find it difficult to identify when people who have conditions other than cancer, including frailty and dementia, are likely to be in the last 12 months of life
- health professionals' understanding of the Mental Capacity Act 2005 is patchy, and varied in relation to assessment and decision making. Only 4 out of 11 (36%) people with dementia in their case note review had evidence of a mental capacity assessment in their records
- staff not having the right skills to care for people with dementia was a barrier to receiving good, personalised end of life care. Several people highlighted problems such as a lack of staff training, staff not supporting people to eat and drink, and a lack of understanding

⁵⁰ Carers Trust (2016) [Retirement on Hold: Supporting Older Carers](#)

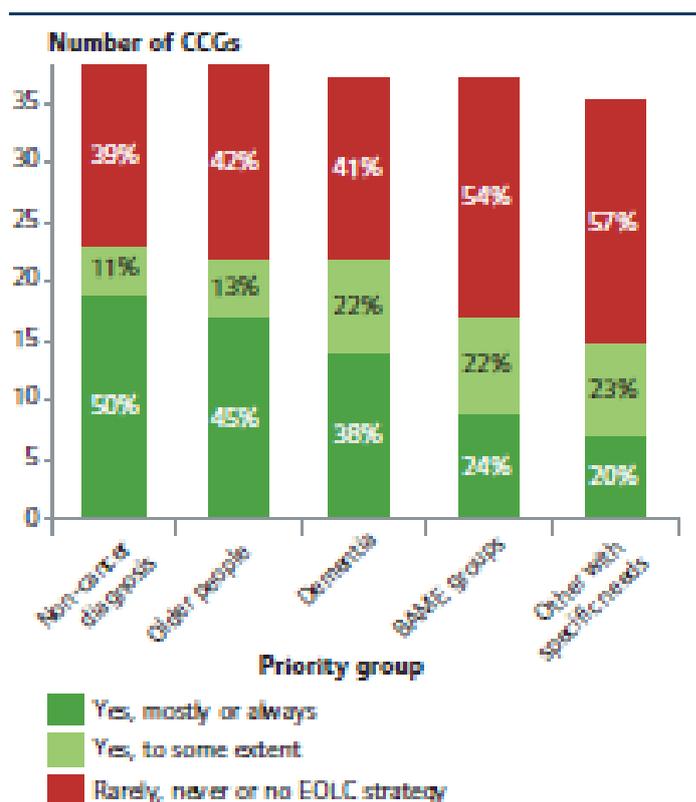
⁵¹ Marie Curie and Alzheimer's Society (2014) [Living and dying with dementia in England: Barriers to care](#)

⁵² Care Quality Commission (2016) [A different ending – Addressing inequalities in end of life care: overview report](#)

- people said that people with dementia did not have access to the same end of life care services as those with other conditions, and poor end of life care in hospital was a particular concern for older people, people with dementia and people with conditions other than cancer

Figure 9 below shows the proportion of CCGs that consider dementia in their End of Life Care strategy, and how this compares to other conditions and population groups.

Figure 9: Number of CCGs considering different groups in their End of Life Care Strategy (based on 38 responses)



Source: CQC survey of CCGs, November 2014

A Marie Curie and Alzheimer's Society report on quality of end of life care⁵³ also reported that people with dementia are not being appropriately identified for end of life care, and that they have less access to, and receive poorer quality, care than people with other terminal illnesses.

A review of evidence on the equity of palliative care provision in the UK⁵⁴ also reports that people with dementia have symptoms that are commonly not effectively addressed and are less likely to be referred to palliative care teams, and the dying

⁵³ Marie Curie and Alzheimer's Society (2014) [Living and dying with dementia in England: Barriers to care](#)

⁵⁴ Personal Social Services Research Unit, London School of Economics and Political Science (2015) [Equity in the Provision of Palliative Care in the UK: Review of Evidence](#)

phase may frequently go unrecognised. It also found that healthcare professionals are discouraged from taking a palliative approach to people with dementia due to difficulties making decisions for people with dementia, and this leads them to admit people to hospital or to administer aggressive treatments.

Data relating to place of death from Public Health England's Dementia Profile⁵⁵ shows that the place of death for 57.6% of people with dementia (aged 65+) in 2016 was a care home, for 30.9% it was a hospital and for 9.7% it was home. Public Health England's data analysis report on Dying with Dementia⁵⁶ reports that the proportion of deaths at home has significantly increased from 4% in 2001.

The House of Commons Health Committee report on End of Life Care⁵⁷, based on written evidence received from 77 organisations and evidence from 13 witnesses, found that hospitals, on discharging patients who have dementia or are frail elderly, may send them to a care home rather than back to their own home without discussing their end of life care wishes.

4.8.4 Resource impact

This area was not included in the resource impact report for NG97. No changes were made to the original guideline that would have a significant resource impact (>£1m in England each year).

⁵⁵ Public Health England (2018) [Dementia Profile](#)

⁵⁶ Public Health England (2016) [Data Analysis Report Dying with Dementia](#)

⁵⁷ House of Commons Health Committee (2015) [End of Life Care - Fifth Report of Session 2014–15](#)

4.9 Supporting carers

4.9.1 Summary of suggestions

Stakeholders suggested that carers should be educated in practical skills and managing day to day life, such as managing medication and incontinence, informed of what services and support are available, including crisis support, and how to access them, and offered psychoeducation. Identifying carers and supporting them to maintain their own health and wellbeing, and deal with their own health issues, such as mental health problems, was considered an important way of ensuring they are able to continue caring for the person with dementia, and reduce care home admissions. Support for families and carers after the diagnosis and access to psychological therapies, so that they understand the diagnosis and what it means, was felt to be an area for quality improvement.

4.9.2 Selected recommendations from development source

Table 10 below highlights recommendations that have been provisionally selected from the development source that may support potential statement development. These are presented in full after table 10 to help inform the committee's discussion.

Table 10 Specific areas for quality improvement

Suggested quality improvement area	Selected source guidance recommendations
Supporting carers	Supporting carers NICE NG97 Recommendations 1.11.1 to 1.11.4

Supporting carers

NICE NG97 – Recommendation 1.11.1

Offer carers of people living with dementia a psychoeducation and skills training intervention that includes:

- education about dementia, its symptoms and the changes to expect as the condition progresses
- developing personalised strategies and building carer skills
- training to help them provide care, including how to understand and respond to changes in behaviour
- training to help them adapt their communication styles to improve interactions with the person living with dementia
- advice on how to look after their own physical and mental health, and their emotional and spiritual wellbeing

- advice on planning enjoyable and meaningful activities to do with the person they care for
- information about relevant services (including support services and psychological therapies for carers) and how to access them
- advice on planning for the future.

NICE NG97 – Recommendation 1.11.2

Ensure that the support provided to carers is:

- tailored to their needs and preferences and to what they want it to achieve (for example, providing information on carer's employment rights for carers who work or want to work)
- designed to help them support people living with dementia
- available at a location they can get to easily
- provided in a format suitable for them (for example individual or group sessions, or online training and support)
- available from diagnosis and as needed after this.

NICE NG97 – Recommendation 1.11.3

Be aware that carer interventions are likely to be most effective when provided as group sessions.

NICE NG97 – Recommendation 1.11.4

Advise carers about their right to the following and how to get them:

- a formal assessment of their own needs (known as a 'Carer's Assessment'), including their physical and mental health
- an assessment of their need for short breaks and other respite care.

4.9.3 Current UK practice

Public Health England's Dementia Profile⁵⁸ shows that the carer-reported quality of life score for people caring for someone with dementia in 2016/17 was 7.5 (the maximum score possible is 12).

An Alzheimer's Society report⁵⁹ on the unheard voices of people with dementia surveyed 500 people who look after or support someone with dementia. Of the carers surveyed:

- 27% feel 'cut-off from society'

⁵⁸ Public Health England (2018) [Dementia Profile](#)

⁵⁹ Alzheimer's Society (2017) [Turning Up the Volume: unheard voices of people with dementia](#)

- 61% say their health has been negatively affected
- 37% say their personal relationships and social life have been affected
- difficulty accessing support, or information on what support is available, contributed to the sense of isolation and feeling that there was no one else to help
- 18% said they had felt depressed and 35% reported feeling stressed
- 17% gave up work to provide care and a further 25% reduced their hours
- 26% said their financial situation got worse
- 17% agree with the statement 'there is enough support available for those who care for people with dementia'. However 65% disagree, with 31% saying they strongly disagree. 27% say that no one has provided them with advice or support about caring for someone with dementia
- 57% are aware of a Carer's Assessment (as a right in legislation) or of the existence of NHS Continuing Healthcare. 41% know that it is also possible to have a Carer's Personal Budget to support them to carry out their vital role.

The National Audit of Dementia Care in General Hospitals 2016-2017⁶⁰ reported that:

- in Round 3 of the audit, 67% (2605/3868) of carers had their needs assessed prior to discharge of the person with dementia. In Round 2, 72% were assessed.
- in response to a question about how supported carers felt by the hospital while the person they care for was admitted, 50% (2204/4379) said that they were very satisfied with the support they received and 34% (1487/4379) said they felt somewhat satisfied. 16% (688/4379) of carers said that they felt somewhat or very dissatisfied.

An Alzheimer's Research UK report on the impact of dementia on carers⁶¹, which carried out 4 ethnographic studies of family carers for people with dementia, found that of the carers involved:

- there was limited understanding of dementia and the diseases that cause it; their knowledge was based on their personal experience. They had little understanding of the deterioration that takes place and why this occurs
- all understood that dementia changes behaviour and personality.
- all were aware that respite care was available and could be used to provide a much needed break. However, a sense of duty and responsibility meant that none of the carers sought or received this support
- their mental and physical health was poor and appeared to be related to the progression of the condition
- all experienced high levels of stress and depression and symptoms were exacerbated by social isolation.

⁶⁰ Royal College of Psychiatrists 2017). [National Audit of Dementia care in general hospitals 2016-2017: Third round of audit report](#)

⁶¹ Alzheimer's Research UK (2015) [Dementia in the Family: The impact on carers](#)

- many were exhausted because of sleep deprivation, carrying out all of the household chores, extra cleaning and laundry as well as moving or lifting their loved one.

The Royal College of Psychiatrists audit of memory clinics in England⁶² reports that education and support for carers is available to almost all clinics (98%).

In a survey of provision of dementia adviser services⁶³, 99% of commissioners of local dementia services who responded say that support for carers is available in their service area.

An Alzheimer's Society survey that received responses from over 500 people with dementia in England in January to March 2015⁶⁴ found that 49% of respondents said that their carer did not receive help, while 39% said their carer did receive help and 12% said they did not know.

4.9.4 Resource impact

The resource impact assessment work for NG97 identified recommendation 1.11.1 as a recommendation that has still not been fully implemented meaning there could be a resource impact locally.

This training may be delivered using existing staff or could be commissioned as a separate service. The key cost driver is either staff time to deliver the training or the cost of procuring the training from external organisations.

Feedback suggests that due to the number of carers this recommendation is relevant to, this training may need to be a specifically commissioned service.

Psychoeducation and skills training for carers may prevent carer breakdown and may delay or avoid the need for residential care. Placements in a residential home are estimated to cost £28,860-£39,520 per annum depending on whether the provider is for- or not-for profit, whether it is a dementia residential home and whether the room is single or shared (PSSRU, Unit Costs of Health and Social Care 2017).

⁶² Royal College of Psychiatrists (2015) [Second English National Memory Clinics Audit Report](#)

⁶³ Ipsos MORI (2016) [Dementia Advisers Survey: Survey of provision of dementia adviser services](#)

⁶⁴ Alzheimer's Society (2015) [Dementia 2015: Aiming higher to transform lives](#)

4.10 Additional areas

Summary of suggestions

The improvement areas below were suggested as part of the stakeholder engagement exercise. However they were felt to be either unsuitable for development as quality statements, outside the remit of this particular quality standard referral or require further discussion by the committee to establish potential for statement development.

There will be an opportunity for the committee to discuss these areas at the end of the session on 21st November.

Staff training

The training of staff to ensure they have the skills and competencies to support people with dementia was suggested as an area of quality improvement. Specific skills that stakeholders felt that staff need training in include lumbar puncture for cerebrospinal fluid examination, delivering person-centred care, communication, knowledge of the pathology and signs and symptoms of dementia, understanding LGBT issues, managing behaviour that may challenge and deprivation of liberty safeguards.

This suggestion has not been progressed. Quality statements focus on actions that demonstrate high quality care or support, not the training that enables the actions to take place. The committee is therefore asked to consider which components of care and support would be improved by increased training. However, training may be referred to in the audience descriptors.

Nutrition

A stakeholder suggested that people with dementia are at higher risk of undernutrition, and raising awareness of this is a quality improvement area. Another stakeholder highlighted that difficulty swallowing can affect people with dementia, and there have been patient safety incidents due to confusion over appropriate forms of food to give people. Nutrition support is covered in the NICE quality standard on [nutrition support in adults](#).

Equality

Stakeholders suggested that service providers should monitor sexual orientation and trans status of service users to better understand and meet lesbian, gay, bisexual and trans (LGBT) people's needs. Including LGBT people in designing dementia services was also suggested as a way to empower people. Carrying out equality assessments to make sure that groups with protected characteristics, such as LGBT people, people in prison and BAME populations, are considered when looking at

quality of services. NICE considers equality issues throughout the development of quality standards.

Learning disabilities

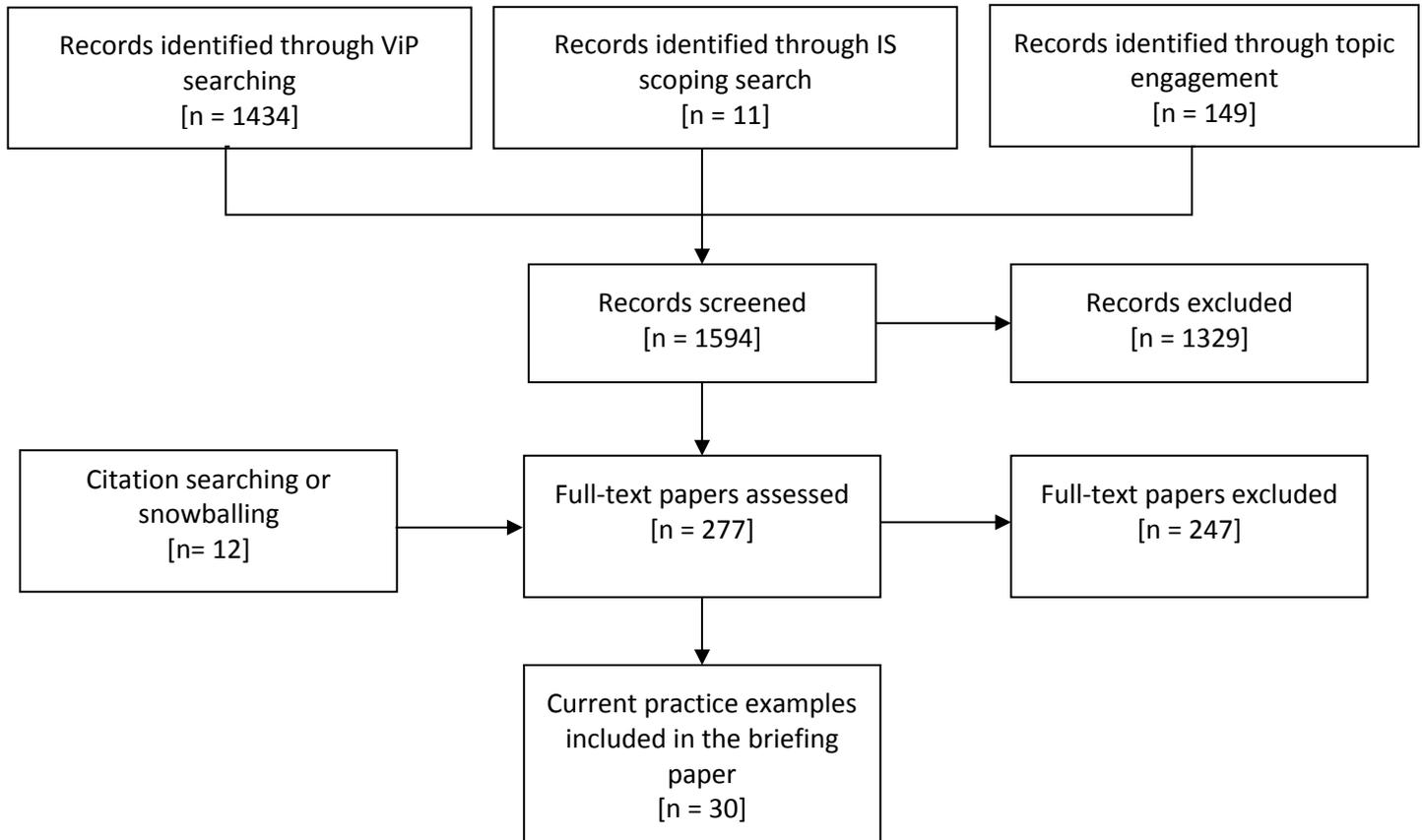
Stakeholders highlighted the increased risk of developing dementia, and developing it at a younger age, among people with learning disabilities. It was felt that there are inequalities in dementia services for people with learning disabilities. Training for people with learning disabilities and their families and carers about the signs of dementia, and the risk of developing it, was also suggested as a quality improvement area. There is a quality standard on [care and support of people growing older with learning disabilities](#), which is currently in development.

Use of superabsorbent polymer gel granules

NHS Improvement Patient Safety highlighted that there have been patient safety incidents due to superabsorbent polymer gel granules, which are used to solidify bodily fluids to reduce the risk of slips in hospitals. There have been deaths and severe harm to people with dementia after swallowing the gel sachets when they been left at the patient bedside. This area is not covered by the NICE guideline on [dementia](#).

© NICE [2018]. All rights reserved. Subject to [Notice of rights](#).

Appendix 1: Review flowchart



Appendix 2: Suggestions from stakeholder engagement exercise – registered stakeholders

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?
General comments				
1	Action on Hearing Loss	<p>About us Action on Hearing Loss, formerly RNID, is the UK’s largest charity working for people with deafness, hearing loss and tinnitus. Our vision is of a world where deafness, hearing loss and tinnitus do not limit or label people and where people value and look after their hearing. We help people confronting deafness, tinnitus and hearing loss to live the life they choose, enabling them to take control of their lives and removing the barriers in their way. We give people support and care; develop technology and treatments and campaign for equality.</p> <p>Throughout this response we use the terms 'people with hearing loss' to refer to people with all levels of hearing loss and 'people who are deaf' to refer to people who are profoundly deaf who use British Sign Language (BSL) as their first or preferred language.</p>		
2	Action on Hearing Loss	<p>Introduction Action on Hearing Loss welcomes the opportunity to submit evidence on the key areas of quality improvement that we would like to see covered by the forthcoming NICE Dementia (update) Quality Standard. Evidence suggests that there is an association between hearing loss and dementia- people with mild hearing loss have twice the risk of developing dementia and in people with severe hearing loss; up to five times the risk. Hearing loss has been reported to have lead to misdiagnosis within cognitive function tests for dementia and those with cognitive decline or dementia may not be aware of their hearing loss nor have the capacity to ask for help. In addition, families or carers may not consider hearing loss as an issue due to other their other heath needs. If hearing loss is not addressed early, it can lead to isolation and withdrawal, which can exacerbate underlying cognitive difficulties, which in turn can be misdiagnosed as reduced cognition.</p> <p>Hearing aids, especially if fitted early, improve quality of life and enable people to maintain communication. Research has also shown that hearing aids can reduce the risks of developing dementia and cognitive decline; however, research shows that only two-fifths of people who need hearing aids have them. A recent Lancet Commission on dementia prevention, intervention and care, identified hearing loss as the largest modifiable risk factor for dementia in people who are middle aged.</p> <p>The recently published NICE Hearing Loss in Adults Guideline takes into consideration the evidence linking hearing loss and dementia and the importance of ensuring hearing loss is assessed. The guideline recommends that people with diagnosed or suspected dementia or mild cognitive decline should be considered for referral for a hearing assessment as hearing loss may be a comorbid condition. In addition, it also recommends that a referral for a hearing test to audiology should be considered every two years in the same instance, if the person has not already been diagnosed with hearing loss.</p> <p>In this response, we set out three key areas that would improve quality of care and support for people growing old with dementia. For ease of reference, the three key areas for quality improvement are listed below:</p>		

ID	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?
			<ol style="list-style-type: none"> 1. Ensuring deafness and hearing loss are included as part of dementia assessments 2. Improving the diagnosis and management of hearing loss in people with dementia 3. Improving the accessibility of dementia services for people with hearing loss 	
3	Alzheimer's Research UK		<p>Alzheimer's Research UK is the world's leading dementia research charity dedicated to causes, diagnosis, prevention, treatment and cure.</p> <p>Backed by our passionate scientists and supporters, we're challenging the way people think about dementia, bringing together the people and organisations who can speed up progress, and investing in research to make life-changing breakthroughs possible.</p> <p>Our mission is to bring about the first life-changing dementia treatment by 2025. Our vision is a world where people are free from the fear, harm and heartbreak of dementia.</p> <p>We focus our energies in four key areas of action to make this mission a reality.</p> <ul style="list-style-type: none"> Understand the diseases that cause dementia. Diagnose people earlier and more accurately. Reduce risk, backed by the latest evidence. · Treat dementia effectively. <p>Through these important strands of work, we're bringing about breakthroughs that will change lives</p> <p>Alzheimer's Research UK welcomes the opportunity to comment on the Dementia quality standards topic engagement consultation.</p>	
4	British Geriatrics Society		We didn't receive any feedback on this from our specialists, so we have nothing to add.	
5	Department of Health and Social Care		Thank you for the opportunity to comment on the topic engagement for the above quality standard I wish to confirm that the Department of Health and Social Care has no substantive comments to make, regarding this consultation.	
6	National Clinical Director for Dementia		<p>The following reports might be interesting:</p> <p>NHS England care planning guidance - https://www.england.nhs.uk/wp-content/uploads/2016/04/core-info-care-support-planning-1.pdf</p> <p>NHS England End of Life Care guidance - https://www.england.nhs.uk/personalised-health-and-care/eolc/resources-for-end-of-life-care/</p> <p>Thinking ahead document from ARUK - https://www.alzheimersresearchuk.org/wp-content/uploads/2016/09/Treatments-of-tomorrow-web.pdf</p> <p>Long guide –NCCMH publication for the 6 week waiting list - https://www.kingsfund.org.uk/sites/default/files/media/Becki%20Hemming.pdf</p>	

4.1 Approaches to prevent or delay onset of dementia				
Raising awareness				
7	Dementia Industry Group	Early diagnosis of Dementia	Moving towards earlier diagnosis will require an increase in public and health professional understanding that Alzheimer's starts long before symptoms are present ¹ . Therefore, it is necessary to scope the barriers and opportunities within the NHS to shifting towards earlier and molecular-based diagnosis.	To move towards earlier diagnosis, it will be important to improve the public's and healthcare professional's understanding of Alzheimer's as a disease that starts long before symptoms are present, and to challenge the misconception that dementia is a condition of old age ¹
8	Roche Products Limited	Public health campaign to Increase the awareness of brain health including dementia among the general public Specifically the importance of early detection of dementia which could lead to earlier diagnosis	<p>More consideration needs to be given to the whole pathway. Early detection leading to early diagnosis is important. The two must be given equal priority to best support appropriate care provision and treatment.</p> <p>The early signs of dementia are not well known by the majority of the public and often go undetected. Those who could benefit from treatment may not be aware of the benefit of earlier detection of Dementia.</p> <p>An accurate and early diagnosis of dementia is highly dependent on friends and family members making a critical intervention which results in an engagement with an informed healthcare professional.</p> <p>For this to happen, an increase in awareness of early signs and symptoms is important among the general public.</p> <p>A public health campaign is needed to raise awareness of brain health and dementia in a similar way to the FAST stroke campaign. This would help to raise awareness what dementia is and why it is important to detect</p>	<p>To facilitate a move towards earlier diagnosis, it is important to improve the public's and health professionals' understanding of Alzheimer's as a disease that starts long before symptoms are present⁽¹⁾</p> <p>Also to challenge misconceptions of the disease such as; dementia is a condition of old age. Currently, only 23% of people recognise dementia as being caused by brain diseases (2)</p>

			it early. Consideration should be given too to the education and training available for healthcare professionals, particularly in primary care, to ensure they are also able to spot the early signs of dementia in their patient interactions.	
9	SCM 1	Additional developmental areas of emergent practice: Influence of media on public perception of dementia prevention.	Most people get their information on health issues from the media. TV, newspapers etc. This can significantly influence their belief system on a topic.	Most advice on healthy living is focussed on outcomes around cardiovascular disease, cancer and respiratory disease. We have not yet made a concerted effort to use the issue of dementia in encouraging healthier lifestyles in individuals and as a lever to encourage wider system change to create environments that support people to pursue healthier behaviours that may contribute to lower risk of developing dementia.
10	Royal college of Psychiatrists – Faculty of Old Age Psychiatry	Additional developmental areas of emergent practice	Raising awareness and engagement with research (as per PM dementia challenge) ... Training underpins all of the above.	Role for training with greater clarity on the distinction between the neurocognitive (amnesia, agnosia, apraxia and agnosia); and neurobehavioural (apathy, disinhibition) components of the full range of dementias. Alongside the common neuropsychiatric associates (e.g. generalised anxiety disorder). Awareness should be raised that certain neurobehavioural phenotypes can have significant impact at an early stage preceding significant cognitive decline.
Prevention				
11	Alzheimer's Research UK	Priority 1. Mid-life dementia risk reduction	We would like to highlight the need to ensure the quality standards cover dementia prevention and risk reduction for all age groups and for both those with and without a diagnosis of dementia. There is a growing evidence base to suggest that several lifestyle and health factors that may reduce the risk of developing dementia, as recognised in the 2015 NICE Public Health guidance (NG16).	Public awareness of the potential to reduce the risk of developing dementia through modifiable lifestyle and health factors is low. Recent polling for Alzheimer's Research UK by YouGov indicates only 34% of UK adults think it's possible to reduce the risk of dementia, compared to over three quarters (77%) who recognise that the risk of heart disease can be reduced. Current research estimates that up to 30% of dementia cases may be avoidable through changes to these lifestyle and health factors. Without greater public knowledge and understanding of the

			Given that over 850,000 people in the UK currently have dementia and there is currently no disease modifying intervention to slow or delay the disease progression, all opportunities to reduce the risk of developing dementia should be explored.	role of part of a range of actions, the general public will not be fully able to make choices about reducing their risk of developing dementia.
12	British and Irish Hypertension Society	Treatment for hypertension	There is overwhelming evidence from longitudinal studies that good control over blood pressure in mid-life prevents loss of cognition in later life. This is now accompanied by exciting clinical trial data.	Hypertension is often referred to as the 'silent killer'. As a result many patients remain undiagnosed. Furthermore, up to a third of patients may not have their hypertension treated to the current guidelines. Broader education and access programmes are needed if the dementia associated with poorly controlled hypertension is to be prevented.
13	North West Boroughs NHS Foundation Trust	Additional developmental areas of emergent practice	NICE Guidance should include information about Dementia prevention	The number of people with dementia is expected to almost double in the next two decades. 35% of dementia is attributable to the following modifiable risk factors: Education to a maximum of age 11–12 years, midlife hypertension, midlife obesity, hearing loss, late-life depression, diabetes, physical inactivity, smoking, and social isolation.
14	Nottinghamshire County Council Public Health	Key area for quality improvement 1 Include potential dementia prevention benefits of healthy lifestyle changes in activities and wellbeing programmes promoting healthy lifestyles and Making Every Contact Count (MECC)	There is good evidence that some common unhealthy behaviours can increase the risk of dementia and that addressing those behaviours will reduce the likelihood of developing dementia as well as other non-communicable chronic conditions. https://www.nice.org.uk/guidance/ng16	Mental health problems (including Dementia) and promotion of positive mental wellbeing often receives limited attention in health improvement work, and is not well integrated with action on other priority public health issues such as tobacco, alcohol or obesity https://www.kingsfund.org.uk/sites/default/files/field/field_publication_file/Bringing-together-Kings-Fund-March-2016_1.pdf
15	Royal College of Nursing	Key area for quality improvement 1]Risk reduction of dementia	In our view, dementia risk reduction is a priority area for quality improvement. The Alzheimer's Research UK Risk Reduction Policy Statement (2018) outlines	It is expected 30% of vascular dementia could be prevented by living well. This is the same message as healthy heart = healthy brain. All health and social care professionals should routinely promote risk reduction at every contact with

			scientific evidence which supports public policies aimed at dementia risk reduction.	patients, the benefits of this will also promote a healthier lifestyle, prevent obesity and other diseases. The approach to this varies across the UK.
16	SCM 1	Key area for quality improvement 1: Alcohol	Alcohol consumption is likely to have significant impact on onset of cognitive impairment. There are populations of people across socio economic groups who are consuming alcohol at volumes likely to cause cognitive issues. Whilst some of these groups are more affluent and so historically not generally as targeted a population as less affluent groups we may see high risk groups for dementia emerging which would create some inequality. Simultaneously it seems that whilst recent evidence shows a downturn in alcohol consumption in some groups of young people it may well be that they are better educated and have more family income than other groups who we know continue to drink at higher levels. Again this is an equality issue.	Alcohol is deeply embedded in many social interactions. Consumption is widespread and further powerful alcohol advertising and new products brought to market are likely to keep alcohol an ever-present risk factor for some considerable time to come. Not only is alcohol a significant factor in increasing the risk of development of dementia but could also exacerbate symptoms and problems if people in any stage of dementia continue to drink. There is very little local action to address prevention in relation to alcohol. The majority of effort and funding is put into treatment services for those who have significant drug and alcohol problems. On a population level this treatment provision will not have an impact. Even if large numbers of people with alcohol issues pass through the services (which they don't or if they do, do not complete the full programme or even if they do often relapse) it will not provide a population level upstream intervention. There is a sense that politically or within health sector removing or disinvesting in individual treatment sessions would be hard and therefore there is no likelihood of any real investment in prevention of alcohol problems.
17	SCM1	Key area for quality improvement 2: Stress		
18	SCM 1	Key area for quality improvement 3: Physical activity		

19	SCM 1	Key area for quality improvement 4: Managing dementia has more focus than prevention.	The majority of funding and effort is seemingly being invested in managing onset of dementia and very little is being directed towards prevention. Dementia friendly is now widespread and continuing to develop. Whilst this is welcome the sole focus on this aspect of dementia cannot be the most sensible approach to tackling dementia overall.	There appears to be very little (if any) focus within public health and wider health settings on the prevention of dementia. Even though there may be discreet and specific activities that may be preventative such as physical activity options, reducing smoking these are not in place to prevent dementia or are not promoted as such. When cost effectiveness is being taken into account for the collection of programmes that may contribute to prevention and funding is being allocated to put that programme in place, no connection is made to it contributing to dementia prevention. This not only reduces the potential impact of such programmes due to reduced funding but the concept of dementia prevention is not being considered in public health and other health agencies so it does not increasingly increase its importance in local decision making. It would help the concept of dementia prevention if all programmes know to contribute to reduction always had included in measure and outcomes as much as for example cardiovascular disease or cancer.
20	SCM 2	Clear guidance on the best methods for reducing the risk of developing the various dementias.	Many people do not believe that you can reduce the risk of developing dementia.	With suitable advice and guidance and support services we could significantly delay the progression of dementia in the population and greatly reduce the increasing costs of health and social care and the related costs to the economy.
4.2 Diagnosis				
Earlier diagnosis				
21	Alzheimer's Research UK	Priority 2. Diagnosis of dementia – sustaining current rates and moving towards earlier diagnosis	<ul style="list-style-type: none"> a. Dementia diagnosis rate remains at 70% in England, which while having improved considerably in recent years, does mean that significant numbers of people remain unaware of their condition. b. Earlier diagnosis of Alzheimer's disease has several benefits, from enabling people to get access to the right care and support to being able to participate 	<ul style="list-style-type: none"> a. Sustaining the dementia diagnosis rate is essential to ensure people with dementia and their families can access the support and care available after diagnosis. b. For any new treatment to be effective we need to offer diagnosis at a much earlier stage, possibly before clinical symptoms of dementia are present. The new NICE dementia guideline highlights the role of CSF and PET scanning to

			<p>in research. Alongside this, current research evidence suggests that disease modifying drugs are likely to offer maximum benefit at the earliest stages of disease. However there remains low awareness and understanding amongst the public, clinicians and the wider health service of this potential.</p>	<p>help diagnose dementia, which can support earlier and often more accurate diagnosis.</p>
22	Alzheimer's Society	Ensuring everyone with dementia receives a timely, accurate and appropriate diagnosis	<p>A diagnosis opens the door to the support and information needed to help people manage the condition and plan for the future, to maintain independence and reduce deterioration of health and prevent future crises.</p> <p>The Dementia Statements include 'We have the right to an early and accurate diagnosis'.</p> <p>The report 'Unlocking diagnosis' (2015) from the All Party Parliamentary Group (APPG) on Dementia documents evidence of the importance of diagnosis.</p>	<p>Whilst huge improvements have been made in diagnosis since 2012, and the national diagnosis rate now reaches 67.8%, it is estimated that there are still over 200,000 people with dementia in England without a diagnosis, which means they are without access to the information and support that can help them to live well. There is also considerable regional variation across the country, with 77 CCGs not having met the government's two thirds diagnosis rate target.</p>
23	Dementia Industry Group	NHS use of diagnostic tests for Dementia	<p>This is vital because future treatments are likely to deliver the greatest benefit to patients when initiated at the early stages of the disease and a diagnosis provides people with dementia with an opportunity to plan for their future care needs. (NICE) To support the early diagnosis of dementia, we suggest that NICE recommends that the diagnosis of dementia is integrated and aligned with Public Health England's NHS Health Check programme on dementia and clinicians are supported to understand the very early signs and symptoms of dementia and Alzheimer's disease.</p>	<p>To move towards earlier diagnosis, it will be important to improve the public's and health professionals' understanding of Alzheimer's as a disease that starts long before symptoms are present, and to challenge the misconception that dementia is a condition of old age¹. Currently, only 23% of people recognise dementia as being caused by brain diseases².</p> <p>Reference 2: YouGov polling for Alzheimer's research UK</p>

24	NHS England Dementia Policy Team	Key area for quality improvement 1 Dementia Diagnosis	<ul style="list-style-type: none"> • A timely dementia diagnosis is the gateway to help ensure that people living with dementia receive the right support and treatment which will enable them to lead full lives, engaged with their families and communities, for as long as possible. • Early diagnosis gives people the best opportunity to plan for the future, and can help prevent crises. • To support the introduction of new treatments into the health system, the infrastructure needs to be set for getting the right people the right care at the right time. Early diagnosis is essential for this. 	Since the national challenge on dementia 2020 to increase access to formal diagnosis from less than half to two-thirds of people affected, considerable progress has been made. However, unwarranted variation exists between areas and needs to be addressed.
25	Roche Products Limited	<p>Public health campaign to Increase the awareness of brain health including dementia among the general public</p> <p>Specifically the importance of early detection of dementia which could lead to earlier diagnosis</p>	<p>More consideration needs to be given to the whole pathway. Early detection leading to early diagnosis is important. The two must be given equal priority to best support appropriate care provision and treatment.</p> <p>The early signs of dementia are not well known by the majority of the public and often go undetected. Those who could benefit from treatment may not be aware of the benefit of earlier detection of Dementia.</p> <p>An accurate and early diagnosis of dementia is highly dependent on friends and family members making a critical intervention which results in an engagement with an informed healthcare professional.</p> <p>For this to happen, an increase in awareness of early signs and symptoms is important among the general public.</p>	<p>To facilitate a move towards earlier diagnosis, it is important to improve the public's and health professionals' understanding of Alzheimer's as a disease that starts long before symptoms are present(1)</p> <p>Also to challenge misconceptions of the disease such as; dementia is a condition of old age. Currently, only 23% of people recognise dementia as being caused by brain diseases (2)</p>

			A public health campaign is needed to raise awareness of brain health and dementia in a similar way to the FAST stroke campaign. This would help to raise awareness what dementia is and why it is important to detect it early. Consideration should be given too to the education and training available for healthcare professionals, particularly in primary care, to ensure they are also able to spot the early. Signs of dementia in their patient interactions.	
26	SCM 3	Key area for quality improvement 1 Opportunities for early assessment where concerns about dementia	Assessment in GP surgeries as well as specialist services that are accessible in a reasonable time frame for the individual.	People who are concerned about a possible dementia should be able to access an assessment close to home by someone with the appropriate expertise. The earlier people can access this the better able individuals can navigate the health and social care systems when required and can be more involved in making decisions about their future care.
Diagnosis				
27	Association of British Neurologists	Services that diagnose people with young onset Alzheimer's disease and vascular dementia, and people with bvFTD at any age have access to genetic counselling and testing.	Patients with young onset Alzheimer's disease and vascular disease, and FTD are at increased risk of harbouring a causative genetic mutation.	Knowledge of a genetic mutation has implications for individuals and for family members who may be at risk of dementia on this basis. There is large variation across the country for genetic testing
28	Association of British Neurologists	Services that diagnose dementia have access to biomarkers as recommended by NICE, e.g. CSF biomarkers and FDG-PET for the diagnosis of Alzheimer's Disease, FDG-PET for the diagnosis of frontotemporal dementia and DaT for the	Accurate diagnosis of dementia subtypes increasingly relies on biomarkers, as reflected by NICE guidance	There is very considerable variation in provision of biomarkers recommended by NICE

		diagnosis of Dementia with Lewy Bodies.		
29	Association of British Neurologists	Key area for quality improvement 4	Brain imaging performed for dementia diagnosis is reported according to standardised criteria by radiologists with appropriate training in brain radiology.	NICE guidance suggests that as part of the the assessment of patients with dementia, clinicians should: <i>“Offer structural imaging to rule out reversible causes of cognitive decline and to assist with subtype diagnosis, unless dementia is well established and the subtype is clear”</i> The utility of scanning is highly dependent on the quality of the scan report – which is very variable. Criteria for rational scan reporting, including simple visual rating scales and standards are available and have but these are used very variably.
30	Biogen	Initial assessment in non-specialist clinic 1.2.6 % of patients with suspected dementia seen by a specialist dementia diagnostic service	Specialist assessment to increase diagnosis accuracy will be important as new treatments become available	As new treatments become available correct diagnosis will become more important
31	Biogen	Diagnosis in a specialist dementia diagnostic service 1.2.9 Diagnose a dementia subtype (if possible) if initial specialist assessment (including an appropriate neurological examination and cognitive testing) confirms cognitive decline and reversible causes have been ruled out	Correct diagnosis of dementia subtype will determine the treatment and management plan	As new treatments become available correct diagnosis of dementia subtype will become more important
32	Biogen	Diagnosis in a specialist dementia diagnostic service Further tests for Alzheimer’s disease	Correct diagnosis of Alzheimer’s pathology will determine the treatment and management plan	No disease modifying treatments for Alzheimer’s are currently available but there are potential treatments in clinical development that are likely to require this information before treatment initiation

		<p>1.2.15 If the diagnosis is uncertain (see recommendation 1.2.14) and Alzheimer's disease is suspected, consider either:</p> <p>FDG-PET (fluorodeoxyglucose-positron emission tomography-CT), or perfusion SPECT (single-photon emission CT) if FDG-PET is unavailable Or examining cerebrospinal fluid for:</p> <ul style="list-style-type: none"> ◦either total tau or total tau and phosphorylated-tau 181 and ◦either amyloid beta 1–42 or amyloid beta 1–40 		
33	Imperial College Healthcare NHS Trust	Key area for quality improvement 1	Use of Amyloid PET Imaging in the Diagnosis of Alzheimer's Disease in Atypical and Young Onset Cases	Patients with young onset and atypical dementia often have delayed diagnosis with adverse effects on patients and their carers. Delayed diagnosis also delays treatment and limits access to appropriate clinical trials
34	London Dementia Clinical Network	<p>Key area for quality improvement 5</p> <p>Timely diagnosis; with the aim of achieving the 6 week time frame from referral to diagnosis.</p>	<p>Improved/quicker access to post diagnostic interventions; for example, pharmacological, Cognitive Stimulation Therapy, Carer support/START.</p> <p>LPA (Lasting power of attorney) while person has capacity.</p> <p>Within the NICE guidelines</p>	Process of diagnosis often hindered by delays in memory service pathways. There are considerable variations across services which are dependent on commissioning and resources. Delays related to staffing levels, clinic space, access to timely scans etc
35	Mencap	People with a learning disability and dementia receive timely, accurate diagnosis. Health and social care professionals involved in their care are aware of signs of	Late dementia diagnosis can result in unnecessary transfer to residential or nursing care homes and loss of contact with social networks and activities. Early diagnosis provides the opportunity for advanced planning. This may involve	<p>Diagnosis of dementia is often late in people with a learning disability, due to different presenting and diagnostic overshadowing.</p> <p>Baselines, though now included in the optional annual health check template from NHS England, are</p>

		dementia and, where appropriate, how to adjust diagnostic pathways to meet the needs of people with a learning disability.	ensuring that there is a good record of an individual's likes and dislikes in relation to food, clothes, people, or places, for when they are no longer able to express preferences.	not always taken. These can provide a key indication of changing needs or deterioration.
36	National Clinical Director for Dementia	Maintaining the current dementia diagnosis rate which is consistently around two thirds (i.e. the number of people recorded as having dementia on QOF registers in primary care divided by the estimate of prevalence)		
37	National Clinical Director for Dementia	People with dementia having access to new techniques for early diagnosis – the ARUK report “Thinking Ahead” is a good example here		
38	National Clinical Director for Dementia	People with dementia having access to a waiting time of six weeks between referral to first assessment and care plan		
39	NHS England Dementia Policy Team	Key area for quality improvement 2 Dementia care pathways: referral and treatment	<p><u>NHS Operational Planning and Contracting Guidance 2017-18</u> sets an expectation in providing dementia care to:</p> <p>Increase the number of people being diagnosed with dementia, and starting treatment, within six weeks from referral.</p> <p><u>NOTE: The Dementia Care Pathway details this as: if a person is diagnosed with dementia</u></p> <p>They have met with a named coordinator of care; and a care plan of NICE-recommended care for dementia has been agreed with them (and, if appropriate, their family and/or carer).</p> <p>Improve the quality of post-diagnostic treatment and support for people with dementia and their carers.</p> <p>The Implementation and Resource Pack for Dementia Care indicates that clinical</p>	<p>There is significant unwarranted variation between areas and clinics in the number of people being diagnosed with dementia and starting treatment, and therefore access to appropriate post diagnostic support. Also, the visibility in the quality of post diagnostic support is highly limited.</p> <p>Data from the Second English National Memory Clinics Audit Report, indicates significant variation between clinics and that the average waiting time from referral to assessment was 5.4 weeks, with a further 8.6 weeks between that assessment and receiving a diagnosis.</p>

			pathways should be tailored to people's personal circumstances. Case studies involving service users and carers in service design include: Newcastle Memory Assessment & Management Service and Gellwood House memory service, Carlisle	
40	Parkinson's UK	Improve diagnosis of people with dementia with Lewy bodies in clinical settings.	<p>It is important for people to receive a diagnosis of dementia with Lewy bodies so that family, carers and partners can plan for a person's care needs and help prepare emotionally for potential behavioural changes.</p> <p>These plans can also ensure that people with dementia with Lewy bodies avoid being prescribed potential harmful anti-psychotic medication. (Galvin, J. E., & Balasubramaniam, M. (2013). 'Lewy Body Dementia: The Under-Recognized but Common FOE'. Cerebrum: The Dana Forum on Brain Science, 2013, 13.)</p>	<p>The proportion of people with dementia getting a diagnosis of dementia with Lewy bodies in the UK is low compared to other countries in Europe.</p> <p>(Freer Joseph. (2017) 'UK lags far behind Europe on diagnosis of dementia with Lewy bodies' <i>BMJ</i> ;358 :j3319).</p> <p>It is recognised that there are difficulties in diagnosing dementia with Lewy bodies due to overlapping features with Alzheimer's disease, however this is not helped by a lack of understanding of this sub-type among clinicians. However, there are several symptoms that make dementia with Lewy bodies distinct from Alzheimer's disease, for example Parkinson's like movement symptoms, visual hallucinations, and rapid eye movement sleep behaviour disorder.</p> <p>(Galvin, J. E., & Balasubramaniam, M. (2013). 'Lewy Body Dementia: The Under-Recognized but Common FOE'. Cerebrum: The Dana Forum on Brain Science, 2013, 13).</p> <p>If left undiagnosed there is a risk of being prescribed anti-psychotic medication used for people with different types of dementia but is harmful to people with dementia with Lewy bodies and Parkinson's dementia. This important feature was recognised in the recently updated NICE Dementia: assessment, management and support for people living with dementia and their carers guideline [NG97]. This</p>

				shows the importance of the need for improvement in diagnosis rates of dementia with Lewy bodies.
41	Parkinson's UK	Increase the proportion of people with suspected dementia who are referred to a memory assessment service specialising in the diagnosis and initial management of dementia.	<p>The diagnosis of people with Parkinson's dementia and dementia with Lewy bodies will often not be done in a memory clinic.</p> <p>It is crucial to get an accurate indication of people with a diagnosis of Parkinson's dementia and dementia with Lewy bodies and using a memory clinic alongside other services may assist in improving services for people with Parkinson's dementias.</p>	<p>The current metric used in quality statement 2 - People with suspected dementia are referred to a memory assessment service specialising in the diagnosis and initial management of dementia in 'Dementia: support in health and social care (QS1)' needs to be expanded to include neurology (movement disorder) services and geriatric medicine services, to include more people with Parkinson's related dementias.</p> <p>This is important in terms of planning services and ensuring people receive a joined-up approach to care and access to memory services for those not diagnosed in a memory assessment service.</p>
42	Roche Products Limited	Improved early diagnosis of dementia	<p>Variation exists in performance of the 2/3 diagnosis target across CCGs. There should be a focus on consistent delivery of this goal so that the health system is better placed to give people with dementia the right treatment at the right time. This should include assessing if any clinical trials could be appropriate.</p> <p>Better understanding of the current state of the art automated biomarker protein assays would make access to early diagnosis easier.</p> <p>Practicalities of increased demand on the healthcare system for sample taking for biomarker screening should a DMT become available.</p>	<p>Variation exists across CCGs in diagnosis of dementia</p> <p>Some areas in England fall short of the 2/3rd diagnosis rates set e.g. West Somerset at 45.1% or City of London 48.3%(3) Each CCG area in England should be achieving the 2/3rd dementia diagnosis rate target by 2020.</p> <p>Better informed dialogue on the availability of automated biomarker assays in the CSF for help in early diagnosis and continued discussion on the increased reliability of these assays.</p> <p>Clinical discussions on the practicalities of increased uptake of CSF sampling should a DMT become available. Potential for blood based biomarkers.</p>

43	Roche Products Limited	Early detection of Dementia utilising risk-profiling and molecular-based tests	<p>Current scientific evidence suggests that if disease-modifying treatments become available they will be most effective at the earlier stages of Alzheimer's. The health system should be proactive in preparing for how DMTs can be integrated into the patient pathway to deliver maximum benefit to people with dementia and the health system.</p> <p>Alzheimer's Research UK modelling shows that by treating earlier, people will live with mild symptoms for longer before these symptoms worsen, and there will be fewer people living with dementia (1)</p> <p>Moving towards earlier diagnosis will require an increase in public and health professional understanding that Alzheimer's starts long before symptoms are present. Therefore, it is necessary to scope the barriers and opportunities within the NHS to shifting towards earlier biomarker protein detection and/or molecular-based diagnosis.</p>	<p>To move towards earlier diagnosis, it will be important to improve the public's and healthcare professional's understanding of Alzheimer's as a disease that starts long before symptoms are present, and to challenge the misperception that dementia is a condition of old age.</p> <p>To enable patients to have access to newer disease modifying treatments, it is vital to utilise data in risk-profiling at risk populations, in combination with a molecular - based diagnosis so that treatment begins as early as possible.</p>
44	Royal College of General Practitioners	Keeping a register of patients with dementia	The key aspect of this is the removal of the questionable use of diagnosis rates, which is a current indicator. There are strong arguments that this is unethical, can lead to overdiagnosis and that true diagnosis rates are extremely difficult to estimate.	The emphasis needs to be on accurate, timely diagnosis, not a drive for diagnosing in order to achieve a target. Contrary to other quality indicators (eg prescribing a statin in heart disease), a patient cannot opt out of a diagnosis in the same way that they can choose not to take a pill.
45	Royal Liverpool & Broadgreen University Hospitals NHS Trust	Key area for quality improvement 1 QS1 Dementia Delirium		
46	SCM 4	Key area for quality improvement 3	There is clinical variation in whether people with dementia are appropriately considered for acetylcholinesterase inhibitor	There is variation amongst services as to how a diagnosis is reached and when medication is offered. This is evident in varied commissioning arrangements

		People with dementia should be provided with a specific diagnosis and be offered medications in line with NICE guidance	medication. For consideration of medication a diagnosis of a specific dementia subtype is necessary.	between CCG. Some of this data is available through local services but is not routinely reported or collected.
4.3 Care coordination				
Coordinated care				
47	Alzheimer's Society	Access to a single person coordinating care	<p>This is important so the person with dementia and their carers have access to the personalised and tailored support and information they need to manage the condition and plan for the future. This can help maintain good health and quality of life, and can avoid or delay crises. This is particularly important considering the number of different professionals people with dementia often come into contact with. A single named care coordinator is also important to ensure the individual's changing needs continue to be met as the condition progresses.</p> <p>Analysis of care navigators conducted by NEF Consulting found for every £1 invested, £3.84 worth of value is created. Support from a navigator resulted in increased knowledge and information, increased peer support networks, and reduced carer breakdown.</p> <p>Access to a named person coordinating care is recognised in the NICE guideline (1.3).</p>	<p>We often hear of people who have received virtually no support between diagnosis and developing significant care needs. In our Turning up the volume report people told us they felt like they had been left to fend for themselves, with no offer of help and little hope for assistance in the future.</p> <p>The Challenge on Dementia implementation plan states from its consultation work, 'We heard a consistent message from people who reported that on receiving their diagnosis, they faced a bewildering future and felt alone in facing this. People with dementia and carers told us of their urgent need for information, advice and support both immediately after diagnosis and to help them through the stages of their journey with dementia.'</p>
48	Association of Directors of Adult Social Services	Improvements in partnership working between Health and Social care with all team members- acknowledging their own responsibilities and have appropriate skills, knowledge and understanding in this field. Managers making decisions about future of Dementia care to fully involve informal Carers and the general workforce from both Health & Social Care teams		

49	The Down's Syndrome Association	Streamlined working across health and social care settings and workforces, including seamless budgets and information sharing.	Individuals with dementia and their family-carers often fall between the gaps between health and social care. Dementia is undoubtedly a health / medical condition but much of the support necessary maybe provided with a social-care context.	Widespread acknowledgement amongst health and social care professionals, the media, politicians and policy makers and the general public. There seems to be a consensus that this needs to be addressed and a new way of working developed.
50	London Dementia Clinical Network	Key area for quality improvement 1 Everyone with dementia has a named coordinator of care	NICE has recommended that everyone with dementia should have a care coordinator. People living with dementia and cares have also highlighted how valuable this is. Important to have a named person as point of contact who can provide advice and support as the person deteriorates & their needs change.	We have found that provision of this various, our London audit highlighted that only 66% of people were referred to a dementia advisor and this was a low as 49% in one borough. Service users and carers have reported frustration & distress at not having a contact person to contact in times of need. Good care plan and named contact person may decrease hospital admissions as help is sought at an earlier stage. There are different models of care coordination and a lack of systematic commissioning and implementation of this. Process of diagnosis often hindered by delays in memory service pathways. There are considerable variations across services which are dependent on commissioning and resources. Delays related to staffing levels, clinic space, access to timely scans etc
51	Royal College of Nursing	Key area for quality improvement 4 Integrated care and support	There is evidence that outcomes are improved for people living with dementia requiring services from health and social care with improved communication between services and organisations	Integrated care and support can prove difficult with different budgets and accommodation. Integrated care models vary across the UK. The Red Bag pathway is an initiative which supports integration, however this has not been adopted by all.

52	Royal College Of Speech & Language Therapists	Key area for quality improvement 2 Moving towards a community based model of care	<ul style="list-style-type: none"> • Enhanced communication across care services • Coordinated care • Reducing exposure to infection • Reducing admission into busy chaotic hospital environments 	<p>To improve care by enabling multidisciplinary teams to make recommendations to care/nursing homes and in this way supporting people living with dementia.</p> <p>Reduce hospital admissions which can be confusing for people with dementia</p> <p>community workforce to support frail older people at all stages</p> <p>Ensuring teams are equipped with models of care to support the individual, as best as possible in their own home rather than for the person with dementia to be over medicalised and admitted for a joint multidisciplinary approach.</p> <p>Implementing the new models of care</p>
53	SCM 5	Key area for quality improvement 2 Identification of a single named professional who will plan and co-ordinate care	If care is not co-ordinated, it can seem fragmented to people with dementia and carers, who may not know who to turn to for advice, while health and social care professionals may assume that other members of the multi-disciplinary team are co-ordinating care provision when this is not the case. It is important therefore to ensure that care is co-ordinated and this is best achieved by nominating a single individual to hold this responsibility.	Evidence from studies of case management indicates that it is beneficial to have a single named person co-ordinating care and that this improves quality of life for people with dementia and reduces burden for carers.
54	SCM 6	Key area for quality improvement 4 Effective on-going care coordination for the person with dementia.	Effective care coordination supports continued independence for the person with dementia and carers of people with dementia.	The organisation, delivery and frequency of care coordination for people with dementia is variable in its delivery and effectiveness. There is no clear model for which local services should co-ordinate this. "The number of people with dementia admitted to hospital in an emergency rose by 48% between 2008 and 2013. Around a fifth of these admissions related to potentially preventable acute conditions such as urinary tract infections, pneumonia, and other respiratory infections."

				<u>Public Health England (2018) Dementia: applying 'All Our Health'.</u>
55	SCM 7	Care planning and care co-ordination	Standardising and providing information and advice in a planned way to allow individuals to access the correct care and support in a timely manner and when necessary.	Evidence indicates that individuals who are provided a plan of care and support with a named person is effective
56	SCM 7	Additional developmental areas of emergent practice	Place based care / care closer to home.	There are emerging local and integrated care organisations that are facilitating joint funding arrangements in the delivery of integrated health, mental health and social care to provide streamlined care closer to home and reduce the frequency of hospital admissions and admissions to long term care.
Care planning				
57	Alzheimer's Society	Use of person-centred, holistic care plans, developed in partnership with the person with dementia	This is important because the needs of a person with dementia are complex and also change over time as the condition progresses. Person-centred planning is vital to ensure the right support is delivered at the right time to maintain health, independence and quality of life, and to avoid or delay crises, and plans should be recorded in a care plan. The Dementia Statements reflect things that are important to people with dementia, and care plans developed in partnership with the person with dementia can help meet the statement, 'We have the right to be respected, and recognised as partners in care, provided with education, support, services, and	<p>We frequently hear from people that report not receiving the support they need. As per the previous response, in our Turning up the volume report people we interviewed told us they felt like they had been left to fend for themselves, with no offer of help and little hope for assistance in the future.</p> <p>This suggests that whilst statistics from NHS Digital report around 65% of people with a diagnosis of dementia have a care plan that has been put in place or reviewed over the past 12 months, these may not always be fit for purpose. It may be that care plans are not sufficiently person-centred or developed in partnership with the person with dementia.</p> <p>NHS England developed a guide, NHS England Dementia: Good Care Planning, to help improve care</p>

			<p>training which enables us to plan and make decisions about the future’.</p> <p>Care plans are recognised in the NICE guideline (1.3).</p>	<p>planning by supporting a standardised approach and helping to reduce local variation in practice.</p>
58	Care & Repair England	Support for people to remain independent as long as possible in a home that meets their needs as dementia progresses	<p>Having a good, decent, warm, accessible home is important in supporting the delivery of good care and support services people with dementia.</p> <p>Housing interventions such as repairs and adaptations to the home to make the home more suitable or a well thought through move to more supported or specialist housing, if appropriate, are essential ingredients in delivering good care and support services for people with dementia</p> <p>Ensuring that a person’s home environment is considered when a person is diagnosed with dementia and as the condition progresses makes good sense where the aim is to enable people to live with dignity and independence in the community.</p>	<p>Evidence that areas requires improvement include: -</p> <p>Information and advice Information on the options available and related advice are key to ensuring a positive experience of the provision of care and support services. We consider this should include housing options and solutions more clearly in considerations of a person’s social care and support needs. This has not always been the case. A short study undertaken by older people in the NW of England, for example, identified shortcomings in the information and advice available on housing options locally. We know that this is also the case in other parts of the country. Offering bespoke advice and information at the right time and in the right format is crucial to enable people with dementia and their carers to make the best choices for them.</p> <p>http://ageactionalliance.org/search-engine-failure-housing-and-care-advice-in-the-north-west/</p> <p>Care assessment Ensuring housing factors are properly considered will mean that people dementia live in the right (warm, safe, secure) environment to provide the foundation for their care and support, and their health and wellbeing as they age.</p> <p>The Care Act 2014 expects that housing factors are part of an integrated assessment. It also calls for housing options to be considered in the provision of information and advice highlighted above. This</p>

				<p>recognises that a consideration of people's housing needs and circumstances is essential to good social care and support. We would suggest that the variable practice in this area could be improved by adding a consideration of where and how people live – their housing - to this quality standard.</p> <p>Care planning and provision</p> <p>We would like to see more focus on ensuring that the care plan and thus the provision on offer includes the person's housing circumstances and needs. This means identifying and planning actions that will improve their home circumstances as people with dementia age - for example home adaptations, home repairs or moving options. It also means ensuring that the support needed to undertake these agreed housing changes can be identified, put in place and monitored over time.</p>
59	London Dementia Clinical Network	<p>Key area for quality improvement 2</p> <p>Everyone with dementia has a care plan that is able to be shared and is reviewed at least annually using a very effective IT (Information Technology) system allowing for sharing of care plans ideally hospital, social services and community services IT linked.</p>	<p>NICE has recommended that a care coordinator should develop a care and support plan and that Service providers should ensure that information can be easily transferred between different care settings. The care plan should reflect change in needs</p> <p>Care planning can prevent crisis and hospital admissions</p>	<p>Care planning is very variable, particularly the quality of care plans. There is also poor sharing of plans.</p> <p>Holistic care ensuring all agencies are informed of changing needs allowing them to address these needs and ensure less admissions to hospital and long term care</p> <p>NHS England (2017) Dementia: Good Care Planning - https://www.england.nhs.uk/publication/dementia-good-care-planning-information-for-primary-care-and-commissioners/</p>
60	Neurology Academy Limited	Key area for quality improvement 5	Ensuring all patients have a care plan	<p>When a diagnosis of dementia has been made, each person and their family and/or carer should be offered a consistent level of post-diagnostic support. Personalised dementia care planning is a crucial factor in helping to ensure the right care is delivered at the right time for people living with dementia, and supporting their families and carers.</p>

				<p>The Dementia Care Pathway sets out that the 'post-diagnostic treatment and support' offered should be NICE-recommended, and support needs should be outlined in the initial care plan. This care plan should be reviewed within at least 12 months of being agreed, then reviewed every 12 months in accordance with changes in the person's needs. Revisions should be jointly developed and agreed with the person (and, if applicable, their carer). A good example of the implementation of this would be a dementia advisor, or coordinator of care, with whom the person diagnosed with dementia can co-create a meaningful care plan in which they feel invested.</p>
61	NHS England Dementia Policy Team	<p>Key area for quality improvement 3</p> <p>Post diagnostic treatment and support for people with dementia and their carers</p>	<p>When a diagnosis of dementia has been made, each person and their family and/or carer should be offered a consistent level of post-diagnostic support. Personalised dementia care planning is a crucial factor in helping to ensure the right care is delivered at the right time for people living with dementia, and supporting their families and carers.</p> <p>The Dementia Care Pathway sets out that the 'post-diagnostic treatment and support' offered should be NICE-recommended, and support needs should be outlined in the initial care plan. This care plan should be reviewed within at least 12 months of being agreed, then reviewed every 12 months in accordance with changes in the person's needs. Revisions should be jointly developed and agreed with the person (and, if applicable, their carer).</p> <p>A good example of the implementation of this would be a dementia advisor, or coordinator of care, with whom the person</p>	<p>Quality Outcomes Framework (QOF) data indicates that 77% of patients with a recorded diagnosis of dementia received a face to face care plan review in the previous 12 months, but <u>this does not record whether their care plan was of high quality.</u></p>

			diagnosed with dementia can co-create a meaningful care plan in which they feel invested.	
62	SCM 1	Key area for quality improvement 5: Housing		
63	SCM 5	Key area for quality improvement 5 Transfer of information between care settings	People with dementia are likely to experience transitions between care settings, for example from home to care home, or from either of these to and from hospital. During these transitions there may be a failure to effectively communicate information about the person's needs and wishes. Staff receiving a person with dementia need to understand that person's wishes and preferences for care in order to be able to provide good-quality person-centred care and ensure appropriate decisions are taken (e.g. decisions about attempting resuscitation).	Important information is commonly missing following transfers or is in a form that means it is not readily understood. There is a need to ensure that information accompanies the person and is provided in an accessible format.
64	SCM 8	Additional developmental areas of emergent practice	Use of technology to support people to live well, independently.	Support independence, and manage safety, choice and dignity.
Making services accessible				
65	Action on Hearing Loss	Improving the accessibility of dementia services for people with hearing loss	The NICE guidelines for Dementia: Assessment, management and support for people living with dementia and their carers[37] notes "there are many subgroups of people living with dementia who may have different information needs" which need to be considered. People with hearing loss will have different communication needs and, in addition, someone with dementia may require information in easy read format or advocacy support. Aside from information in accessible formats, such as Easy Read or advocacy support, people with dementia who are deaf or have hearing loss may	Although all organisations that provide NHS services are legally required to follow the Accessible Information Standard, research shows that often this is not the case. Findings from NHS England's review on the Accessible Information Standard showed that although there was widespread support for the Standard, significant challenges remained in terms of its implementation. For example, more than half (53%) of patients who responded to NHS England's survey said they had not experienced any improvement in getting accessible information or communication support over the last six months. Many people who are deaf or have hearing loss who provided feedback to NHS England as part of their review also said they were still experiencing barriers

			<p>need a range of support to communicate well. This could include:</p> <ul style="list-style-type: none"> • Many people who are deaf or have hearing loss will find it difficult or impossible to use the telephone and may benefit from alternative contact options such as email, Text messages, Next Generation Text Relay (NGTR) or BSL Video Relay Services (VRS) • For face-to-face contact, people with hearing loss may need other people to follow simple communication tips such as speaking clearly and avoid obstructing their lip movements with hand gestures or other objects. People who use hearing aids may benefit from hearing loop systems that make speech clearer by reducing background noise. • Some people who are deaf or have hearing loss will need support from a communication professional to follow conversations, such as a British Sign Language (BSL) interpreter or Speech-To-Text-Reporter (STTR). • English may not be the first or preferred language of people who are deaf, so information should be written in Plain English. While many people who are deaf can read and write English, some cannot, so services should consider producing BSL videos of key documents or other information and promote these to the Deaf community. <p>Poor communication may cause considerable stress and anxiety for people who are deaf or have hearing loss and may lead to missed appointments and ineffective</p>	<p>to communication when accessing health and social care.</p>
--	--	--	--	--

			<p>care. Improving the accessibility of care settings will also save the NHS money:</p> <ul style="list-style-type: none"> • NHS England estimates that the cost of people with hearing loss missing appointments – because they didn't hear their name being called in the waiting room – could be as high as £15m every year. • The Ear Foundation estimates that, because of communication difficulties, people with hearing loss cost the NHS £76m in extra GP visits every year. • SignHealth estimates that missed diagnosis and poor treatment of people who are deaf costs the NHS £30m every year. 	
4.4 Management				
Interventions to promote cognition, independence and wellbeing				
66	Parkinson's UK	Improve non-pharmacological interventions for Parkinson's dementia and dementia with Lewy bodies.	There are limited drug therapies for these dementias, with many people already exposed to polypharmacy. They are reluctant to add cognitive enhancing medications.	<p>There is limited availability of non-pharmacological interventions for people with Parkinson's dementia and dementia with Lewy bodies. (Sindhi A, Leroi I. (2013) 'Non-pharmacological therapies for cognitive enhancement in Parkinson's disease: Applying old interventions in a new setting?' <i>Neurodegenerative Disease Management</i>; 3(6); p 539-547).</p> <p>There is a lack of quality evidence on the efficacy of non-pharmacological interventions for Parkinson's dementia and dementia with Lewy bodies. (Michael H. Connors et. al (2018) 'Non-pharmacological interventions for Lewy body dementia: a systematic review' <i>Psychol Med</i>. Aug; 48(11): 1749–1758.). For example in cognitive training interventions (Orgeta V, McDonald KR, Poliakoff E, Hindle JV, Clare L, Leroi I. (2015) 'Cognitive training interventions for dementia and mild cognitive impairment in Parkinson's Disease'. <i>Cochrane Database of Systematic Reviews</i>, Issue 11)</p>

				<p>There are some small pilot studies that have shown positive outcomes from non-pharmacological interventions for people with Parkinson's dementia and dementia with Lewy bodies but there is a need for a full effectiveness trial in these cases. (McCormick SA...Leroi I. (2017). Psychosocial therapy for Parkinson's-related dementia: Study protocol for the INVEST randomised controlled trial. <i>BMJ Open</i>, 7 (6). doi:10.1136/bmjopen-2017-016801; Hindle, John & Watermeyer, TJ & Roberts, Julie & Martyr, Anthony & Lloyd-Williams, Huw & Brand, Andrew & Gutting, Petra & Hoare, Zoe & Tudor Edwards, Rhiannon & Clare, Linda. (2016). Cognitive rehabilitation for Parkinson's disease demantia: A study protocol for a pilot randomised controlled trial. <i>Trials</i>. 17)</p>
67	Sunrise Senior Living	<p>Key area for quality improvement 2</p> <p>Cognitive assessment and a strengths-based approach to individual treatment, support and activity planning for individuals with dementia who are receiving health and social care</p>	<p>NICE Guidance recommends that individuals with dementia are offered a range of activities to promote wellbeing that are tailored to the person's preferences</p> <p>However, good care and enabling support needs to also identify the cognitive and functional ability of each individual in order for activities that foster abilities and address disabilities can be planned and delivered.</p>	<p>Individuals with dementia can achieve quality of life and often have higher functional potential than facilitated within a model that only addresses the psychosocial components of care. A truly person-centred approach addresses not only an individual's lifestyle preferences and emotional needs but also addresses the cognitive impairments that are undermining the person's ability to engage in these activities</p>
68	Sunrise Senior Living	<p>Key area for quality improvement 3</p> <p>Cognitive Rehabilitation Therapy for people with dementia in health and social care settings</p>	<p>NICE Guidelines recommend the consideration of Cognitive Rehabilitation Therapy in order to support the improvement of function of people with early to moderate dementia. This approach supports the emotional well-being of the individual and their family carers, provides opportunity to reduce or prevent disability and, reduces dependency on services and on others</p>	<p>Awareness of the need to improve accessibility of services and opportunities for people with disabilities is growing, but people with "hidden" disabilities such as dementia can be excluded from these developments. There is a growing social movement led by people with dementia, Alzheimer associations, and supporters that promotes acceptance, inclusion, and awareness of rights to treatment and services that can reduce disability</p>

69	SCM 3	Key area for quality improvement 3 People living with dementia are able to access interventions to promote independence, cognition and wellbeing	There is evidence that support to overcome barriers and maintain activities of daily living can improve and maintain function for longer and thus reduce carer burden. This should be accessible at all stages of the disease.	Any support that delays the requirement additional support from health or social care and maintains independence in activities of daily living to maintain the person at home, reduce carer burden and delay admission to a care facility. It will also impact on the persons mood and quality of life
70	SCM 3	Key area for quality improvement 5 People living with dementia are offered appropriate support to proactively maintain their physical and mental health and wellbeing	There is evidence to show that there is correlation between cognitive impairment and a reduced physical and mental health and wellbeing. This can increase likelihood of increased demand on health system either through GP, hospital admissions or community health services. There is a strong evidence about increased risk of falls and significant injury as a cognitive impairment increases	
71	SCM 8	Key area for quality improvement 3 Using non pharmacological approaches	Promote the use of social activities and engagement with meaningful occupation to avoid – reduce unnecessary use of medications	Use of medications to manage behaviour and use of anti depressants in dementia care could be reduced to improve quality of life.
Pharmacological interventions				
72	Royal College of Nursing	Key area for quality improvement 6 Safe use of antipsychotic medication	NICE guidelines (NG97) recognise that some medication used for treating dementia and Alzheimer's disease may cause cognitive impairment. NICE supports minimising the use of medicines associated with increased anticholinergic burden as well as the provision of guidance on medication reviews.	Without guidance, pathways etc. the cause of distress may be overlooked. Pain assessment and management should be prioritised over use of antipsychotic medication and pain as cause of distress should be excluded as best practice when considering antipsychotic medication.
73	SCM 4	Key area for quality improvement 4 Regular review of medications	As per NICE guidance there are a number of medications which can impair cognition. There are also medications recommended only for short term use for symptoms of dementia that may cause harm if continued long-term.	Medication, particularly anti-cholinergic medication, is often not reviewed or discontinued for people with a diagnosis of dementia. Similarly NICE gives clear guidance regarding medications for use for symptoms of agitation in dementia. Review of anti-psychotics is high profile, however other non-evidence based medications may be started and not reviewed eg anti-depressants and benzodiazepines.

74	SCM 6	Key area for quality improvement 3 Ensuring systems are in place to enable people experiencing Alzheimer's disease already prescribed an AchE inhibitor to access Memantine when clinically indicated.	Prior to the publication of the updated NICE Dementia guideline, many Area Prescribing Committees nationally recommended the option of either an AchE inhibitor or Memantine. There are therefore predicted to be many people living with moderate Alzheimer's disease who may now benefit from Memantine in addition to an AchE inhibitor.	There is local variation in prescribing practice and no clear recommended process for local healthcare systems to identify people with moderate Alzheimer's disease who may now benefit from Memantine in addition to an AchE inhibitor.
75	SCM 6	Key area for quality improvement 1 Minimising the use of commonly prescribed medicines associated with increased anticholinergic burden and therefore cognitive impairment.	Some commonly prescribed medicines may increase anticholinergic burden and therefore cognitive impairment for people living with dementia	Effective medication management for people living with dementia can promote independence and avoid unnecessary hospital admission or distressing unnecessary increased cognitive impairment.
Managing non-cognitive symptoms				
76	London Dementia Clinical Network	Key area for quality improvement 4 Supporting people with behavioural and psychological symptoms of dementia in care homes	NICE has recommended that As initial and ongoing management, offer psychosocial and environmental interventions to reduce distress in people living with dementia.	Some people in care homes with BPSD (Behavioural and psychological symptoms of dementia) are being unnecessarily admitted to hospitals and not being able to be discharged. Commissioning of environmental interventions in care homes various and care home need to be supported to support people with BPSD to remain in their care.
77	NHS England Dementia Policy Team	Key area for quality improvement 5 Improving crisis care and support in the community	Episodes of disturbed behaviour, such as agitation, aggression, distress and psychosis, referred to as the Behavioural & Psychological Symptoms of Dementia (BPSD), will occur in over 90% of people with dementia at some point. Managing BPSD can be difficult, particularly for carers and care home staff, who aren't always equipped or sufficiently trained to respond to challenging behaviours.	Evidence suggests that the pathway for care managing crisis for people with dementia varies widely across services in England. A key gap in service provision is the lack of information and support for people with dementia and their carers requiring immediate help. Mental health crisis services available for younger age groups intend to provide coping strategies, and attempt to address social and family factors that can lead to a crisis to help them manage their condition

			<p>In too many cases, BPSD will result in a hospital admission or delay a transfer of care from the hospital to home or a care home, due to a lack of adequate crisis support in the community. In most cases, hospital admissions for people with dementia lead to poorer outcomes with increased length of hospital stay, earlier admissions to institutional care and mortality.</p> <p>Once in hospital, people with dementia stay for twice as long as people without the condition, and are more likely to fall.</p> <p>In 2016/17 there were more than 50,000 hospital admissions for people with dementia that could have been avoided.</p> <p>In addition, there have been concerns around the inappropriate use – particularly in care homes – of antipsychotic medications to address disturbed behaviour in people in dementia, which can result in serious adverse effects.</p>	<p>and avoid hospital admissions. Similar services for people with dementia are not provisioned as equitably.</p> <p>There is evidence that dementia crisis/intensive support/rapid response teams, including in care home settings, lead to long-term savings, often through reductions to hospital admissions and can help prevent crises from escalating and the need for costly, intensive services.</p> <p>The support provided by early intervention can also improve the well-being of people with dementia and carers.</p> <p>Similarly, a lack of education and training across services, including among care home staff, impact on the ability of carers and staff to address crisis and challenging behaviours in the community, which can result in further deterioration of the person's condition and avoidable hospital admission.</p>
78	Royal College of Occupational Therapists	Key area for quality improvement 1 Psychosocial interventions, as part of post-diagnostic support provision	MSNAP recommendations section 6 (and section 2.8.7 - staff training) improving what is offered to people post diagnosis of dementia	Within those recommendations, perhaps a key area is memory services / services for people with dementia post diagnosis auditing / reviewing what non pharmacological interventions are actually offered to people, numbers who take up the offers and any outcomes collected. This could help commissioners and services consider the role / weight / resource for psychosocial approaches as well pharma.
79	SCM 5	Key area for quality improvement 4 Use of psychosocial and environmental interventions to	People with dementia, especially in the moderate to severe stages, may become distressed for many reasons, and demonstrate this distress through their behaviour, which can be perceived as	There is insufficient understanding among care staff about the nature of distress as demonstrated through behaviour that challenges, and insufficient access to specialist advice on how to respond to distress and behaviour that challenges. There is considerable

		reduce distress in people with dementia, as both initial and ongoing management, and the need for staff training to support this	challenging. Distress is not an inevitable symptom, and the reasons for the distress may very well be modifiable. We now understand that giving medication, especially anti-psychotic medication, is not an appropriate first-line response and can be very harmful. It is important to assess the possible reasons for any distress, which might include for example unrecognised pain or environmental triggers, and apply appropriate psychosocial and environmental interventions to reduce distress.	specialist knowledge and guidance in this area that can potentially be applied to create a more effective response.
Personalised interventions				
80	Mencap	Dementia services are appropriate to people's needs and age, and reasonable adjustments are made as required at the commissioning and service level.	There should be clear multidisciplinary pathways for people with a learning disability who develop dementia. People should be given age appropriate support, recognising that often people with a learning disability develop dementia at a younger age than the general population. Care must be adjusted to ensure that it meets the needs of people with a learning disability.	People with a learning disability may be placed in mainstream older adults dementia services, due to lack of specialist provision, or early planning. These services may not always be age appropriate or not able to meet the needs of someone with a learning disability.
81	Neurology Academy Limited	Key area for quality improvement 2	Development of subtype- specific treatment pathways	Whilst interpersonal variability if the rle and clinic-pathological correlation is still poor there are certain aspects of dementia subtypes which require certain inputs in terms of care and diagnosis Subtype specific carer groups , clinics and treatment pathways would improve recruitment to clinical trials, improve carer knowledge and improve outcomes for patients with Dementia, Lewy Bodies and Frontotemporal dementia
82	Royal college of Psychiatrists – Faculty of Old Age Psychiatry	Key area for quality improvement 3	Age appropriate services for Young Onset including post diagnostic support	People with YOD should have access to a specialised service

83	SCM 5	Additional developmental areas of emergent practice Provision of personalised psychological interventions to support adjustment, address specific symptoms (e.g. depression), and optimise functioning	Personalised psychological interventions are important in helping people with dementia and carers to manage the effects of the condition and to 'live well' with dementia. These include self-management approaches to support adjustment, psychological treatments for mental health problems such as depression, and rehabilitative approaches to optimise everyday functioning and independence.	Many people with dementia, and carers, do not have access to psychological interventions. In some cases local resources may be dedicated to providing interventions that are not widely acceptable to people with dementia and may have limited uptake. There is emerging evidence about the effectiveness of personalised psychological interventions. Resources currently devoted to less helpful approaches could be redirected to provide interventions that are meaningful and acceptable to people with dementia and carers and that make a real difference in their everyday lives.
4.5 Assessing and managing other long-term conditions in people living with dementia				
84	Action on Hearing Loss	Ensuring deafness and hearing loss are included as part of dementia assessments	<p>Evidence suggests that hearing loss is associated with cognitive decline and dementia.^[1] People with mild hearing loss are at twice the risk of developing dementia; with a 3-fold increase for those with moderate hearing loss and 5-fold the risk for those with severe hearing loss.^[2] Hearing loss not only is associated with the risk of onset dementia, but also accelerates the onset of cognitive decline.^[3] Hearing loss can be misdiagnosed as dementia or make symptoms of dementia appear worse.^[4] Symptoms of hearing loss and dementia are usually first presented in primary care at the GP.</p> <p>Research shows that hearing aids may reduce the risk of developing dementia,^[5] however evidence shows that only two fifths of people that need hearing aids have them. ^[6] A recent study identified hearing loss as the largest modifiable risk factor for dementia. If removed, the study states that 9% of dementia cases could be prevented.^[7]</p>	<p>The Department of Health and NHS England's Action Plan on Hearing Loss [8] states that hearing loss is a "major public health issue" and in older age, "people with hearing loss can find it difficult to follow speech without hearing aids and are at great risk of social isolation and reduced mental well-being. Social isolation has an effect on health and in older people; there is strong correlation between hearing loss and cognitive decline, mental illness and dementia."</p> <p>The Action Plan also states that "older adults with age related hearing loss are the largest patient population in need of hearing healthcare."^[9] "Adult onset hearing loss is among the top 10 disabilities in terms of years lived with disability (YLD) for those over 60 years in England and as life expectancy increases, YLD increases."^[10]</p> <p>Current evidence shows that hearing loss is the largest modifiable risk factor for dementia.^[11] Other studies have demonstrated that hearing aids slow down cognitive decline^[12] and may even slow down the risk of developing dementia.</p> <p>Research shows that people wait ten years on average before seeking help for their hearing loss</p>

			<p>Hearing loss is a serious health condition that can have an adverse impact on a person's health and quality of life.^[15] Hearing loss has been associated with an increased burden of disease amongst adults and an increased risk of mortality.^[16] Hearing loss has been associated with depression, anxiety and other mental health problems.^[17] Evidence suggests that hearing loss doubles the risk of depression.^[18]</p> <p>Unaddressed hearing loss can lead to social isolation, emotional distress and withdrawal from social situations.^[19] For example, one study found that hearing loss is associated with feelings of loneliness – but only for people who don't wear hearing aids.^[20]</p> <p>It is therefore crucial that adults with diagnosed or suspected dementia or mild cognitive impairment are referred to audiology service for an assessment and are provided with appropriate management for their hearing loss early; enabling them access to communication. Evidence also shows that the ability to maintain and adapt to hearing aids becomes increasingly difficult the older people are when they present for assessment and intervention.^[21]</p> <p>Considering hearing loss and dementia often co-occur and are particularly difficult to manage when they are experienced together, this suggests that there is significant benefit in ensuring that hearing loss is identified early, so that people can</p>	<p>and when they do, GPs fail to refer up to 45% of those reporting hearing loss to hearing services.¹⁸ There is also considerable variation across England in terms of how many people are referred to audiology.</p> <p>Improving early diagnosis and management of hearing loss is particularly important in the prevention and management of dementia.^[22] However, ensuring earlier identification and management of hearing loss in the diagnosis and management of long term conditions such as dementia are not always realised in practice.</p>
--	--	--	--	--

			<p>adapt before the onset or progression of dementia and are provided with appropriate care from the offset. As highlighted in NHS England's Commissioning Framework for Adult Hearing Loss Services, given the growing prevalence and impact of deafness and hearing loss, relying on past activity alone to plan future services will result in avoidable budget pressures and increase the already high level of unmet need.</p>	
85	Action on Hearing Loss	Improving the diagnosis and management of hearing loss in people with dementia	<p>Gold-standard evidence shows that hearing aids are a cost effective form of treatment that improve quality of life and the listening ability of people with hearing loss. Hearing aids have been shown to have a positive impact on overall health. Research shows that hearing aids reduce the risk of loneliness and depression and early evidence suggests that they may even reduce the risk of dementia.</p> <p>NICE's Hearing Loss in Adults Guideline recommends that GPs should consider referring people with suspected or diagnosed dementia for a hearing assessment every two years, because hearing loss is a comorbid condition.</p> <p>The NICE Hearing Loss in Adults Guideline notes that some people with dementia may not be aware of their hearing loss or face difficulties seeking help due to communication problems. The longer people wait before seeking help for their hearing loss, the less likely they are to benefit from hearing aids. The Guideline</p>	<p>Despite gold-standard evidence that hearing aids improve quality of life and reduce health risks, research shows that only two-fifths of people who need hearing aids have them. Negative stereotypes about hearing loss and hearing aids as well as fear of stigma itself can be a significant barrier stopping people from seeking help.</p> <p>Older people may view hearing loss as an inevitable part of the ageing process and may find it difficult to access support for their hearing loss due to communication or memory problems caused by dementia or other long-term conditions.</p> <p>Research shows that people wait ten years on average before seeking help for their hearing loss and when they do, GPs fail to refer up to 45% of those reporting hearing loss to hearing services.¹⁸ There is also considerable variation across England in terms of how many people are referred to audiology.</p> <p>The NHS England Atlas of Variation shows an 11 fold variation in the rate of audiology assessments in different areas across the UK, suggesting that GPs vary greatly in terms of how many people with hearing loss they refer.</p>

				The NICE development committee for the Hearing Loss in Adults Guideline noted that people with dementia have regular health checks, but there are no national recommendations for assessing hearing of those with dementia and current practice is unclear.
86	Alzheimer's Research UK	Priority 3. Dementia as a multi-morbidity	We think the quality standards should explicitly consider dementia within the context of being one of several coexisting health conditions. There is a lack of detail regarding the challenge of dementia as a multi-morbidity within the new dementia clinical guidelines (NG97) which the quality standards could address.	The quality standards could build on the existing NICE guidance on multi-morbidities (NG56) to consider how high dementia care may benefit other conditions and vice versa. For example, without a holistic approach, someone with dementia may forget to take a prescription for diabetes or may not remember to attend a clinical appointment to manage their blood pressure.
87	British Association of Audiovestibular Physicians	Hearing tests as part of the assessment for dementia.	Hearing loss in older people can mimic dementia and a hearing loss would make it difficult for someone to follow questions asked of them as part of the assessment process. Hearing loss and dementia are comorbid conditions in the older age group such that a recent Lancet Commission quoted: 'NICE and NIH identify social isolation and peripheral hearing loss as potentially modifiable dementia risk factors.' (Livingston 2017) making it important to identify this factor and address it. Lin 2011 reported a 2-fold increased incidence of dementia in those with a mild hearing loss and a nearly 5-fold increase in those with severe hearing loss.	Hearing loss in the elderly can be effectively managed if it is identified and proper care sought and followed. A lot of older people are not aware of hearing loss until they are tested. Only one in three people who would benefit from a hearing aid has been provided with them. (Action on Hearing Loss 2011). Those with dementia will not report hearing loss. Hearing loss makes it difficult to understand what is said and can thus lead to confusion, isolation and depression. Good management of hearing loss can facilitate communication and reduce confusion.

			We know that 41.7% of over 50 year olds have a hearing loss and that figure rises to 71.1% of those over 70, in which group the majority have a moderate hearing loss.	
88	The College of Optometrists	Increased awareness of the link between vision and dementia	<p>It is essential that once someone is diagnosed with dementia they continue to regularly see their optometrist for eye examinations, and that the optometrist is informed of their diagnosis. This allows the optometrist to adjust the eye examination to suit their needs, and allows the optometrist to manage any visual impairment, something that our research has shown is more common in people with dementia.[1] It is important that the patient and their general health, including vision, is not forgotten. This is especially important in dementias that initially involve predominantly visual symptoms, such as Posterior Cortical Atrophy. The successful management of visual impairment can also improve the quality of life of people with dementia.</p> <p>Dementia and sight loss develop independently, but both dementia and the main causes of sight loss are age-related. The ageing population trends mean that more people will have both together. Dementia alone has a significant impact on quality of life, and visual impairment in older people can lead to functional impairment, which may adversely affect quality of life even further.⁵ The ability of a person with dementia to cope with visual impairment is also reduced, which means the effects of both concurrently can be much more</p>	<p>Our research found that the prevalence of visual impairment was higher on average among those living with dementia than the general population, and yet many are not getting the eye care that they need.¹ Other research has indicated that the effects of having both sight loss and dementia are much more severe than those resulting from either dementia or sight loss alone, and that there are genetic links between the risk of developing dementia and the risk of developing cataract.^{[2],[3],[4]}</p>

			<p>severe on activities of daily living and cognitive performance.⁶</p> <p>Detecting and correcting impaired vision and refractive error can improve quality of life and reduce related co-morbidities among the dementia population. The Prevalence of Visual Impairment in People with Dementia (PrOVIDe) study (2016) (Bowen, M., Edgar, D. F. et al, <i>Health Services and Delivery Research</i>, 4(21), pp. 1–200. doi: 10.3310/hsdr04210) shows that finding and correcting impaired vision in the dementia population is often not as difficult as many believe. Optometrists have the skills, equipment and expertise to perform a comprehensive eye examination on most people with dementia. At dementia diagnosis stage, correcting the impaired vision with up-to date spectacles or referring for cataract surgery could have a significant positive impact on a dementia patients' ability to live life independently for longer. As the extra time needed by optometrists to examine people with dementia is not currently funded, there will need to be commissioned elements to allow optometrists to allocate the time that people with dementia need.</p>	
89	Optical Confederation	<p>Key area for quality improvement 1</p> <p>That the standard incorporates the need for all patients with dementia to receive appropriate eye care.</p>	<p>Often people with dementia are less able to verbalise their deteriorating sight, which in turn reduces their ability to engage in the world around them. This withdrawal is often attributed to increased dementia by carers.</p>	<p>The Alzheimers society amongst others have been very clear on the importance of regular sight tests for those with dementia, due to the increased impact that increased sensory deprivation can have on these patients https://www.alzheimers.org.uk/info/20064/symptoms/213/sight_and_hearing_loss</p>

90	Royal College of Nursing	Additional developmental areas of emergent practice Pain assessment and management	NICE guidelines (NG97) recommend using a structured observational pain assessment tool to manage pain in people with dementia.	There is a breadth of evidence to demonstrate poor pain assessment in people living with dementia. There is variation of practice in the UK.
4.6 Risks during hospital admission				
91	Association of Directors of Adult Social Services	Reducing inappropriate hospital admissions and length of stay with planned discharge- acknowledging expectations of both patient and family of what support and services are available		
92	SCM 4	Key area for quality improvement 1 Care review after each transition of care	People with dementia are particularly vulnerable to multiple care transitions. People with dementia are at risk of admission to hospital after a transition of care. People with dementia are known to be at high risk of readmission to hospital (CQC, Care update 2013), and at risk of deterioration in hospital (Reynish et al, 2017). NICE guidance states the persons needs and wishes should be reviewed after every transition of care.	Aaltonen et al (2012) showed that for people living at home 2 years before death people with dementia had 32% more care transitions than people without dementia. The average number of transitions was highest in last 3 months of life. This would suggest that either care needs frequently change in the later stages of dementia or that care transitions are detrimental. In either case care review would seem necessary to review care needs and care plan and to prevent readmission to hospital. Currently review after care transition is not a part of standard clinical practice.
93	SCM 8	Key area for quality improvement 2 Hospital care for acute admissions	Hospital care of people living with dementia which manages their wellbeing safely and by doing no harm.	Whilst hospital care is improving care for people living with dementia care of people with confusion and behaviours which challenge are misunderstood and managed disproportionately in some instances in a hospital setting.
94	SCM 8	Key area for quality improvement 1 Transition between hospital and social care setting	To provide a cohesive joined up approach between the two settings to improve communication and positive outcomes	Joined up working practices leads to improved communications which in terms improves outcomes for people.
4.7 Involving people living with dementia in decisions about their care				
Involving people in decision-making				
95	Association for Family Therapy and		Including the person with dementia in an assessment of emotional, psychological	Current quality standards emphasise the needs of carers but not the person living with dementia. There

	Systemic Practice (AFT-UK)		and social needs, and addressing these needs.	are good support groups in some places run by the Alzheimer's Society and other groups. People living with dementia get enormous support from these, and from meeting other people living with dementia.
96	Royal College of Nursing	Key area for quality improvement 2 Person centred-care	There is good evidence that person-centred care has positive outcomes for people living with dementia. This includes reducing avoidable harm (such as falls and pressure damage), hospital admissions and reducing inappropriate anti-psychotic use. In addition, it can improve the quality of life for people living with dementia by improving the quality of care and support delivered, improve communication, enhance emotional well-being and enhance development of therapeutic relationships between carers and the person.	It is important to ensure that care for people living with dementia meets Human Rights/ Charter of Rights for People Living with Dementia. Time, resources and knowledge can influence the application of person-centred care, where there is a lack of any one of these the delivery of person-centred care is compromised. The use of 'This is Me' and Life Story work are tools that can offer a valuable perspective to the person-centred care approach, however their use (or similar tools) is not consistent across the UK.
97	Royal College of Nursing	Key area for quality improvement 5 Positive interactions	There is evidence to indicate that positive interactions improve health and wellbeing for people living with dementia.	For interactions to be effective they should be positive, Kitwood (1997) did a lot of work on this. This approach to care and support sits well with person-centred care delivery.
98	Royal College Of Speech & Language Therapists	Key area for quality improvement 1 Shared Decision-Making	Person centred care People are excluded from decision making	Involving people living with dementia in decisions about their care. This would enable a person centred approach to managing for eg decisions on nutrition in dementia. Supporting people to be involved in decision making would result in their needs being better met and their consent to treatment and care
99	Royal Liverpool & Broadgreen University Hospitals NHS Trust	Key area for quality improvement 2 QS1 Dementia	Supporting Patient at the beginning of their diagnosis to understand the importance around This is Me document	
100	SCM 3	Key area for quality improvement 4 People living with dementia are supported to be involved in	All health and social care delivery should ensure the person living with dementia is supported to express their wishes and be involved in decision making about them.	There are still pockets of practice where the person living with dementia is assumed to not have capacity and so decisions made about them without using the appropriate capacity and best interest processes. Being disempowered can increase resistance and

		making decisions about their care and support		cooperation from the person living with dementia which can impact negatively on their care delivery, independence, and mental and physical health
101	Social Policy Research Unit, University of York	Assessing and monitoring person-centred care in home support	There is growing evidence that person-centred care improves both experiential and health outcomes amongst people with dementia [1]. Existing NICE guidance for dementia [NG97] asserts that the ‘principles of person-centred care underpin good practice in dementia care, and they are reflected in the recommendations’. However, if providers do not evaluate or monitor the person-centred quality of their support they are unable to identify problems or improve standards.	There is widespread anecdotal concern that home care services are unable to deliver person-centred care, due to tight rostering of care visits, time and task approaches, and very high staff turnover. Measures of person-centredness for use in home care are not widely available [2]. Yet there is evidence that the lack of measures is a concern for service users themselves because it limits their potential to improve the quality of person-centred care [3]. That measuring person-centred care is a priority was supported by leading experts in the field [4]. Where such measure have been applied in cross-sectional data (but with regression controls), it has been identified that domiciliary care is delivering poorer person-centred care than other community services for people with dementia and other mental health needs [5].
Providing information				
102	Alzheimer’s Research UK	Priority 5. Supporting people with dementia to participate in research	Given that recruitment of people to dementia studies is a well-recognised challenge in the field, we would highlight the need for the Quality Standards to promote research opportunities. There may be local studies but there is also the national initiative Join Dementia Research, which offers all people (both those with and without a diagnosis of dementia) an opportunity to register their interest in getting involved in research. There are recognised benefits and reasons why people choose to take part in research,	Given the current lack of disease modifying treatments for dementia, research is the only way that we are going to make progress. According to a YouGov poll commissioned by Alzheimer’s Research UK in 2015, whilst almost two thirds of the general public (62 per cent) would be willing to take part in dementia research, more than four out of five people (81 per cent) would not know how to volunteer. This is improving with the introduction of Join Dementia Research and the Quality Standards can help to promote and enable opportunities to get involved in research. More than 34,000 people took part in dementia research in

			<p>which benefits not only research but critically the individual taking part:</p> <ul style="list-style-type: none"> • Studies can provide an opportunity to learn more about dementia and health. • People often feel research is something positive they can do in the face of a progressive condition. • Volunteers may feel part of a community with other people taking part. • Some studies involving people with dementia include regular monitoring by doctors. • Research will lead to outcomes that could benefit those taking part or future generations. 	<p>2015/16, an increase of 156% over the previous two years.</p> <p>The willingness of people to help research is vital for us to make progress. Join Dementia Research makes it easier for people to get involved in dementia research studies, we must embed Join Dementia Research in core NHS diagnostic pathways to ensure all people with a dementia diagnosis are offered the opportunity to take part in research.</p> <p>There is a national target set by the Department of Health and Social Care for 25% of people with a diagnosis of dementia involved in research by 2020 (approximately 100,000 people), if we are to meet this target it is crucial that encouraging people to take part in research is part of the guideline.</p>
103	Alzheimer's Society	Telling people living with dementia about research studies they can participate in	<p>As government and charity funding for dementia research has doubled, researchers urgently need more people to participate in studies. There is a national ambition for a cure or condition changing treatment by 2025 which will require increased participation in dementia research if it is to be achieved. The Government's Challenge on Dementia 2020 includes the commitment to increase numbers of people with dementia participating in research, to 25% of people diagnosed with dementia registered on Join Dementia Research. The importance of research to people with dementia is reflected in the Dementia Statements, which reflect things people with dementia have said are essential to their quality of life. This states <i>'We have the right to know about and decide if we want to be involved in research that looks at cause, cure and</i></p>	<p>National Institute for Health Research figures (from 2015) show only 5% of people with dementia are involved in research studies. Many people are not routinely offered information on research opportunities or are offered this when it is too late to take part.</p> <p>There is also evidence of willingness to take part in dementia research – in a YouGov poll for Alzheimer's Research UK (2015), 62% of people said they would be willing to take part in dementia research, but only 19% thought they would know how to volunteer.</p> <p>Compared to other conditions, fewer people with dementia are taking part in research, for example for cancer, in 2010, 1 in 6 UK cancer patients were taking part in research and 27% of UK cancer patients reported having a discussion about whether they want to take part in research.</p>

			<p><i>care for dementia and be supported to take part</i>.</p> <p>Telling people about research is included in the NICE dementia guideline (1.1.11).</p>	
104	Association of British Neurologists	Key area for quality improvement 3	All patients to be informed about possible opportunities to participate in trials/research at, or soon after, diagnosis	The Prime Minister's Challenge on Dementia 2020 sets the challenge of increasing " <i>numbers of people with dementia participating in research, with 25 per cent of people diagnosed with dementia registered on Join Dementia Research and 10 per cent participating in research, up from the current baseline of 4.5 per cent</i> "
105	The Down's Syndrome Association	Greater support provided to individuals with dementia (and their family carers once a diagnosis has been made).	Dementia diagnosis is only the beginning of the journey. Some people shy away from seeking a diagnosis because they fear that little can be done to help or that support will not be available.	Campaigning organisations such as The Alzheimer's Society want the public to understand that there are interventions which can be helpful and that it is possible to live well with dementia.
106	National Clinical Director for Dementia	Everyone with dementia having access to high quality post diagnostic support – access to a dementia advisor could be one example of this.		
107	National Institute for Health Research	Key area for quality improvement 1: Improve provision of information about research to all people with dementia and support them to take part, for example, through initiatives such as Join Dementia Research, funded by the Department of Health and Social Care.	<p>NICE clinical guidelines Dementia: assessment, management and support for people with dementia and their carers (NG97) state:</p> <p>"1.1.11 Tell people living with dementia (at all stages of the condition) about research studies they could participate in."</p> <p>There is good evidence that being given the opportunity to participate in research produces benefits for both patients and carers. The vast majority of participants report a positive experience and that they would take part in future studies. There is also evidence that it improves people's sense of control and empowerment in relation to their condition: that they are taking the initiative around their health and its management, taking a positive step in</p>	Research is included in the NHS constitution, however, there is still evidence of significant disparities in the offering and take-up of research opportunities.

			<p>the face of a serious and life-limiting condition that can create a sense of vulnerability. Participants report altruistic benefits, from helping others through research, and research studies offer the potential for improved prevention, care and treatment in the future.</p> <p>There is also evidence from research into other conditions that research participants benefit from higher quality care and better outcomes, and that research-active hospital trusts had lower risk-adjusted mortality for acute admissions.</p> <p>There is also evidence to suggest that people want to find out about dementia research opportunities, but they don't know where to seek this information. Clinicians and health and social care providers are trusted intermediaries who can signpost to reliable sources of information.</p>	
108	Neurology Academy Limited	Key area for quality improvement 3	Participation in clinical research	All patients diagnosed with dementia should be offered the opportunity to enrol in clinical research. The percentage taking part should be a core quality metric
109	NHS England Dementia Policy Team	Access to potential new treatments for people with Alzheimer's	<p>The Government has committed to finding a disease-modifying treatment for dementia by 2025 and the Prime Minister's Challenge has made dementia research a priority in the UK.</p> <p>There is no cure for Alzheimer's disease or a way to stop its progression; however there are treatments in development and the number of clinical trials for dementia has doubled compared with three years ago.</p>	It is imperative to help ensure that when research results in effective new treatments, that they can be accessed by people living with dementia as quickly as possible.

			There are challenges to measuring the gradual change/ progression of Alzheimer's disease over the period of a clinical trial which is relatively short. Consequently, supporting early access to safe and innovative treatments, while collecting ongoing evidence of effectiveness in a real world context, will be important.	
110	Office of the National Director for Dementia Research	Dementia Research	Guidance published by NICE has included a statement around research, and how care providers should support people to become involved in research. Specifically, "1.1.11 Tell people living with dementia (at all stages of the condition) about research studies they could participate in."	Good care should include offering patients and carers information about, and access to, research opportunities.
111	Royal college of Psychiatrists – Faculty of Old Age Psychiatry	Key area for quality improvement 1	Post diagnostic support and monitoring for all dementia patients regardless of diagnosis– especially for patients not on medication	<p>People with non-Alzheimer's form of dementia should also have access to improved assessment and treatments (e.g. vascular disease, lewy body disease...) with some access to subtype specific treatment pathways. There should be</p> <ul style="list-style-type: none"> • greater continuity and range of post-diagnostic care, support and follow-up. • Greater focus on measures aimed at relieving carer burden/strain. • Diagnostic accuracy should be prioritised rather than rates or targets.
112	The Society and College of Radiographers	<p>Key area for quality improvement 1</p> <p>NICE Dementia: assessment, management and support for people living with dementia and their carers</p> <p>Section 1.17</p> <p>If it has not been documented earlier, ask the person at diagnosis:</p>	To encourage and enable people living with dementia to give their own views and opinions about their care. To ensure that people with reduced capacity to consent are able to give or withdraw informed consent to procedures and are also supported to make decisions about their care.	Diagnostic and Therapeutic Radiographers and associated workforce report that a lack, or poor sharing, of information can result in decreased support and enablement for people living with dementia. Diagnosis, treatment and care in diagnostic clinical Imaging and radiotherapy departments depends upon the clinicians who refer people to these services sharing decisions documented in a person's records; for example, stating when a person is living with dementia and providing any relevant information e.g. if the person

		<ul style="list-style-type: none"> • for their consent for services to share information • which people they would like services to share information with (for example family members or carers) • What information they would like services to share. • Document these decisions in the person's records. 		<p>has advance decision making in place, sharing their decisions and wishes.</p> <p>Measurable via audit of information recorded at diagnosis. Direct comparison can be made with information shared with services (documented in patient notes / examination and treatment request cards and letters in secondary care); information available electronically for audit.</p>
113	SCM 2	Clear Dementia Care Pathway for Diagnosis and On-going Support	The client and their carer(s) need a clear dementia care pathway so that they know what to expect prior, at, and post (positive or negative) diagnosis.	The fear of and the reality of a diagnosis of dementia is very distressing for the client and their carers. The client and their carer(s) need to understand the process and the support that will be available at each stage of the process.
114	SCM 2	Active signposting for the client and their families/carers	Slowing down the progression of the disease and supporting the family/carers.	Often clinicians are not aware of the national and local support available for people living with dementia and their carers. They are particularly not aware of how these condition support groups, carer support groups, and local community groups can improve the quality of life and health of this group. It can significantly improve self-management, slow down the progression of the disease, prevent carer breakdown, and reduce on-going care costs including avoidable hospital admissions. A list of effective interventions and their benefit would be very helpful. Also highlighting key cultural/faith considerations in the management/support of people living with dementia.
115	SCM 3	Key area for quality improvement 2 Initial support and advice post diagnosis	Many people newly diagnosed with dementia and their carers identify they require support to understand the diagnosis and identify resources and strategies to maintain independence and come to terms with the diagnosis.	Many people newly diagnosed with dementia and their carers still report a lack of support and information immediately following diagnosis and are rarely followed up if not prescribed medication.

116	SCM 4	Key area for quality improvement 2 Consent to share information with a relative and other healthcare providers	People with dementia may be seen by multiple services with separate information systems. Sharing of information is important to ensure continuity of care and reduce burden on the person with dementia and carers to provide information. Consent for services to share information is referred to in the NICE guidance.	Currently consent may be sought within a single service, be that primary care, memory clinic or social services. This may be around consent to share correspondence with a relative. However there is no standard to gain consent from people with dementia and/or their carers to share information and contact details between services. Given that people access a number of services this is important to ensure quality of care, particularly around transitions of care.
117	SCM 5	Key area for quality improvement 1 Provision of information and appropriate follow-up at the point of diagnosis	Providing information about the condition forms a basis for enabling people to adjust and plan for the future. Most people diagnosed with dementia, and family members, wish to receive information about the condition. This is a life-changing diagnosis and as part of these post-diagnosis discussions it is vital that people are directed to available sources of further information and support, should they so wish.	It is not sufficient for the diagnosis of dementia to be communicated in a single session with no follow-up. The diagnosis itself and any related information can take time to assimilate, and this is likely to require more than one appointment, and subsequent follow-up and signposting to other suitable services. Information provided must be accessible and understandable, and tailored to specific needs and circumstances (e.g. different types of dementia, different age-groups, etc).
118	SCM 6	Key area for quality improvement 2 Ensuring high quality Dementia diagnosis in Acute Hospital settings	Acute Hospital settings are key environments where dementia is identified and diagnosed.	The quality of information and signposting following a dementia diagnosis in an Acute Hospital needs to mirror the standard expected from diagnosis in a memory service setting to ensure the quality of diagnosis regardless of the setting.
119	SCM 7	Post diagnostic support and information for people with dementia and carers	Post diagnostic support provides a toolkit for individuals to self-manage and links to their neighbourhood/community resources and a pathway to make informed choices and take control.	There is a lack of standardisation across all sectors on the quality, frequency and provision on how post diagnostic support is delivered and commissioned. In addition, psychoeducation for carers and skills training for carers will support skills, knowledge and experience.
4.8 Palliative care				
Advance care planning				
120	Compassion in Dying	Advance Care Planning (ACP)	There is clear evidence that advance care planning (ACP) results in significant benefits for individuals and care providers: in addition to increased satisfaction with	A report into inequalities in end of life care by the Quality Care Commission (CQC) showed that people with dementia received worse end-of-life care than people with other conditions. The report

			<p>overall care, people receive fewer aggressive medical interventions, have fewer hospital admissions and benefit from increased use of palliative care services.</p> <p>Early conversations about ACP for people with dementia and taking steps to ensure recorded wishes are updated, communicated and respected should therefore form a key part of the Quality Standard.</p> <p>The recent ‘Dementia: assessment, management and support for people living with dementia and their carers guideline’ emphasised the necessity of giving individuals with dementia early and ongoing opportunities to plan for their future care and providing information on the legal ACP tools available to them to do so (recommendation 1.1.12).</p> <p>Dementia will cause a person’s capacity to fluctuate and some may lose all capacity to make decisions about their treatment and care. If people haven’t documented their wishes for future decisions or appointed someone they trust to make decisions on their behalf then they are left to healthcare professionals. Therefore people with dementia must be given opportunities to discuss advance care planning in a timely manner to ensure their future care and treatment is aligned with their preferences and values.</p> <p>Research shows that a reduction in emergency hospital admissions for those who have an advance care plan in place</p>	<p>acknowledged that “identifying dementia early, so that people have the opportunity to consider advance care planning and make meaningful choices at an appropriate time, is particularly important as the person will progressively lose the mental capacity to make decisions about their end of life care.”</p> <p>In 2014-16 Compassion in Dying ran a community outreach service My Life, My Decision. 20.41% of the people we supported through the service to make an Advance Decision to Refuse Treatment, an Advance Statement, or a Lasting Power of Attorney for Health and Welfare had a diagnosis of dementia. These people felt an urgent need for them to plan ahead, as they were facing the prospect of losing capacity to make decisions in the relatively near future.</p> <p>However, whilst research shows that ACP results in significant benefits for individuals and healthcare providers, awareness and uptake is low. In 2018, only 4% of people had made an Advance Decision to Refuse Treatment and just 7% had appointed a Lasting Power of Attorney for Health and Welfare (YouGov, 2018).</p> <p>The Government’s response in 2014 to a House of Lords Select Committee Report on the Mental Capacity Act stressed the urgency to: “promote better understanding among health care staff of Advance Decisions”.</p> <p>In 2015, the House of Commons Health Select Committee reported that care staff often feel that they lack understanding of the mechanisms available to patients and carers under the Mental Capacity Act which allow people to make their wishes clear. The Committee recommended that all staff who provide palliative and end of life care to people with life-</p>
--	--	--	---	--

			<p>leads to fewer days in hospital in the last year of life and reduced hospital costs incurred as a result of emergency admissions - a mean reduction of 28% and 8% respectively (Abel et al. 2013).</p>	<p>limiting conditions should receive training in advance care planning.</p> <p>Despite these warnings, our own research has found that people who want to plan ahead still face unnecessary barriers, both from individual healthcare professionals and from wider system failures.</p> <p>A recent Freedom of Information Request to Ambulance Trusts by Compassion in Dying highlighted a lack of a unified system for recording and implementing advance care plans, and a widespread absence of systems for monitoring and analysing adherence to advance care plans. For example, 23% of Trusts have no systems at all for holding advance care plans for patients in their areas, while 31% of Trusts will only accept advance care planning forms from healthcare professionals.</p> <p>“As a paramedic it is immensely frustrating and upsetting when things aren’t put in place allowing us to leave someone at home where they wish to be. I was not prepared for the heartache of having to take a dying patient away from their home and into general hospital.” (The role of Ambulance Trusts in respecting people’s end of life wishes, 2018)</p> <p>A further FOI to all Clinical Commissioning Groups (CCGs) in England found that while 87% of CCGs provide information to GP practices on advance care planning, not all CCGs consistently and explicitly covered the topics of Advance Decisions, Lasting Powers of Attorney and Do Not Attempt Resuscitation orders. Templates used for Advance Decisions did not have accompanying guidance notes, resulting in inadequate support, not only for individuals but also for healthcare professionals. (Advance care planning in general practice – does policy match reality? 2018)</p>
--	--	--	---	---

				As dementia is now the most common cause of death in England and Wales, it is vital that advance care planning is valued as a key component of care and prioritised for improvement.
121	Mencap	People with a learning disability and dementia have access to regular reviews, which are proactive in their approach to identifying changing needs, including the need to access end of life care.	Forward planning is important to ensure that people have access to the support they need, when they need it. Without this, crises can develop, resulting in drastic changes to accommodation, loss of social networks or unmet needs. Baseline recordings can help effectively track changing needs over time, particularly in a sector where staff turnover can be high.	CIPOLD (2013) found a significant amount of planning that related to people with a learning disability and dementia was responsive to a difficulty or problem, rather than proactive or in advance in anticipation of needs that were likely to change. This made people more vulnerable to issues which were likely to have a severe impact on their health and/or quality of life.
122	National Clinical Director for Dementia	Everyone with dementia having an advanced care plan.		
123	NHS England Dementia Policy Team	Key area for quality improvement 4 Advance care planning and personalised end of life care	People with dementia have the right to live as well as possible and die with dignity. Advance care planning helps to ensure people living with dementia have the same equal opportunities as those diagnosed with other life limiting conditions / diseases, in terms of accessing palliative care services / support. It also enables a record of the individual's wishes and preferences, which guides the person's care when they have lost mental capacity and provides crucial support for families and carers.	Research shows that people with neurological conditions are much less likely to have opportunities to take part in advance care planning or to receive specialist end of life support. The Care Quality Commission (CQC) have identified that people living with dementia are one of the 'groups in society who experience poorer quality care at the end of their lives.
124	Royal College of General Practitioners	Power of attorney discussion	Patients and their families are frequently unaware of the problems that can arise without having an appointed LPA before dementia progresses too far. As a specific issue it is easy to neglect in a 'dementia care plan' and a specific record of this having been discussed could have a significant impact in increasing the awareness of planning for the future.	As well as increasing the number of LPAs, and the reduction of stress in families when an LPA is needed, this is also likely to lead to a general awareness of future planning – one of the main benefits of timely diagnosis

125	Royal college of Psychiatrists – Faculty of Old Age Psychiatry	Key area for quality improvement 4	Advanced care planning	Dementia should be seen as a chronic illness requiring a model of service provision that reflects this (rather than one of episodic care) Fast track services in general hospital for dementia patients
126	SCM 4	Key area for quality improvement 5 All people with dementia have timely advanced care planning (ACP)	The place of death profile for people who have died with dementia is significantly different compared with the general population. People with dementia are more likely to die in a care home and less likely to die at home than people without a diagnosis of dementia. People with dementia are also less likely to die in a hospice than the general population. Providing high quality at the end of life for people with dementia is important and establishing wishes through advanced care planning is an essential aspect of this.	People with neurological conditions are less likely to take part in advance care planning and hence receive specialist end of life support. The Care Quality Commission (CQC) has identified that people living with dementia experience poorer quality care at the end of their lives than others. Ensuring that people living with dementia have opportunities to create an ACP as early as possible following diagnosis will assist in reducing this inequality.
127	SCM 5	Key area for quality improvement 3 Engaging people with dementia and carers in advance care planning, using a format that can be easily understood across different settings	As dementia progresses, crucial decisions about care will need to be made, but it may become difficult for the person with dementia to be involved in these decisions due to loss of capacity. Therefore it is important that, at an early stage, people with dementia are able wherever possible to express their views and preferences about future care, and update these if they change over time, so that family members and professionals can take these views into account when decisions are required.	There is a need to increase the proportion of people with dementia who have the opportunity to prepare advance care plans. There is a need to make people aware that they can change any advance statements or directives they have made as long as they are able to be involved in decision-making. There is a need to identify suitable formats for recording this information that can be readily transferred between different care settings and easily understood by whoever needs to use them.
128	SCM 7	Increase sharing promotion and completion of Advance Decisions / advance care planning	Advance decision/advance care planning supports the individual right to choose and have their voice considered at a time when they may have lost the ability to communicate this clearly or lacked the capacity to do so.	Advance care planning and decision making isn't standardised across and not shared always shared with other sector areas such as when someone moves into care homes.
Palliative care				

129	Neurology Academy Limited	Key area for quality improvement 4	Access to Palliative and end of life care for people with dementia	From our experience within the Masterclass training programmes there is insufficient training for clinicians in the management of end of life care in dementia coupled with insufficient support within the hospice environment. The RightCare pathway for dementia is a useful way to illustrate how this could happen but the current pathway does not include this.
130	NORTH WEST BOROUGHNS NHS FOUNDATION TRUST	Palliative care	<p>End stage dementia recognition is often missed by professionals and many people with terminal stages of dementia receive investigations that are not appropriate and are admitted to acute Hospitals especially out of hours which can be avoided.</p> <p>NICE guidance should include signs of terminal stages of dementia and patients with end stage dementia should have better access to palliative care services. This will help professionals identify the end stage dementia and provide palliative care for these patients.</p>	Palliative care approach is utilised less often in dementia patients compared to people suffering from other chronic and terminal physical health conditions. They should be given access to palliative care services.
131	Royal college of Psychiatrists – Faculty of Old Age Psychiatry	Key area for quality improvement 5	End of life and palliative care	Linking in with the community palliative care teams including the identification of the patients, consideration of their complex needs, working together with the them and CMC plans, providing care at home in order to prevent admissions to hospitals, providing support for the carers
132	Royal College Of Speech & Language Therapists	<p>Key area for quality improvement 3</p> <p>Quality of life of the individual living with dementia</p>	<ul style="list-style-type: none"> • Meeting the individuals wishes • Supporting the number of people with capacity issues 	<p>A focus on quality of life will prevent over medicalisation of the person reaching the end of their life.</p> <p>A focus on quality of life will support a good death and ensure individuals are in their preferred place of death.</p>
133	Royal College Of Speech & Language Therapists	Key area for quality improvement 4	<p>To use advance care plans from early diagnosis</p> <p>meet the individuals wishes</p>	No co-ordinated approach to using advance care plans. Individual wishes are therefore not being acknowledged

		Planning for palliative and future care	To establish safe eating and drinking practices	<p>Strong evidence about the numbers of people with dementia with eating, drinking and swallowing needs</p> <p>Acknowledge that people may want to feed at risk</p> <p>Support people from going to hospital with secondary infections</p>
134	SCM 8	Key area for quality improvement 4 End of life care	People living with dementia at the end of their lives should receive the care they need and in their best interests.	Use of advance directive and effective LpoA can improve quality of palliative care.
4.9 Supporting carers				
135	Association of Directors of Adult Social Services	To help build on Carers (Informal) resilience at home to enable them to care longer and achieve positive outcomes both practically and emotionally for all parties. e.g. Practical skills , training for day to day life at home, what to do and how.		
136	Association of Directors of Adult Social Services	Education of Carers (Informal) of what services and support are available and how to access both now and in the future to avoid and prior to crisis		
137	Carers Trust	Identification of and support for carers of people with dementia.	<p>It is important to identify and support carers of people with dementia for two reasons:</p> <ul style="list-style-type: none"> • Support carers in maintaining their own health and wellbeing • Enable carers to continue to care for the person with dementia if that is what they want to do. 	<p>In 2013, Carers Trust undertook a research project to look at the support needed by carers of people with dementia. The Road Less Rocky report found that carers of people with dementia are not getting the support and advice they often desperately need. It found that:</p> <ul style="list-style-type: none"> • only 51% of carers questioned said that they were given an opportunity to talk separately about their needs and how much care they felt able to provide. • 56% of carers questioned said that they had not received information about managing the medication of those they cared for. More than half (52%) of carers said that they had been given no information on how to cope with incontinence. <p>Carers Trust believe that by identifying and supporting carers, treating carers as equal partners in care and sharing information with carers (as both the Road Less Rocky document and the Triangle of Care</p>

				<p>for Dementia model advocate) health and social care services would improve the care provided to the person with dementia.</p> <p>NHS and social care services should also be routinely working with local carers organisations like Carers Trust Network Partners with a clear referral route for carers to get the support they need. Many provide services specifically for carers of people with dementia.</p>
138	Carers Trust	Information for carers of people with dementia	<p>It is important to identify and support carers of people with dementia for two reasons:</p> <ul style="list-style-type: none"> • Support carers in maintaining their own health and wellbeing • Enable carers to continue to care for the person with dementia if that is what they want to do. 	<p>In 2013, Carers Trust undertook a research project to look at the support needed by carers of people with dementia. The Road Less Rocky report found that carers of people with dementia are not getting the support and advice they often desperately need. It found that:</p> <ul style="list-style-type: none"> • only 51% of carers questioned said that they were given an opportunity to talk separately about their needs and how much care they felt able to provide. • 56% of carers questioned said that they had not received information about managing the medication of those they cared for. More than half (52%) of carers said that they had been given no information on how to cope with incontinence. <p>The research found that although there is no typical caring journey there are ten points in the caring journey where, if carers had more information and support the experience of caring for someone with dementia would have been made a little easier.</p>
139	London Dementia Clinical Network	<p>Key area for quality improvement 3</p> <p>Access to psychoeducation for carers</p>	<p>NICE has recommended to offer carers of people living with dementia a psychoeducation and skills training</p> <p>Intervention</p>	<p>There is variation in commissioning this service.</p> <p>Carers of people living with dementia have particularly highlighted to us the lack of emotional support and training for carers</p>

140	NORTH WEST BOROUGH NHS FOUNDATION TRUST	Supporting carers with dementia	<p>Spouses of people with dementia are at six times the risk of developing dementia compared to spouses of people who do not have dementia</p> <p>Resources for Enhancing Alzheimer's Caregiver Health (REACH) intervention—should be provided to carers</p>	<p>About 40% carers are known to suffer from mental health problems like anxiety or depression</p> <p>REACH intervention has been shown to reduce the number of care home admissions</p>
150	Parkinson's UK	Provide ongoing support for carers and partners of people with Parkinson's dementia and dementia with Lewy bodies.	<p>The care burden in Parkinson's dementia and dementia with Lewy bodies differs from other dementias and resources are limited for these carers;</p> <p>Also, this is not simply a matter of 'health related Quality of Life (QOL)' for carers – the Relationship Quality (RQ) should also be taken into consideration. This relationship will be the core to successful 'aging in place' for a person with Parkinson's dementia and dementia with Lewy bodies.</p>	<p>There is evidence that suggests the burden carers of people with Parkinson's related dementias experience is multidimensional and complex. The support needs to be directed at the specific types of burden faced by this group to help improve Relationship Quality (RQ) and Quality of Life (QOL). (Vatter S.,Leroi I. (2018) 'Multidimensional care burden in Parkinson's-related dementia'. Journal of Geriatric Psychiatry and Neurology; Vatter A, Leroi I. (2018) 'A qualitative study of female caregiving spouses' experiences of intimate relationships as cognition declines in Parkinson's disease.' <i>Age and Ageing</i>, Volume 47, Issue 4, 1 July, Pages 604–610).</p>
151	Royal College of General Practitioners	Meaningful support for families – the quality indicator could be for a discussion about the benefits of education, or referral to an educational programme (in much the same way as the diabetes prevention programmes)	<p>Patient groups consistently say that support after a diagnosis of dementia is the most important aspect of care, yet it is often the most neglected. The reality is that follow up after a diagnosis often revolves around follow up of medication and test results rather than helping patients and their families to understand and adapt to this illness</p>	<p>A diagnosis of dementia brings challenges like no other illness, often bringing a need to re-orientate social roles within a family and learn new ways of interacting with and supporting a loved one – this is far more than basic social care needs and can involve holistic aspects of care such as music, physical and social activity, celebrating retained memories etc. Families are often left to learn this on their own. The opportunity to have education on how to live well with dementia has not been well developed and could be delivered in 1-1 sessions, or group educational activity</p>

152	Royal College of Nursing	<p>Key area for quality improvement 3</p> <p>Education and training including increased supervision to ensure therapeutic interventions that support cognitive impairment.</p>	<p>There is evidence that outcomes for those living with dementia are improved when both formal and informal carers are skilled and supported in caring for them.</p>	<p>Providing care that supports cognition is essential to good Mental Health See NHS Education Scotland Stress and Distress Resources and Newcastle model of care by Ian James.</p> <p>Time, resources and knowledge can influence the application of person-centred care, where there is a lack of any one of these the delivery of person-centred care is compromised.</p> <p>The framework for enhanced care in care homes (NHS England 2016) identifies Vanguard sites where the provision of training and support is effective, however these models have not been replicated across the whole of the UK.</p> <p>An Educated workforce and carers are required to provide this. Human rights approach should be adopted rather than limiting freedom unnecessarily, Feathersotne, K. Northcott, A. (2018) - An evidence based investigation into the care that people living with dementia receive following an acute hospital admission.</p>
153	Royal college of Psychiatrists – Faculty of Old Age Psychiatry	<p>Key area for quality improvement 2</p>	<p>Support with challenging behaviour in dementia including: informal carer support and training paid carer education and training services' focus on tailored psychological and functional responses to behaviour rather than "one size fits all" protocols.</p>	<p>Need for Challenging Behaviour support to be available in all settings – not just care homes including the general hospital setting and for people at home also).</p> <p>BPSD specifically dealing with delirium superimposed on dementia</p> <p>Improved competencies in care home staff for managing dementias and BPSD</p>
154	SCM 2	<p>A Dementia Care Pathway must include access to psychological therapies for the client and their carers</p>	<p>Receiving a diagnosis of dementia is very distressing for both the client and their carers and this would enable them to cope better with the diagnosis and ongoing management of the condition. It would also reduce the risk of carer breakdown.</p>	<p>This is a significant factor in maximising the quality of life of the client and their carers, improving self-management, slowing down the progression of the disease, and reducing on-going care costs and avoidable hospital admissions.</p>

155	SCM 2	Carer Support	Carers often neglect their own physical, mental/emotional and spiritual health and wellbeing when caring for a friend or relative.	In neglecting this the NHS has two or more sick people to care for and ultimately this can result in carer breakdown significantly increasing the demand on health and social care services.
156	SCM 7	Carers offered assessment and interventions tailored to their needs		Recognising and identifying carers and providing the appropriate education, advice and support to allow them to continue to care for people supports longer term care at home and reduces unnecessary hospital or long term care admissions
157	SCM 8	Key area for quality improvement 5 Family members /carer receive support in crisis	A carer may not know where to turn for support of their loved one's care is no longer manageable but the person declines care, is self funding and	To improve signposting, access to care and support and advice, single point of contact and carer support.
4.10 Additional areas				
Staff training				
158	Alzheimer's Research UK	Priority 4. Skills and competencies of health and social care practitioners	Health and social care practitioners in a wide range of settings need to have the right knowledge and skills to be able to support people with dementia and their families.	Given that many patients with dementia access care in a range of clinical and care settings, it is crucial that all health and care staff across the NHS have consistent skills and competencies. This approach is also important in terms of considering multimorbidities as outlined in priority 3. There are also specific skills required to support earlier diagnosis of dementia, as outlined in priority 2. This includes lumbar puncture for CSF sampling.
159	Alzheimer's Society	Training of health and care professionals supporting someone with dementia	Training in dementia is important so professionals can meet individuals' needs, which are complex and can be hard to understand without training. Staff must be equipped with skills to confidently deliver person-centred care. The Dementia Training Standards, commissioned by the Department of Health and developed by Skills for Health, Skills for Care and Health Education England,	Currently many health and care professionals supporting people with dementia are not trained in dementia to an appropriate level. We found more than 8 in 10 care professionals said they would be able to provide better quality care if they had appropriate dementia training. Our investigation for our Fix Dementia Care: Homecare report found that 38% of homecare workers do not receive any dementia training and

			<p>recommends professionals involved in direct care for people with dementia should be trained to Tier 2 as defined by the framework.</p> <p>There is evidence that a lack of training can result in poorer care and outcomes. Our Fix Dementia Care: Homecare report found a lack of appropriate training led to emergency admission to hospital from a failure to identify infections, ineffective safeguarding procedures in place, and care workers refusing to make further visits as they felt unprepared and helpless.</p> <p>The need for training is recognised in the NICE guideline (1.13).</p>	<p>most (71%) do not receive dementia training that is accredited. Only 2% of people affected by dementia say homecare workers 'have enough dementia training'.</p>
160	Association of Directors of Adult Social Services	Improvement in staff workforce training to assist with developing the understanding and use of the correct Dementia approaches that are effective. e.g. How to ask questions, how to achieve support needs, working with and not against the service users understanding and ability as well as potential.		
161	Dementia Industry Group	Healthcare professionals understanding of the pathology of dementia and Alzheimer's disease.	<p>The findings from a 2016/17 pilot project on dementia risk reduction, run in partnership between Public Health England (PHE), the Alzheimer's Society and Alzheimer's Research UK, have shown varying levels of knowledge among healthcare professionals. Some were knowledgeable, having worked with the elderly, while others had specialist experience of dementia or have previously undertaken training on the topic. However, others had limited knowledge on the topic and, similar to the general public, were surprised that lifestyle factors and changes to behaviours could reduce the risks of developing dementia.</p>	<p>To enhance understanding of Alzheimer's disease and support the earlier diagnosis of the condition, care and support providers should train healthcare professionals in the pathology of Alzheimer's disease, in addition to the signs and symptoms of the condition, to improve awareness of the very subtle changes associated with early Alzheimer's disease. This pathway should capture the journey from asymptomatic risk, MCI, early, moderate and severe dementia.</p>

162	The Down's Syndrome Association	A health and social-care workforce which is well trained and responsive to the needs of people with dementia.	Individuals with dementia and their carers need to feel confident that the professionals they encounter will have knowledge, skills and understanding to meet their needs.	Many individuals with dementia and their families encounter staff who appear ill-equipped to understand their needs or communicate effectively with them.
163	Mencap	Social care staff supporting people with a learning disability are trained about the signs of dementia. Dementia specialist staff are given learning disability awareness training. All staff are able to easily access further training when required to support individuals with a learning disability and dementia using their services. Good practice is shared within the sector.	Social care staff must be trained in order to support individuals who may develop dementia to get a timely diagnosis. They must be able to access specialist training and input in order to adapt care to meet the needs of individuals with dementia. Specialist dementia healthcare professionals must also understand how to meet the needs of people with a learning disability and be able to access input from learning disability experts where required.	It is important to remember that many people with a learning disability already receive social care. Without training, social care staff are unlikely to spot subtle changing needs or understand how dementia may present in people with a learning disability. When needs change, training may be necessary to enable services to adapt to meet the needs of the individual. This can lead to better outcomes, including less sudden disruptions for the individual.
164	The National LGB&T Partnership	Training Social care providers should ensure that staff receive training on LGB&T issues and are able to sensitively discuss an individual's specific needs in relation to their sexual orientation, gender identity and trans status, so the impact on person-centred and personalised care can be assessed and responded to.	It's important to be able to provide person centred holistic services. Staff need to have a thorough understanding of all the issues relating to LGB&T people with dementia	LGB&T awareness training is not prioritised by main stream services who often have a lack of understanding of issues affecting LGB&T people.
165	Royal college of Psychiatrists – Faculty of Old Age Psychiatry	Key area for quality improvement 2	Support with challenging behaviour in dementia including: informal carer support and training paid carer education and training services' focus on tailored psychological and functional responses to behaviour rather than "one size fits all" protocols.	Need for Challenging Behaviour support to be available in all settings – not just care homes including the general hospital setting and for people at home also). BPSD specifically dealing with delirium superimposed on dementia Improved competencies in care home staff for managing dementias and BPSD

166	Royal College Of Speech & Language Therapists	Key area for quality improvement 5 Staff Training	To support staff	Care homes find communication challenges the number one challenge in caring for people with dementia Communication changes happen in all people with dementia
167	Royal Liverpool & Broadgreen University Hospitals NHS Trust	Key area for quality improvement 3 QS1 Dementia	Dedicated dementia specialist resourcing to support the increasing activity and the development or availability of any guidelines that would help sustain the service	
168	Skills for Care	Basic Dementia awareness training needs to be provided to all staff		
169	Skills for Care	Support and development should be provided to direct care staff to support them to manage behaviour that may challenge		
170	Skills for Care	Further support is needed for staff around DOLS (deprivation of liberty safeguards)		
171	Sunrise Senior Living	Key area for quality improvement 1 A Dementia Care Learning and Development Pathway for all health and social care workers who support individuals with dementia that includes face-to-face Trainer-led education	It is well-documented that well-trained, knowledgeable and skilled staff can provide the right support in the right way in order to support individuals to live well with dementia NICE Guidance recommends that care and support providers should provide all staff with training, including Trainer-led training, in person-centred and outcome-focused care for people living with dementia	Skills for Care state the learning technologies work most effectively when integrated into an overall learning strategy. However, many care providers resort to only using elearning as a training medium because of the reduced costs. Skills for Care explicitly state that whilst e-learning can help staff to develop the knowledge that underpins judgement and decision-making skills, it should always be supplemented with face-to-face guidance, supervision, feedback and discussion. This allows staff the opportunity for reflection and development, and gives managers the opportunity to gauge the ability of staff to apply social care values in practice https://www.skillsforcare.org.uk/Documents/Learning-and-development/Learning-technologies/Learning-technologies-in-social-care-a-guide-for-employers.pdf
Nutrition				
172	British Dietetic Association	Key area for quality improvement 1 Nutrition – specifically the inter-relation between dementia and undernutrition	Undernutrition is still considerably under recognised in the UK by both health and social care professionals and the general public, and is a significant risk for older people.	Those with dementia are likely to be at higher risk than the general older population but often the impact of this on their disease and overall health is not recognised. Despite this, lack of appetite and unplanned weight loss are frequent concerns for relatives and carers, so recognition of this within a

				<p>quality standard on dementia could help to improve both awareness and maintain patient health.</p> <p>I appreciate that nutritional needs are not mentioned within the Clinical Guideline but it would be helpful if this omission could be addressed within the Quality Standard,</p>
173	NHS Improvement Patient Safety	Provision of nutrition in an appropriate form	<p>Dysphagia is the medical term for swallowing difficulties and a sign or symptom of disease, which may be neurological, muscular, physiological or structural. Dysphagia affects people of all ages in all types of care setting. Food texture modification is widely accepted as a way to manage dysphagia.</p> <p>Terms for fluid thickening, such as 'custard thickness', have varied locally and numerical scales have been used by industry. National standard terminology for modified food texture, including terms such as 'fork-mashable', was agreed in 2011 and widely adopted by the hospital catering industry and many clinical settings. However, local variations have persisted for both food and fluid texture, confusing patients, carers and healthcare staff.</p>	<p>A review of National Reporting and Learning System (NRLS) incidents over a recent two-year period identified seven reports where patients appear to have come to significant harm because of confusion about the meaning of the term 'soft diet'. These incidents included choking requiring an emergency team response, and aspiration pneumonia; two patients died. An example incident reads: "Patient with documented dysphagia given soft diet including mince and peas at lunch...unresponsive episode.... Difficulty ventilating patient overnight. Peas [suctioned out via] endotracheal tube." Around 270 similar incidents reported no harm or low harm such as coughing or a brief choking episode.</p>
Equality				
174	The National LGB&T Partnership	<p>Monitoring</p> <p>Commissioners of social care should include a requirement in contracts for service providers to monitor sexual orientation and trans status of service users. Service providers should use this data</p>	<p>Statistics for trans status and sexual orientation are often not collected, and statistics for gender are often restricted to two options: male & female. (Age UK 2007) This means that the needs of older LGB&T people are often ignored. LGB&T people's life experiences are further erased by their invisibility.</p>	<p>Service providers should use this data to better understand and meet LGB&T service users' needs. If a person experiences prejudice or feels isolated because of both their dementia and their sexual orientation, trans status or gender identity, they may be feeling very vulnerable.</p>

		to better understand and meet LGB&T service users' needs.		
175	The National LGB&T Partnership	Equality Impact Assessments Commissioners should use equality impact assessments which include sexual orientation, trans status and gender identity when planning for the needs of people with dementia	Older lesbian, gay, bisexual and transgender (LGBT) people are more likely to be isolated, due to being estranged from their families, or less likely to have children, for example, which increases their need for formal care services. However, LGBT people may have experienced discrimination that makes them reluctant to use services	As LGB&T older people are often doubly marginalised because of their age, gender identity, trans status and/or sexual orientation it is important that they are visible in assessments Formalising visibility using Equality impact Assessments would ensure that they remain visible in services.
176	The National LGB&T Partnership	Engagement, Important to ensure that in order to make a lasting change any project aiming to empower LGB&T people with dementia is driven by LGB&T people with dementia	It is significant that services are created in a co-production way where LGB&T people have a say in the way their services are designed.	If a person experiences prejudice or feels isolated because of both their dementia and their sexual orientation, trans status or gender identity, they may be feeling very vulnerable. Creating services in a co-production way ensures that people feel invested in the process and consequent service
177	Neurology Academy Limited	Key area for quality improvement 1	Equality assessment	Prison populations are increasingly old as cohort effects increase longevity of long-term inmates. The privatisation of prison services has resulted in fractured healthcare provision to these populations and dementia in prisons is not well measured. Dementia must be a priority for the over 65's and there should be no discrimination between this population and others in terms of quality of care BAME populations have higher cardio vascular risk and higher cerebrovascular disease contributing to cognitive impairment These populations are under-represented in memory clinics and will need culturally sensitive dementia care to meet their needs in later stages of dementia. White Irish populations are traditional invisible immigrant populations who as well as migrating to the UK for work often came to avoid persecution for homosexuality, single motherhood, religious difference or escaping violence. These people have higher levels of need and often live in isolated conditions.

Learning disabilities				
178	The Down's Syndrome Association	Addressing health inequalities within dementia services, especially for individuals with a learning disability.	We know that people with a learning disability (people with Down's syndrome especially) are at a much greater risk of developing dementia and onset of the condition is at a younger age.	The Dementia Action Alliance has conducted research and published briefing papers which highlight that people with a learning disability are a seldom heard group, more at risk of experience exclusion from mainstream dementia services https://www.dementiaaction.org.uk/joint_work/dementia_and_seldom_heard_groups/people_with_learning_disabilities
179	Mencap	Other comments:	The NICE guidance is an important level for ensuring high quality care for people with a learning disability and dementia. However, at present, despite the high prevalence amongst people with a learning disability, and the unique challenges those with a dual diagnosis can face in terms of both diagnosis, health and social care, we believe the current guidance from NICE does not fully address the needs of people with a learning disability and dementia. NG97: Dementia: assessment, management and support for people living with dementia and their carers, refers to NG54: Mental health problems in people with learning disabilities: prevention, assessment and management, however this actually contains quite a sparse amount of information on the topic. We would welcome further opportunities to engage with NICE to ensure the guidance is as effective as it can be in ensuring services are commissioned and provided in a way which meets the needs of people with a learning disability and dementia.	
180	SCM 6	Key area for quality improvement 5	People with a learning disability (especially Down's syndrome) can develop dementia at an earlier age than the general population.	Dementia diagnosis may be delayed and support and treatment not accessed at an appropriately early stage if the signs and symptoms of dementia are not

		Delivery of training for people with learning disabilities, their families and carers about dementia.		well understood by the person with a learning disability and/or their family members or carers.
Use of superabsorbent polymer gel granules				
181	NHS Improvement Patient Safety	Use of superabsorbent polymer gel granules in clinical areas where dementia patients are admitted	<p>Recently superabsorbent polymer gel granules are increasingly used to solidify urine, vomit and other bodily fluids to reduce the risk of slips and falls and potentially infection control; although evidence is poor.</p> <p>These granules are often packaged in sachet form and left in the urinal or bowel at the patient bedside.</p> <p>There have been a number of deaths and severe harm incidents relating to occasions when patients suffering dementia (as well as delirium) have swallowed the sachets. Clearly when the sachets have come into contact with liquid in the mouth and throat they have expanded and caused respiratory arrest.</p>	Despite issuing a Patient Safety Warning Alert in relation to this issue, incidents continued to be reported; including one incident where the CQC have investigated and financially penalised the organisation.