

# NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

## Health and social care directorate

### Quality standards and indicators

#### Briefing paper

**Quality standard topic:** Older people with social care needs and multiple long term conditions

**Output:** Prioritised quality improvement areas for development.

**Date of Quality Standards Advisory Committee meeting:** 17 February 2016

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## **1 Introduction**

This briefing paper presents a structured overview of potential quality improvement areas for older people with social care needs and multiple long term conditions. 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 source**

The key development source referenced in this briefing paper is:

[Older people with social care needs and multiple long-term conditions](#). NICE guideline 22 (2015)

No review schedule presented.

## **2 Overview<sup>1</sup>**

### **2.1 Focus of quality standard**

This quality standard will cover the planning and delivery of co-ordinated person-centred social care and support for older people with social care needs and multiple long-term conditions. The quality standard is focussed on people over 65 but may also be relevant to some people under 65 with complex needs. It will include older people living in their own homes, in specialist settings or in care homes and will also address the needs of carers.

### **2.2 Definition**

A long-term condition is one that generally lasts a year or longer and impacts on a person's life. Examples include arthritis, asthma, cancer, dementia, diabetes, heart disease, mental health conditions and stroke. Long-term conditions may also be known as 'chronic conditions'.

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<sup>1</sup> Unless otherwise referenced, sections 2.2 to 2.4 are adapted from NICE guideline NG22 [Older people with social care needs and multiple long-term conditions](#) (2015)

Having multiple long term conditions means a person is living with more than 1 condition. The impact and symptoms of these conditions may fluctuate and people may or may not need to take medication for their conditions. Having multiple long-term conditions is likely to mean having complex care needs, that is to say, a wide range of needs, many of which may be serious.

[The Health and Social Care Act](#), section 65 (2012) defines a person with identified social care needs as someone needing personal care and other practical assistance because of their age, illness, disability, pregnancy, childbirth, dependence on alcohol or drugs, or any other similar circumstances.

### **2.3 Incidence and prevalence**

The prevalence of long-term conditions is strongly linked to ageing and the number of people with multiple (2 or more) long-term conditions in England is projected to rise to 2.9 million by 2018 ([Long term conditions compendium of information third edition](#) Department of Health).

A King's Fund report on [Long term conditions and mental health](#) suggests that depression is 7 times higher in those with 2 or more long-term conditions or chronic health complaints. In addition, the National Development Team for inclusion report [A Long Time Coming Part 1](#) indicates that these depressive symptoms can often go untreated and affect the abilities of older people to manage their own conditions.

People with long-term conditions account for around 50% of all GP appointments, 64% of all outpatient appointments, and 70% of all inpatient bed days. In 2013-14, 860,000 older people over 65 used social care funded by local authorities, with total local authority spending on social services for older people of £8.8 billion ([Community care statistics: social services activity, England 2013–14, final release](#) Health and Social Care Information Centre).

Although the number of older people in the population is rising, the number receiving publicly funded care is falling. Eligibility thresholds have risen over recent years and there is evidence that many local authorities now offer social care services only to those who have the highest levels of need.

Overall, a significant proportion (70%) of government health and social care spending is attributed to the care of older people with long-term conditions and the costs per individual increase with the number of conditions the person has. The Department of Health [Long Term Conditions Compendium of Information](#) estimated in 2012 that the annual health and social care bill for a person with 1 long-term condition is £3000, 3 times the bill for a person without a long-term condition. This figure rises to £6000 for a person with 2 conditions and approximately £7800 for a person with 3.

## **2.4      *Management***

There is significant variability in the commissioning and provision of health and social care for older people in England.

Despite recent policy focusing on integrated health and social care services, people are not always treated as a whole person and there can be poor co-ordination of care for their different conditions or symptoms. A National Voices report [Integrated care: what do patients, service users and carers want?](#) indicates that people with multiple long-term conditions want joined-up, coordinated services but often find they are hard to access and fragmented. The British Geriatrics Society [Quest for Quality](#) report also suggests that the need to deliver integrated support to people with long-term conditions who live in nursing and care homes has been particularly neglected.

Long-term conditions can produce a complex range of symptoms and may fluctuate over time. These complex changes can pose challenges for the workforce, especially for workers in the social care sector who may not be adequately trained or resourced to support people with complex or specialist health needs. Older people with long-term conditions are vulnerable to hospital admission, sometimes for routine complaints. A King's Fund report on [Avoiding hospital admissions](#) suggests that if social care staff were skilled up to detect problems early and manage conditions better, hospital admissions may be avoided.

Older people may not know what care they are entitled to or what their funding options might be. It has been argued that this may lead to older people's needs being left unmet because they are not claiming support. Options for people who pay for their own care and individual budget holders can be complicated and people may not be aware how to fund residential care if their conditions worsen.

[The Care Act 2014](#) gave local authorities a duty to prevent, delay or reduce the development of people's social care needs, so far as possible, and to work in an integrated, person-centred way, with all other support agencies including those in the third sector. Local authorities also have a duty to provide information and advice for the whole population, not just those who are receiving services that they fund. The Care Act also recognises the important role played by carers and the fact that many carers are themselves older people with complex social care needs.

## **2.5      *National Outcome Frameworks***

Tables 1–3 show the outcomes, overarching indicators and improvement areas from the frameworks that the quality standard could contribute to achieving.

**Table 1 [The Adult Social Care Outcomes Framework 2015–16](#)**

Domain	Overarching and outcome measures
<p>1 Enhancing quality of life for people with care and support needs</p>	<p><b>Overarching measure</b></p> <p>1A Social care-related quality of life**</p> <p><b>Outcome measures</b></p> <p><b>People manage their own support as much as they wish, so they are in control of what, how and when support is delivered to match their needs</b></p> <p>1B Proportion of people who use services who have control over their daily life</p> <p><b>Carers can balance their caring roles and maintain their desired quality of life</b></p> <p>1D Carer-reported quality of life**</p> <p><b>People are able to find employment when they want, maintain a family and social life and contribute to community life, and avoid loneliness or isolation</b></p> <p>1I Proportion of people who use services and their carers, who reported that they had as much social contact as they would like</p>
<p>2 Delaying and reducing the need for care and support</p>	<p><b>Overarching measure</b></p> <p>2A Permanent admissions to residential and nursing care homes, per 100,000 population</p> <p><b>Outcome measures</b></p> <p><b>Everybody has the opportunity to have the best health and wellbeing throughout their life, and can access support and information to help them manage their care needs</b></p> <p><b>When people develop care needs, the support they receive takes place in the most appropriate setting and enables them to regain their independence</b></p> <p><i>Placeholder 2F Dementia – a measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life**</i></p>

<p>3 Ensuring that people have a positive experience of care and support</p>	<p><b>Overarching measure</b>  <b>People who use social care and their carers are satisfied with their experience of care and support services</b>            3A Overall satisfaction of people who use services with their care and support            3B Overall satisfaction of carers with social services  <i>Placeholder 3E The effectiveness of integrated care</i>  <b>Outcome measures</b>  <b>Carers feel that they are respected as equal partners throughout the care process</b>            3C The proportion of carers who report that they have been included or consulted in discussions about the person they care for  <b>People know what choices are available to them locally, what they are entitled to, and who to contact when they need help</b>            3D The proportion of people who use services and carers who find it easy to find information about support  <b>People, including those involved in making decisions on social care, respect the dignity of the individual and ensure support is sensitive to the circumstances of each individual</b>            This information can be taken from the Adult Social Care Survey and used for analysis at the local level.</p>
<p>4 Safeguarding adults whose circumstances make them vulnerable and protecting from avoidable harm</p>	<p><b>Overarching measure</b>            4A The proportion of people who use services who feel safe**  <b>Outcome measures</b>  <b>Everyone enjoys physical safety and feels secure</b>  <b>People are protected as far as possible from avoidable harm, disease and injuries</b>  <b>People are supported to plan ahead and have the freedom to manage risks the way that they wish</b>            4B The proportion of people who use services who say that those services have made them feel safe and secure</p>
<p><b>Alignment with NHS Outcomes Framework and/or Public Health Outcomes Framework</b>            * Indicator is shared            ** Indicator is complementary            Indicators in italics in development</p>	

**Table 2 [NHS Outcomes Framework 2015–16](#)**

<b>Domain</b>	<b>Overarching indicators and improvement areas</b>
<p>2 Enhancing quality of life for people with long-term conditions</p>	<p><b><i>Overarching indicator</i></b></p> <p><b>4</b> Health-related quality of life for people with long-term conditions**</p> <p><b><i>Improvement areas</i></b></p> <p><b>Ensuring people feel supported to manage their condition</b></p> <p>2.1 Proportion of people feeling supported to manage their condition</p> <p><b>Reducing time spent in hospital by people with long-term conditions</b></p> <p>2.3 i Unplanned hospitalisation for chronic ambulatory care sensitive conditions</p> <p><b>Enhancing quality of life for carers</b></p> <p>2.4 Health-related quality of life for carers**</p> <p><b>Enhancing quality of life for people with dementia</b></p> <p><i>ii A measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life***</i></p> <p><b>Improving quality of life for people with multiple long-term conditions</b></p> <p><i>2.7 Health-related quality of life for people with three or more long-term conditions**</i></p>
<p>4 Ensuring that people have a positive experience of care</p>	<p><b>Improving the experience of care for people at the end of their lives</b></p> <p>4.5 Bereaved carers' views on the quality of care in the last 3 months of life</p> <p><b>Improving people's experience of integrated care</b></p> <p><i>4.9 People's experience of integrated care**</i></p>
<p><b>Alignment with Adult Social Care Outcomes Framework and/or Public Health Outcomes Framework</b></p> <p>* Indicator is shared</p> <p>** Indicator is complementary</p> <p>Indicators in italics in development</p>	

**Table 3 [Public health outcomes framework for England, 2013–2016](#)**

<b>Domain</b>	<b>Objectives and indicators</b>
1 Improving the wider determinants of health	<p><b>Objective</b></p> <p>Improvements against wider factors that affect health and wellbeing and health inequalities</p> <p>1.18 Social isolation*</p> <p>1.19 Older people’s perception of community safety</p>
2 Health improvement	<p><b>Objective</b></p> <p>People are helped to live healthy lifestyles, make healthy choices and reduce health inequalities</p> <p>2.23 Self-reported well-being</p> <p>2.24 Injuries due to falls in people aged 65 and over</p>
4 Healthcare public health and preventing premature mortality	<p><b>Objective</b></p> <p>Reduced numbers of people living with preventable ill health and people dying prematurely, whilst reducing the gap between communities</p> <p><b>Indicators</b></p> <p>4.13 Health-related quality of life for older people</p> <p>4.14 Hip fractures in people aged 65 and over</p> <p>4.15 Excess winter deaths</p> <p>4.16 Estimated diagnosis rate for people with dementia</p>
<p><b><i>Alignment with Adult Social Care Outcomes Framework and/or NHS Outcomes Framework</i></b></p> <p>* Indicator is shared</p> <p>** Indicator is complementary</p> <p>Indicators in italics in development</p>	



## **3 Summary of suggestions**

### **3.1 Responses**

In total 16 stakeholders responded to the engagement exercise (15/12/15 – 8/1/16). 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 4 for further consideration by the Committee.

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

**Table 4 Summary of suggested quality improvement areas**

<b>Suggested area for improvement</b>	<b>Stakeholders</b>
<b>Comprehensive assessment of care needs</b>	HLIN, SCMs, SfC, RCN, LFEPA, ENT, BAA, NAT, CENT
<b>Care planning</b> <ul style="list-style-type: none"> <li>• Involving people and their carers</li> <li>• Comprehensive care plan</li> <li>• Reviews</li> </ul>	RPS, RCN, AS, SCM, HLIN, SfC, CSP, RCN, LFEPA, BAA, AS, NHSE AS
<b>Care co-ordinator</b>	SCM, SfC, SPRU, AS, NHSE, SfC
<b>Providing information</b> <ul style="list-style-type: none"> <li>• Accessing social care</li> <li>• Educating carers</li> <li>• Preventing social isolation</li> </ul>	SPRU, RCN, IA SfC SCM2, NHSE
<b>Technology and telecare</b>	HLIN, SfC
<b>Additional areas</b> <ul style="list-style-type: none"> <li>• Skills and training</li> <li>• Confidentiality</li> <li>• Reablement</li> <li>• Transition to/from hospital</li> <li>• Housing</li> <li>• Medication reviews</li> <li>• Specific conditions</li> <li>• Data collection</li> </ul>	SCM, NAT, AS, NHSE, SfC NAT SCM, CSP, RCN SCM, RPS HLIN RPS SCM, ENT, NIHR, BAA, CENT, NHSE, MSAT, NAT SPRU
<p>AS, Alzheimer's Society                      BAA, British Academy of Audiology                      CENT, Cochrane ENT                      CSP, The Chartered Society of Physiotherapy                      ENT, evidENT                      HLIN, Housing Learning and Improvement Network                      IA, Independent Age                      LFEPA, London Fire and Emergency Planning Authority                      MSAT, Multiple System Atrophy Trust                      NAT, National Aids Trust                      NHSE, NHS England                      NIHR, NIHR Clinical Research Network                      RCN, Royal College of Nursing                      RPS, Royal Pharmaceutical Society                      SCM, Specialist Committee Member                      SfC, Skills for Care                      SPRU, Social Policy Research Unit</p>	

### **3.2      *Identification of current practice evidence***

Bibliographic databases were searched to identify examples of current practice in UK health and social care settings; 692 studies were identified for QS topic. In addition, current practice examples were suggested by stakeholders at topic engagement (59 studies), internally at project scoping (13 studies) and via additional searching (5).

Of these studies, 13 were assessed as having potential relevance to this topic and the suggested areas for quality improvement identified by stakeholders (see appendix 1). A summary of relevant studies is included in the current practice sections for each suggested area of improvement.

## 4 Suggested improvement areas

### 4.1 Comprehensive assessment of care needs

#### 4.1.1 Summary of suggestions

Stakeholders highlighted that older people with multiple long term conditions should have a comprehensive assessment of their care needs in order to improve their quality of life. Some specific areas were highlighted as needing more attention including identifying physical (such as hearing loss, continence, frailty, dental health, vision, foot care), psychological, social, emotional, sexual and environmental (such as fire risk) needs. It was suggested that the assessment should focus on what people can do rather than what they can't do due to their health conditions.

#### 4.1.2 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**

<b>Suggested quality improvement area</b>	<b>Suggested source guidance recommendations</b>
Holistic assessment of care needs	<p><b>Identifying and assessing social care needs</b> NICE NG22 Recommendation 1.1.1, 1.1.2 and 1.1.3</p> <p><b>Supporting self-management</b> NICE NG22 Recommendation 1.5.9</p>

#### **Identifying and assessing social care needs**

##### NICE NG22 – Recommendation 1.1.1

Health and social care practitioners should consider referring older people with multiple long-term conditions to the local authority for a needs assessment as soon as it is identified that they may need social care and support.

##### NICE NG22 – Recommendation 1.1.2

Consider referral for a specialist clinical assessment by a geriatrician or old-age psychiatrist to guide social care planning for older people with social care needs and multiple long-term conditions:

- whose social care needs are likely to increase to the point where they are assessed as having a significant impact on the person's wellbeing

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- who may need to go into a nursing or care home

### NICE NG22 – Recommendation 1.1.3

When planning and undertaking assessments for older people with social care needs and multiple long-term conditions, health and social care practitioners should:

- always involve the person and, if appropriate, their carer
- take into account the person's strengths, needs and preferences
- involve the relevant practitioners to address all of the person's needs, including their medical, psychological, emotional, social, personal, sexual, spiritual and cultural needs; sight, hearing and communication needs; and accommodation and environmental care needs
- ensure that if a person and their carer cannot attend an assessment meeting, they have the opportunity to be involved in another way, for example in a separate meeting or through an advocate
- give people information about the services available to them, their cost and how they can be paid for.

### **Supporting self-management**

#### NICE NG22 – Recommendation 1.5.9

Health and social care providers should recognise incontinence as a symptom and ensure people have access to diagnosis and treatment. This should include meeting with a specialist continence nurse.

#### **4.1.3 Current UK practice**

[The Care Act 2014](#) requires local authorities to assess people's support needs and prepare a care plan if they are eligible.

Qualitative and quantitative research (interviews and discussions and a survey of 1436 family carers) carried out by the Alzheimer's Society<sup>2</sup> indicated that although people with dementia and carers were generally positive about their experience of the social care assessment process, some reported problems getting an assessment in the first place.

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<sup>2</sup> [Support. Stay. Save Care and Support for people with dementia in their own homes](#) Alzheimer's Society 2011

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A NHIR School for Social Care Research scoping review of research evidence about self-funders of social care in England published since 2000 (71 references)<sup>3</sup> concluded that self-funders lack access to local authority assessments and advice.

A qualitative focus group study of access to social care with over 40 carers from diverse ethnic groups caring for stroke survivors<sup>4</sup> found that accessing and engaging with services required huge effort. Their difficulties were exacerbated by unresponsive services and large amounts of paperwork. Paperwork was described as lengthy and 'horrendous' adding to the considerable time required to access services. Assessments often came to nothing, adding to their frustration.

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<sup>3</sup> [People who fund their own social care](#) Baxter and Glendinning NHIR School for Social Care Research 2014

<sup>4</sup> [Qualitative focus group study investigating experiences of accessing and engaging with social care services: perspectives of carers from diverse ethnic groups caring for stroke survivors](#) Greenwood, Holley, Elmers et al BMJ Open 2016

## 4.2 **Care planning**

### 4.2.1 **Summary of suggestions**

#### **Involving people and their carers**

Stakeholders highlighted the importance of involving older people with long term conditions and their carers in care planning. It was suggested that older people should have access to independent advocacy if needed and appropriate services should be available.

#### **Comprehensive care plan**

It was highlighted that a comprehensive care plan that is tailored and responsive to the individual’s needs is important in order to enable older people to maintain their independence. Stakeholders emphasised the importance of addressing particular needs in the care plan including reducing social isolation, end of life care, incontinence, physical activity, and homelessness. The care plan should be shared across all health and care providers.

#### **Reviews**

It was suggested that care plans should be updated at least annually and after a significant change such as a hospital admission to ensure it reflects the person’s current needs.

### 4.2.2 **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**

<b>Suggested quality improvement area</b>	<b>Selected source guidance recommendations</b>
Involving people and their carers	<b>Care planning</b> NICE NG22 Recommendation 1.2.2, 1.2.3, and 1.2.9 <b>Delivering care</b> NICE NG22 Recommendation 1.5.4
Comprehensive care plan	<b>Care planning</b> NICE NG22 Recommendation 1.2.2, 1.2.5, 1.2.11, and 1.2.12
Reviews	<b>Care planning</b> NICE NG22 Recommendation 1.2.4

## Care planning

### NICE NG22 Recommendation 1.2.2

Offer the person the opportunity to:

- be involved in planning their care and support
- have a summary of their life story included in their care plan
- prioritise the support they need, recognising that people want to do different things with their lives at different times, and that the way that people's long-term conditions affect them can change over time.

### NICE NG22 Recommendation 1.2.3

Ensure the person, their carers or advocate and the care practitioners jointly own the care plan, sign it to indicate they agree with it and are given a copy.

### NICE NG22 Recommendation 1.2.4

Review and update care plans regularly and at least annually to recognise the changing needs associated with multiple long-term conditions. Record the results of the review in the care plan, along with any changes made.

### NICE NG22 Recommendation 1.2.5

Ensure care plans are tailored to each person, giving them choice and control and recognising the inter-related nature of multiple long-term conditions. Offer the person the opportunity to:

- address a range of needs including medical, psychological, emotional, social, personal, sexual, spiritual and cultural needs, sight, hearing and communication needs and environmental care needs
- address palliative and end-of-life needs
- identify health problems, including continence needs and chronic pain and skin integrity, if appropriate, and the support needed to minimise their impact
- identify the help they need to look after their own care and support, manage their conditions, take part in preferred activities, hobbies and interests, and make contact with relevant support services
- include leisure and social activities outside and inside the home, mobility and transport needs, adaptations to the home and any support needed to use them.



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### NICE NG22 Recommendation 1.2.9

With the person's agreement, involve their carers or advocate in the planning process. Recognise that carers are important partners in supporting older people with social care needs and multiple long-term conditions.

### NICE NG22 Recommendation 1.2.11

Ensure that care plans enable older people with social care needs and multiple long-term conditions to participate in different aspects of daily life, as appropriate, including:

- self-care
- taking medicines
- learning
- volunteering
- maintaining a home
- financial management
- employment
- socialising with friends
- hobbies and interests.

### NICE NG22 Recommendation 1.2.12

Ensure that care plans include ordinary activities outside the home (whether that is a care home or the person's own home), for example shopping or visiting public spaces. Include activities that:

- reduce isolation because this can be particularly acute for older people with social care needs and multiple long-term conditions
- build people's confidence by involving them in their wider community, as well as with family and friends.

## **Delivering care**

### NICE NG22 Recommendation 1.5.4

Inform people about, and direct them to, advocacy services.

### 4.2.3 Current UK practice

#### Involving people and their carers

A House of Commons Health Committee report 2014-15<sup>5</sup> identified a systematic and cultural shift towards greater personalisation of health and care services, and greater involvement of service users in constructive discussions about how their long term conditions are treated.

A Care Quality Commission special review of the provision of health care to those in care homes<sup>6</sup> found that in the majority of homes (present in 77% of case files inspected) there was evidence that care planning took into account the views of the person. However, some homes did not adequately demonstrate person-focused care planning, and in many homes the views of the person's relatives and carers were not taken into account or not documented in care plans.

An Alzheimer's Society survey of 1,139 family members of people with dementia in care homes<sup>7</sup> found that only 29% agreed that the home involved the person with dementia in decisions about their care. In contrast, 59% of care home staff were positive about engagement with people with dementia in the care homes they worked in.

A small scale qualitative study of older people with multiple long term conditions in 3 integrated care pilot areas in England<sup>8</sup> found that no participants reported experiencing explicit care planning discussions or receiving written documentation setting out a negotiated care plan and they were unfamiliar with the term 'care planning'. However, most described some components of care planning which occurred over a number of contacts with health care professionals which the authors described as "reactive" care planning. In these circumstances key elements of care planning including goal setting and action planning were rare.

#### Comprehensive care plan

The Minister of State at the Department of Health has indicated that "significant change" in health and care services for long term conditions would be seen across England by 2015, boosted by the introduction of the Better Care Fund and the pooling of a proportion of health and care budgets. The House of Commons Health Committee<sup>9</sup> suggested, however, that it is unlikely that the changes in local health

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<sup>5</sup> [Managing the care of people with long-term conditions](#) House of Commons Health Committee Second Report of Session 2014-15

<sup>6</sup> [Health care in care homes](#) CQC 2012

<sup>7</sup> [Low expectations Attitudes on choice, care and community for people with dementia in care homes](#) Alzheimer's Society 2013

<sup>8</sup> [Experiences of care planning in England: interviews with patients with long term conditions](#) Newbould et al BMC Family Practice 2012 13:71

<sup>9</sup> [Managing the care of people with long-term conditions](#) House of Commons Health Committee Second Report of Session 2014-15

systems necessary to support full-scale individual care planning for long term conditions will be in place by 2015 and the scale and pace of the promised change will only become apparent once clinical commissioning group plans for the shape of local services to 2018/19 are collated and assessed by NHS England.

A small survey of 89 residential care home managers in England in 2009<sup>10</sup> found that 60% indicated they were involved in integrated care planning with NHS colleagues such as continence care.

## **Reviews**

No published studies on current practice were found for this suggested area for quality improvement; this area is based on stakeholder's knowledge and experience.

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<sup>10</sup> [Integrated working between residential care homes and primary care: a survey of care homes in England](#) Gage et al BMC Geriatrics 2012 12:71

### 4.3 **Care co-ordinator**

#### 4.3.1 **Summary of suggestions**

Stakeholders suggested that a named care co-ordinator is needed to help older people with multiple long term conditions to: navigate a complex web of health and social care services and funding systems; access information; self-manage their conditions; and plan for the future. It was emphasised that care co-ordinators need expert knowledge and skills so that they are qualified to give advice. The care co-ordinator has an important role in facilitating access to specialist support and ensuring information about the person is shared between health and care services.

#### 4.3.2 **Selected recommendations from development source**

Table 6 below highlights recommendation that has been provisionally selected from the development source that may support potential statement development. This is presented in full after table 6 to help inform the Committee’s discussion.

**Table 6 Specific areas for quality improvement**

<b>Suggested quality improvement area</b>	<b>Selected source guidance recommendations</b>
Care co-ordinator	<p><b>Care planning</b> NICE NG22 Recommendation 1.2.1</p> <p><b>Delivering care</b> NICE NG22 Recommendation 1.5.12</p>

#### **Care planning**

##### NICE NG22 Recommendation 1.2.1

Ensure that older people with social care needs and multiple long-term conditions have a single, named care coordinator who acts as their first point of contact. Working within local arrangements, the named care coordinator should:

- play a lead role in the assessment process
- liaise and work with all health and social care services, including those provided by the voluntary and community sector
- ensure referrals are made and are actioned appropriately.

#### **Delivering care**

##### NICE NG22 Recommendation 1.5.12

Named care coordinators should take responsibility for:

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- giving people and their carers information about what to do and who to contact in times of crisis, at any time of day or night
- ensuring an effective response in times of crisis
- ensuring there is continuity of care with familiar workers, so that wherever possible, personal care and support is carried out by workers known to the person and their family and carers
- engaging local community health and social care services, including those in the voluntary sector
- ensuring people and their carers have information about their particular conditions, and how to manage them
- knowing where to access specialist knowledge and support, about particular health conditions
- involving carers and advocates.

### 4.3.3 Current UK practice

A King's Fund review of five co-ordinated care programmes for people with complex chronic conditions<sup>11</sup> found that although there was consistency in the key functions of the care co-ordinator across the different programmes, the type of person undertaking the role varied greatly. Most care co-ordinators had been community or specialist nurses, yet the role had also been taken by non-clinical 'link workers' and health and social care co-ordinators. None of the care co-ordinators had received any specialist training for the role. Most had a good understanding of the local health or social care system. Effective working relationships between care co-ordinators, multidisciplinary teams and wider service providers were important.

An Alzheimer's Society survey of 1.436 carers of people with dementia<sup>12</sup> found that only 26% thought services worked well together and felt this has a negative impact on the person with dementia and their carer's physical and mental health. A later Alzheimer's Society report<sup>13</sup> indicates that early findings from a study on health service delivery for people with dementia (Bunn et al, in press) show:

- a lack of continuity of care for people with dementia and co-morbidities and poorer access to services.
- healthcare professionals frequently prioritise co-morbidity over dementia.

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<sup>11</sup> [Co-ordinated care for people with complex chronic conditions](#) The King's Fund 2013

<sup>12</sup> [Support, Stay, Save Care and Support for people with dementia in their own homes](#) Alzheimer's Society 2011

<sup>13</sup> [Dementia 2014: Opportunity for change](#) Alzheimer's Society

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- the carer of the person with dementia can often end up playing a significant role in co-ordinating healthcare and transferring information across services.

## **4.4**      *Providing information*

### **4.4.1**    **Summary of suggestions**

#### **Accessing social care**

Stakeholders highlighted the need to give information and support to older people with multiple long term conditions to enable them to access social care, including advice about funding options such as personal budgets. A stakeholder identified the importance of providing information and support to enable older people and their families to choose the right residential care home that can meet their needs. It was suggested that information also needs to be easily accessible to people who fund their own social care.

#### **Educating carers**

A suggestion was made to provide online education and training about specific long term conditions to informal carers of older people with multiple long term conditions. This will improve carers knowledge and understanding and enable them to provide appropriate support.

#### **Preventing social isolation**

Stakeholders suggested that it should be a priority for health and social care practitioners to give people advice and information about social activities and opportunities that can help them maintain and develop their social contacts. This is important because it can help them to maintain their independence and quality of life.

### **4.4.2**    **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**

<b>Suggested quality improvement area</b>	<b>Selected source guidance recommendations</b>
Accessing social care	<b>Identifying and assessing social care needs</b> NICE NG22 Recommendation 1.1.3 <b>Care planning</b> NICE NG22 Recommendation 1.2.10 <b>Preventing social isolation</b> NICE NG22 Recommendation 1.6.3
Educating carers	<b>Delivering care</b> NICE NG22 Recommendation 1.5.12
Preventing social isolation	<b>Preventing social isolation</b> NICE NG22 Recommendations 1.6.3 and 1.6.4

### **Identifying and assessing social care needs**

#### NICE NG22 Recommendation 1.1.3 (relevant bullet only)

When planning and undertaking assessments for older people with social care needs and multiple long-term conditions, health and social care practitioners should:

- give people information about the services available to them, their cost and how they can be paid for.

### **Care planning**

#### NICE NG22 Recommendation 1.2.10

Ensure older people with social care needs and multiple long-term conditions are supported to make use of personal budgets, continuing healthcare budgets, individual service funds and direct payments (where they wish to) by:

- giving them and their carers information about different funding mechanisms they could use to manage the budget available to them, and any impact these may have on their carer
- supporting them to try out different mechanisms for managing their budget
- offering information, advice and support to people who pay for or arrange their own care, as well as to those whose care is publicly funded
- offering information about benefits entitlement
- ensuring that carers' needs are taken fully into account.



## **Delivering care**

### NICE NG22 Recommendation 1.5.12 (relevant bullet only)

Named care coordinators should take responsibility for:

- ensuring people and their carers have information about their particular conditions, and how to manage them.

## **Preventing social isolation**

### NICE NG22 Recommendation 1.6.3

Named care coordinators and advocates should provide information to help people who are going to live in a care home to choose the right care home for them, for example one where they have friends or links with the community already.

### NICE NG22 Recommendation 1.6.4

Health and social care practitioners should give people advice and information about social activities and opportunities that can help them maintain their social contacts, and build new contacts if they wish to.

## **4.4.3 Current UK practice**

### **Accessing social care**

[The Care Act 2014](#) requires local authorities to provide people with information and advice relating to care and support in their area.

Analysis of data from the national Personal Social Services Survey of Adult Carers in England in 2014-15 by Which?<sup>14</sup> indicated that nearly a third (31%) of unpaid carers looking after an elderly relative who was receiving social care (65+) struggled to find information about support, services and benefits. The analysis also indicated considerable variation in access to information in different local areas ranging from over half of carers in Brent (55%) finding it difficult to find information compared with 15% in Halton.

A NHIR School for Social Care Research scoping review of research evidence about self-funders of social care in England published since 2000 (71 references)<sup>15</sup> concluded that self-funders lack information or advice at an early stage in their process of finding home care, primarily through a lack of access to local authority assessments and advice, and online information that can be hard to navigate. The

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<sup>14</sup> [Elderly care analysis of HSCIC Personal Social Services Survey of Adult Carers in England in 2014-15](#) Which? 2016

<sup>15</sup> [People who fund their own social care](#) Baxter and Glendinning NHIR School for Social Care Research 2014

review also found that self-funders of care home places generally lack information about fees, top up fees or their financial implications, and also identified evidence of a lack of opportunities for self-funders of residential care to receive initial assessments and ongoing reviews of their care and needs. The review also suggests that many people were not aware that if their needs increased, they may have to move to a more suitable care home. Included studies also found that self-funding residents were not warned that they might have to move to a cheaper care home once their funds ran out.

An Alzheimer's Society survey<sup>16</sup> of 1,139 family members of people with dementia in care homes found that 50% had found it easy to find information on care homes and 24% had found it difficult. Respondents most frequently sought information directly from care homes themselves.

### **Educating carers**

No published studies on current practice were found for this suggested area for quality improvement; this area is based on stakeholder's knowledge and experience.

### **Preventing social isolation**

The Alzheimer's Society survey of 1,139 family members of people with dementia in care homes found that only 26% said the care home was good on opportunities for trips out of the home, and 31% said they were poor. In addition, only 28% said the home was good with regard to volunteers coming into the home and 22% said it was poor.

A 2014 Alzheimer's Society survey of more than 1,327 people with dementia<sup>17</sup> found that less than half (44%) felt part of their community and 40% felt lonely recently.

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<sup>16</sup> [Low expectations Attitudes on choice, care and community for people with dementia in care homes](#)  
Alzheimer's Society 2013

<sup>17</sup> [Dementia 2014: Opportunity for change](#) Alzheimer's Society 2014

## 4.5 *Technology and telecare*

### 4.5.1 Summary of suggestions

It was suggested that improved information and advice on how telecare and technology enabled care products can support older people with multiple long term conditions to self-manage their conditions is needed.

### 4.5.2 Selected recommendations from development source

Table 8 below highlights recommendation that has been provisionally selected from the development source that may support potential statement development. This is presented in full after table 8 to help inform the Committee's discussion.

**Table 8 Specific areas for quality improvement**

<b>Suggested quality improvement area</b>	<b>Selected source guidance recommendations</b>
Technology and telecare	<b>Identifying and assessing social care needs</b> NICE NG22 Recommendations 1.1.6 and 1.1.7

#### **Identifying and assessing social care needs**

##### NICE NG22 Recommendation 1.1.6

The health or social care practitioner leading the assessment should discuss with the person any telecare options that may support them so that they can make informed choices about their usefulness to help them manage their conditions, as well as other potential benefits, risks and costs.

##### NICE NG22 Recommendation 1.1.7

The lead practitioner should consider, in discussion with the person, whether a demonstration of telecare equipment would help them to make an informed decision about it.

### 4.5.3 Current UK practice

An audit of the use of telecare services in 121 of 152 local authorities in England<sup>18</sup> concluded that while there was evidence of some good practice, the general availability of telecare services is fragmented and poorly understood:

- There was significant variation in the number of people using telecare services across different local authorities.

<sup>18</sup> [Care and support at home: An audit of telecare services in England](#) Good Governance Institute 2012

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- Access to telecare varies greatly across the country. 80% of local authorities confirmed they had eligibility criteria or an assessment process in place. The nature of these criteria or processes was inconsistent. Some local authorities had made telecare services universally available.
- There was a poor understanding about what telecare services are and how they should be incorporated into the council's social care services.

A Carers UK survey<sup>19</sup> of over 4,000 carers found that 17% were using some form of technology like telecare to help with caring. Almost two thirds (62%) were, however, unaware of the technology available. Of those who cared for someone who had recently been discharged from hospital, only 3% had been offered a telecare package upon discharge. Even when carers were aware of the support many still did not know how to access it and had not been offered it. Only 6% of carers definitely did not want to access telecare.

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<sup>19</sup> [Carers and telecare](#) Carers UK 2012

## **4.6 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 QSAC to discuss these areas at the end of the session on February 17<sup>th</sup> 2016.

### **Skills and training**

Stakeholders highlighted the importance of health and social care practitioners having the appropriate skills and training to provide care to older people with multiple long term conditions. Particular priorities for training were identified as managing medicines and dementia (in particular tier 3 training). Quality statements on staff training and skills are not usually included in quality standards.

### **Confidentiality**

A stakeholder indicated that there is a need to ensure that information about the person using care services remains confidential; with organisations having appropriate policies in place. Breaches of confidentiality about a person's health status can lead to discrimination and may mean individuals are not willing to share important information with their health and care providers. Confidentiality policies are not included in the development source (NG22).

### **Reablement**

The importance of reablement services to prevent admission to hospital and support early discharge from hospital was highlighted. It was felt there is currently variation in the availability of reablement services in different areas. A stakeholder highlighted the importance of specialist training for staff delivering reablement and for occupational therapists to be involved. This will be covered by a separate quality standard on 'Regaining independence (Reablement): short term interventions to help people to regain independence'.

### **Transition to/from hospital**

It was suggested that health and social care services need to be well integrated when older people with multiple long term conditions are transferred to and from different care settings. In particular, there was concern about the miscommunication

of medicine requirements when people are transferred which can result in too much or too little being taken and patient safety incidents. This will be covered by a separate quality standard on 'Transition between inpatient hospital settings and community or care home settings'.

### **Housing**

A stakeholder suggested that extra care housing services can have positive outcomes for older people with multiple long term conditions as well as reducing NHS costs. It was also suggested that accessible and adaptable housing design can reduce unnecessary hospital admissions and enable older people to stay in their own homes for longer. These issues are not covered in the development source (NG22). It is likely that some issues will be covered in a separate quality standard on 'Housing: planning to improve health and wellbeing'.

### **Medication reviews**

It was suggested that older people with multiple long term conditions should be a target group for community pharmacists to undertake medicine use reviews in order to reduce avoidable harm and unnecessary hospital admissions related to medicine use. This is covered by separate quality standards on 'Medicines optimisation' and 'Medicines management in care homes' and will also be included in another quality standard on 'Medicines management: managing the use of medicines in community settings for people receiving social care'.

### **Specific conditions**

Several stakeholders highlighted the need for improvements in relation to specific conditions as follows:

- Older people living with HIV
- Single conditions that have an impact on multiple functions such as Multiple System Atrophy
- Care pathways for age related hearing loss
- Diagnosis, care and end of life for people with dementia

Some of these will be covered by quality standards on specific conditions including 'Dementia' and 'Hearing loss (adult onset)'. Multiple System Atrophy and HIV are not covered in the development source (NG22).

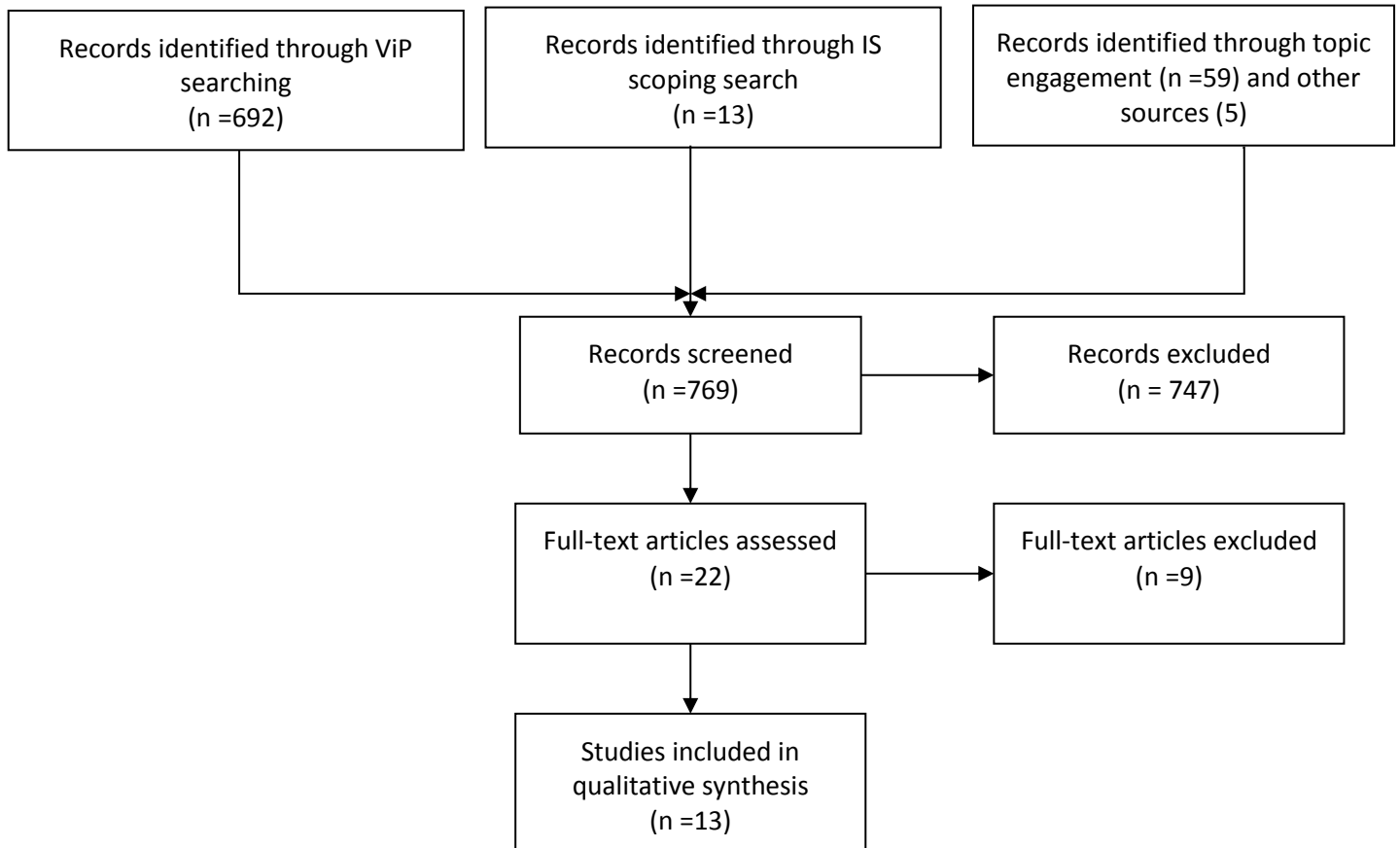
### **Data collection**

There was a suggestion that there is a need for improved data collection relating to patient experience and service quality in social care and for this to be integrated with

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healthcare data. Quality standards do not usually include structural issues and this is not included in the development source (NG22).

## Appendix 1: Review flowchart





**Appendix 2: Suggestions from stakeholder engagement exercise – registered stakeholders**

ID	Report Section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
1	4.1	SCM1	Key area for quality improvement 1	Foot Care	Freedom from pain, mobility	Ill fitting shoes, corns, bunions, nail infections
2	4.1	SCM1	Key area for quality improvement 2	Dental Health	Appearance, function, freedom from pain	Ill fitting dentures, poor oral hygiene, halitosis, angular cheilitis
3	4.1	SCM1	Key area for quality improvement 3	Urinary continence	Control, dignity	Stress incontinence, urge incontinence, urinary infections
4	4.1	SCM1	Key area for quality improvement 4	Sexual health	Appearance, dignity, human interaction, pleasure	The importance of sexuality, appearance and giving and receiving pleasure
5	4.1	SCM1	Key area for quality improvement 5	Hearing	Communication	Hearing aids ill-fitting, not working, hard to manage with arthritic fingers and poor sight
6	4.1	SCM1	Additional developmental areas of emergent practice	Vision	Reading, television, trips to shops, sea, country, museums, galleries, theatres etc	Visual impairments, retinal disease, cataracts, regular sight testing, clean glasses, near vision aids
7	4.1	SCM1	Additional evidence sources for consideration	The experience of working with the elderly as patients or relatives suggests to me that these areas are too easily forgotten and need to be checked out regularly for they are often more important to the quality of life than specific medical interventions for chronic disease.  The supporting epidemiology		

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ID	Report Section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				<p>is often simply not there but care workers with this group identify these as often missed problems. It should be possible to develop indicators for Input, Process and Outcome for each of them.</p> <p>This would best be within a Clinical Governance framework i.e. Audit, Risk Management, Quality, Research &amp; Development, Teaching &amp; Training</p>		

ID	Report Section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
8	4.1	SCM2	Key area for quality improvement 1 Assessment	This key area must be seen as developing a wide understanding of how the person and their carers can be helped to lead as normal a life as possible. It means trying to avoid the need for a high level of care by considering all of the supports available to the person in the community. This might include the use of individual budgets.	Effectiveness in working with the person and their carers will contribute to a sense of well being, improved quality of life and better health outcomes.	See NICE guidelines for social care of older people with multiple long term conditions. <a href="http://www.nice.org.uk/guidance/ng22">http://www.nice.org.uk/guidance/ng22</a>
9	4.1	Skills for Care	Maintaining well-being and preventing social isolation. Holistic assessments to support understanding of what people can do rather than what they can't because of their condition(s)	People whose emotional health is maintained and support manage their long term conditions significantly better and have less reliance on public services.	Long term conditions are difficult to live with and can feel like a 'death sentence' to some. It is important to ensure that patients are given a different perspective and realise that they still can have a life to live. Social inclusion is key to this maintenance of wellbeing as people realise they can still be included in education, social and recreational activities.	
10	4.1	Royal College of Nursing	Key area for quality improvement 6: Recognition of people living with	Emerging research on frailty is relevant to this population and should be mentioned and included in the quality	Frailty is an under recognised and under managed condition which if unsupported can result in	Safe, compassionate care for frail older people using an integrated care pathway: Practical guidance for

ID	Report Section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			frailty.	standards.	preventable hospital admission and reduced quality of life.	<p>commissioners, providers and nursing, medical and allied health professional leaders</p> <p><a href="https://www.england.nhs.uk/wp-content/uploads/2014/02/safe-comp-care.pdf">https://www.england.nhs.uk/wp-content/uploads/2014/02/safe-comp-care.pdf</a></p> <p>Fit for Frailty Part 2: Developing, commissioning and managing services for people living with frailty in community settings Guidance for GPs, Geriatricians, Health Service managers, social service managers and commissioners of services <a href="http://www.bgs.org.uk/campaigns/fff/fff2_full.pdf">http://www.bgs.org.uk/campaigns/fff/fff2_full.pdf</a></p>

ID	Report Section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
11	4.1	London Fire and Emergency Planning Authority (LFEPA)	Reduction in fires, fire deaths and fire injuries for (older) people with social care needs and multiple long-term conditions living in their own homes or in specialist settings/care homes.	The prevalence of (older) people with social care needs arising from multiple long term conditions living in their homes or in specialist settings/care homes in the occurrence of fatal fires and those where injuries were serious enough to require lengthy hospitalisation.	Data demonstrate that opportunities to identify and address fire risk for older people with social care needs and multiple long-term conditions have been missed by care and support agencies.	London Fire Brigade Annual Review Of Accidental Dwelling Fires and Fatalities – FEP 2484  <a href="http://modern.gov.london-fire.gov.uk/mgconvert2pdf.aspx?id=4384">http://modern.gov.london-fire.gov.uk/mgconvert2pdf.aspx?id=4384</a>
12	4.1	ENT, Hearing and Balance National Specialty Group, NIHR Clinical Research Network	Key area for quality improvement 1  Identifying and treating hearing loss and supporting communication	Hearing loss is highly prevalent in older people and those with long term conditions (NHS England, 2015).  Hearing loss impacts on communication ability, causes social isolation and contributes to depression. Untreated hearing loss is independently linked to cognitive decline and worsening of existing long term conditions (NHS England, 2015).  Hearing loss can be treated with hearing aids and/or communication support. This		

ID	Report Section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				<p>improves quality of life as well as improving the ability to self-manage other long term conditions (NHS England, 2015).</p> <p>Objectives 2 and 3 of the DoH Action Plan for Hearing Loss (2015) state that all people with hearing loss should be diagnosed early and managed effectively, with a focus on groups with high risks and prevalence; also that services should be integrated, work collaboratively, and focus upon the individual needs of the person with hearing loss, inclusive of any other co-existing physical and mental health conditions and pathologies, to provide a patient centred management and decision making partnership</p> <p>Reference NHS England and Department of Health 2015. Action Plan on Hearing Loss.</p>		

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ID	Report Section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				<a href="https://www.england.nhs.uk/wp-content/uploads/2015/03/act-plan-hearing-loss-upd.pdf">https://www.england.nhs.uk/wp-content/uploads/2015/03/act-plan-hearing-loss-upd.pdf</a>		

ID	Report Section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
13	4.1	NAT (National AIDS Trust)	Understanding of HIV, and its specific impact on the medical and psycho-social needs of people living with HIV, among care providers.	<p>People over 50 living with HIV have double the number of other long term conditions that is expected in the general population of the same age, and are also more likely to experience mental health problems.</p> <p>These specific health challenges mean that older people living with HIV are especially in need of appropriate support.</p> <p>HIV is a stigmatised condition. Many people living with HIV experience discrimination, often in healthcare settings, and thus have concerns about the prejudice they may face during care provision.</p> <p>Care workers must have training to ensure that people living with HIV receive appropriate care and are treated with respect.</p>		
14	4.1	Cochrane ENT	Age related hearing loss:	As people get older their hearing typically declines.	Hearing loss and its consequences become	Please see:



ID	Report Section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
			<p>Education of carers and health &amp; social care workers about the impact of age related hearing loss on mental and cognitive health in the elderly, including the role of hearing rehabilitation, acoustic measures and communication strategies</p> <p>Development of hearing pathways in older people with social care needs and multiple long-term conditions, including screening for hearing loss and hearing rehabilitation for those diagnosed as with hearing loss</p>	<p>Currently, over 10 million people in the UK are affected by hearing loss; it is predicted that with an aging population, by 2031 there will be more than 14.4 million people with hearing loss and over 2 million with severe hearing loss in the UK. Adult onset hearing loss is in the top 20 causes of disease currently and will be in the top ten of disease burdens in the UK above cataracts and diabetes by 2030 as measured by disability life adjusted years. There is a recognised relationship between hearing loss, social isolation, poor mental health and cognitive decline in older persons. This may have broader health implications.</p> <p>From the DoH and NHS England Action Plan on Hearing Loss: "There is a significant socioeconomic gradient associated with hearing loss bringing greater inequality and an impact that</p>	<p>harder to manage the longer it is ignored. Timely diagnosis and management may improve social interaction; improve mental health and slow cognitive decline.</p> <p>Both the DoH and NHS England Action Plan on Hearing Loss and Monitor on NHS adult hearing services recognise a lack of awareness of hearing loss in older people and its impact on their health (see supporting information) and recommend to review guidelines to ensure health and social care services recognise the risk of dementia presented by severe hearing loss as well as the co-existence of hearing loss with other conditions such as memory loss or visual impairment.</p> <p>In the recently launched UK research agenda for ENT, Hearing and Balance, top</p>	<p>NHS adult hearing services in England: exploring how choice is working for patients <a href="https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/409273/Adult_hearing_services_-_Monitor_s_report.pdf">https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/409273/Adult_hearing_services_-_Monitor_s_report.pdf</a></p> <p>The Ear Foundation, The Impact of Hearing Loss Report <a href="http://www.earfoundation.org.uk/news/articles/438">http://www.earfoundation.org.uk/news/articles/438</a></p> <p>The Department of Health and NHS England's Action Plan on Hearing Loss <a href="https://www.england.nhs.uk/wp-content/uploads/2015/03/act-plan-hearing-loss-upd.pdf">https://www.england.nhs.uk/wp-content/uploads/2015/03/act-plan-hearing-loss-upd.pdf</a></p> <p>ENT UK's Research Agenda for ENT, Hearing and Balance Care <a href="http://entuk.org/generate">http://entuk.org/generate</a></p> <p>Lin FR, Yaffe K, Xia J et al. Hearing loss and cognitive decline in older adults. JAMA Intern Med. 2013 Feb 25;173(4):293-9</p> <p>Matthews, L. (2013) Hearing Loss,</p>

ID	Report Section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				<p>can go unrecognised. Hearing loss is a major reason for poorer and less frequent social interaction, is often a contributor to depression and is independently associated with dementia. People with unmanaged hearing loss and either dementia or mental health problems are more likely to go straight to a higher cost intervention, such as a care home, than would be the case if their hearing loss were effectively managed. Research in care homes suggests high levels of undiagnosed hearing loss, and under-optimisation of hearing aid benefits for users. Staff have a limited understanding of the assistive technology available to people with hearing loss. By 2032, there will be around 620,000 older people living in care homes in England and of these, almost 500,000 will have a hearing loss and will need support to maximise</p>	<p>priorities include better understanding of the impact of hearing loss on the individual, family and population, adult hearing screening, improving hearing aid technologies and developing novel drugs and cell-based therapies for age related hearing loss.</p>	<p>Tinnitus and Mental Health. A literature review. Action on Hearing Loss.</p> <p>Lin, F.R. et al (2011) Hearing Loss and Incident Dementia. Arch Neurol, 2011;68(2):214-20</p>

ID	Report Section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				<p>their independence and wellbeing.</p> <p>It is therefore important that hearing loss is recognised and managed optimally, in particular in the vulnerable population of older people with multiple morbidities.</p>		

ID	Report Section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
15	4.1	British Academy of Audiology	Key area for quality improvement 1 Hearing loss and communication assessment and support	Poor hearing can have devastating impact on communication and thus social isolation and mental health. To ensure maximal independence and quality of life for as long as possible it is vital that patients are given the necessary hearing support by improving their communication abilities.	Currently there varying hearing service provision for this cohort of patients with different criteria. Referrals to hearing services are not always considered and hence patient care for their other medical conditions is affected as patients are unable to hear the professional and thus insufficiently comply with treatment/management plans or make informed decisions.	
16	4.2	SCM3	5. Commissioning independent advocacy to meet duties under the Care Act should be informed by good practice in order to secure best value and outcomes	To ensure that the legal duties under the Care Act 2014 are met by keeping in mind the driving principles of the Care Act: the promotion of wellbeing and the prevention, delay and reduction of the need for care and support.	'Local authorities must involve people in decisions made about them and their care and support. No matter how complex a person's needs, local authorities are required to help people express their wishes and feelings, support them in weighing up their options, and assist them in making their own decisions'. (Care Act, 2014)	See ;Care Act 2014
17	4.2	Royal Pharmaceutical Society	Key area for quality improvement 2 Carer involvement	People over 65 who have multiple LTCs and social care needs often have carer input,	Where a patient relies on the support of a carer who plays a role in managing or	

ID	Report Section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
				<p>either formally or informally.</p>	<p>administering their medicines, the carer should also be part of the medicines review, (i.e. with the patient's consent). Where the patient is unable to give consent, the carer should be involved if the clinician considers it to be in the patient's best interest.</p> <p>Carers are often able to provide useful information on the effects of medicines on the person they care for which may not necessarily be reported by the patient: for example, the patient may spend many hours of the day dozing in a chair, be unsteady on their feet, or depressed and lethargic. In some instances, this could be due to their medicines.</p> <p>The majority of carers are in employment and where their role involves managing someone's medication, and there are many different medications to manage, this</p>	

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ID	Report Section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
					can place significant demands on the carer's time.	

ID	Report Section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
18	4.2	Royal College of Nursing	Key area for quality improvement 3: Better supported management	Many people living with long term conditions (LTC) have a good understanding of their conditions and need to be involved in the planning of their care.	Effective care planning and shared decision making can mean that older people are able to remain in the place of their choice with a robust plan to ensure they are supported	A practical guide to self-management The Health Foundation Dec 2015 <a href="http://www.health.org.uk/publication/practical-guide-self-management-support">http://www.health.org.uk/publication/practical-guide-self-management-support</a>
19	4.2	Housing Learning and Improvement Network	Tackling homelessness	Housing LIN case study on independent research conducted by the University of Plymouth	'Providing support to homeless people when leaving hospital: Proving the case'	<a href="http://www.housinglin.org.uk/HousingRegions/SouthWest/?parent=1025&amp;child=9332">http://www.housinglin.org.uk/HousingRegions/SouthWest/?parent=1025&amp;child=9332</a>
20	4.2	The Chartered Society of Physiotherapy	Key area for quality improvement 1 Access to community based exercise classes specifically for older people with long term conditions	It is widely accepted that exercise for this group is beneficial, as reflected in the Chief Medical Officers guidance on physical activity in people over 65 years old:	Despite the widely known benefits, only between 6-20% of older adults met the physical activity recommendations. All health and social care professionals have a responsibility to promote physically active lifestyles (within the individual's ability) and refer onwards for specialist advice/classes (e.g. from a physiotherapist).	Chief Medical Officer's guidance on physical activity in people over 65 years old: <a href="https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213741/dh_128146.pdf">https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213741/dh_128146.pdf</a> British Heart Foundation National Centre for Physical Activity and Health, older adults evidence briefing: <a href="http://www.bhfactive.org.uk/older-adults-resources-and-publications-item/40/313/index.html">http://www.bhfactive.org.uk/older-adults-resources-and-publications-item/40/313/index.html</a> Role of physiotherapy in older adult social care: <a href="http://www.csp.org.uk/publications/physiotherapy-works-social-care">http://www.csp.org.uk/publications/physiotherapy-works-social-care</a>

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21	4.2	Royal College of Nursing	Key area for quality improvement 2: End of Life Care for frail older people	Older age is often considered to be the usual precursor to death and so end of life care planning and palliative care are sometimes not thought to be necessary.	All older people need to be offered the opportunity to discuss their end of life wishes so that appropriate care coordination and planning can be implemented.	RCN Fundamentals of End of Life <a href="http://www.rcnendoflife.org.uk">www.rcnendoflife.org.uk</a>  One chance to Get it Right NHS England 2014  New Ambitions for End of Life Care <a href="http://endoflifecareambitions.org.uk/">http://endoflifecareambitions.org.uk/</a>
22	4.2	Royal College of Nursing	Key area for quality improvement 4: Flexible social care	Many older people have fluctuating ability and may only need services intermittently. This is currently very hard to arrange and maintain.	By having tailored and flexible support older people are enabled to maintain their independence and control over their lives for example in the winter many older people are frightened to go out but can manage in the summer.	A practical guide to self-management The Health Foundation Dec 2015 <a href="http://www.health.org.uk/publication/practical-guide-self-management-support">http://www.health.org.uk/publication/practical-guide-self-management-support</a>
23	4.2	Royal College of Nursing	Key area for quality improvement 5: Much more nuanced and individualised packages of care	Much of the current care for older people is inflexible and only offers certain things at certain times usually - relating to activities of daily living and doing for and to, rather than with the person.	Ineffective, unwanted support that de-skills and patronises older people results in further deterioration and burden on the system and their relatives.	A practical guide to self-management The Health Foundation Dec 2015 <a href="http://www.health.org.uk/publication/practical-guide-self-management-support">http://www.health.org.uk/publication/practical-guide-self-management-support</a>
24	4.2	Alzheimer's Society	Key area for quality improvement 2 1.4 Integrating health and social care planning	There are around 850,000 people in the UK living with dementia (Prince et al, 2014), with over 42,000 developing the condition before they reach 65. Nearly all people living with dementia will	Current practice around care coordination within in a multidisciplinary team is variable for people living with dementia. However, areas of best practice are emerging.	Prevalence rate: Prince M, Knapp M, et al (2014). Dementia UK: Update. London: Alzheimer's Society <a href="http://www.alzheimers.org.uk/dementiauk">http://www.alzheimers.org.uk/dementiauk</a>



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				<p>require care and support from both the NHS and social care system at some point as a result of dementia having features of neurological disease, mental illness and physical frailty that cross the boundaries of the health and social care system. In addition, research indicates that around 70% of people with dementia live with co-morbidities, (Alzheimer's Society, 2015). To ensure that people with dementia are supported to live as independently and healthily as possible, they must have a comprehensive care plan that sets out of package of support that addresses health and social care needs as well as escalation plans should anything go wrong. This helps ensure people receive integrated, personal support across care settings.</p> <p>Their care plan should be shared with all relevant health and social care practitioners</p>	<p>The MDT should be built around need/aspirations of the person with dementia and should contain health and care professionals as required. Having a dementia expert, such as a Dementia Support Worker, in the MDT can improve outcomes. The Dementia Support worker provides tailored information, advice and signposting. They can support people affected by dementia to navigate a complex web of health and social care services to access appropriate information and can help them to plan for the future and self-manage effectively. This array of knowledge and skills makes them perfectly placed to play the role of care coordinator.</p>	<p>Numbers of people receiving homecare in community Alzheimer's Society (2014a). Dementia 2014: Opportunity for change. London: Alzheimer's Society  <a href="http://www.alzheimers.org.uk/site/scripts/download.php?fileID=2317">http://www.alzheimers.org.uk/site/scripts/download.php?fileID=2317</a></p> <p>Percentage of people receiving home care who have dementia UK Homecare Association (2013). UKHCA Dementia Strategy and Plan, February 2013. Wallington: UK Homecare Association.  <a href="http://www.ukhca.co.uk/pdfs/UKHCADementiaStrategy201202final.pdf">http://www.ukhca.co.uk/pdfs/UKHCADementiaStrategy201202final.pdf</a></p> <p>Dementia and co-morbidities: Alzheimer's Society (2015). Dementia 2015: Aiming higher to transform lives. London: Alzheimer's Society.  <a href="http://www.alzheimers.org.uk/site/scripts/download.php?fileID=2700">http://www.alzheimers.org.uk/site/scripts/download.php?fileID=2700</a></p>

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				<p>so that the person with dementia does not have to relay their story to multiple people.</p> <p>People with dementia have needs which will change, sometimes quite rapidly. Alzheimer's Society supports the guidelines recommendation that care plans should be updated at least annually.</p>		

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25	4.2	NHS England	<p>Key area for quality improvement 5</p> <p>Health and social care providers should recognise incontinence as a symptom and ensure people have access to diagnosis and treatment. This should include meeting with a specialist continence nurse.</p>	<p>The Five Year Forward View set us a challenge of refocusing healthcare to prevent ill health and provide people with greater control over their condition and care. People living with continence needs who, in the past, have often suffered in silence as higher profile conditions attracted attention and resource.</p>		<p>Excellence in continence care: Practical guidance for commissioners, providers, health and social care staff and information for the public</p> <p><a href="https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/11/EICC-guidance-final-document.pdf">https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/11/EICC-guidance-final-document.pdf</a></p>
26	4.3	SCM2	<p>Key area for quality improvement 2: Care planning</p>	<p>This will mean enabling practitioners to achieve the above support, for example by appointing a named care co-ordinator to liaise between the health and social care services</p>	<p>Studies such as Challis (in 2004) have demonstrated that effective liaison between the range of disciplines providing health and care services can improve outcomes and well being of older people with multiple long term conditions.</p>	<p>This means enabling a community-based multidisciplinary which might include for example, a community pharmacist, physiotherapist or occupational therapist, a mental health social worker or psychiatrist, and a community-based services liaison worker.</p>
27	4.3	Social Policy Research Unit	<p>Key area for quality improvement 2</p> <p>Provision of support for</p>	<p>People with complex needs (and those close to them) emphasise the importance of individually tailored support and value a range of person-</p>	<p>People with complex needs value support through the way services are organised as well as at an individual level. There are strong</p>	<p>While this work was conducted in a heterogeneous sample of people the findings applied to all groups. Please see. Gridley, K., Brooks, J. and Glendinning, C. (2014) Good</p>

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			<p>individuals to navigate the social care and healthcare system in relation to Individually tailored support.</p>	<p>centred approaches to social care. Good support requires staff to have the time, and services the flexibility, to respond to each individual's unique needs and preferences. Support should be holistic, addressing social and emotional, not just personal care, needs. It is important that key workers have expert knowledge and the skills to navigate complex services and funding systems, as there seems to be a trend at the moment towards cheaper, lower skilled care navigators or advisers who may not be qualified to give advice.</p>	<p>arguments, for example, in favour of dedicated key workers and case managers to facilitate access to disparate services and coordinate support across sectors and boundaries. Participants wanted key workers to have expert knowledge and the skills to navigate complex service and funding systems. However there is little evidence to support one approach over another.</p>	<p>practice in social care: the views of people with severe and complex needs and those who support them, <i>Health and Social Care in the Community</i>, 22, 6, 588-597.</p>

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28	4.3	Skills for Care	Named Care Co-ordinator	Patients / people who access care and support have too many professionals to deal with and often navigation around services is extremely complicated for them.	<p>One key co-ordinator who has access to better quality and current information about all the services involved in the lives of the person and one personal record giving information about the life history as well as current status.</p> <p>This co-ordinator could also act as a champion, an expert reference, for others with the knowledge and skills to access current information about the condition</p>	
29	4.3	NHS England	<p>Key area for quality improvement 3 Build into service specifications and contracts the need:</p> <p>-to direct older people with social care needs and multiple long-term conditions to different services as needed</p>	The Five Year Forward View highlights the importance of integration	In order to move at pace specifications need to change to drive integration	

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			-for seamless referrals between practitioners, including the appropriate sharing of information			

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30	4.3	Alzheimer's Society	Key area for quality improvement 1 Care planning Co-ordinating care (1.2.1 – 1.2.4)	<p>Alzheimer's Society knows that people living with dementia can find the health and social care system confusing and overwhelming. They can benefit from a care co-ordinator to guide them through assessments, referrals and to support them on their journey. Ideally this person should have dementia specific knowledge and recognise the changing needs and requirements of the condition. A dementia support worker or dementia adviser would be an ideal person to take on this role.</p> <p>The person with dementia must be given the opportunity to contribute to their care plan and should be enabled to do so through the use of an advocate if necessary.</p>	<p>People with dementia must be supported to contribute to their care plan so that it can be moulded around their wants and needs.</p> <p>As the needs and wants of people with dementia can change, sometimes rapidly, the review must be updated at least annually and after a significant event. For example if a person with dementia is admitted to hospital their needs may have changed. In this situation waiting for the next scheduled review would be inappropriate.</p>	
31	4.3	SCM2	Key area for quality improvement 3: Integration	If services are joined up, it will lead to better outcomes, more effective support to the person and it will save time and money.	There is an imperative from the Care Act 2014, but it is good practice and also common sense. .	Research evidence is also available to support this key area.
32	4.3	Skills for Care	Shared	Integrated	One 'live' and shared	

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			information / integrated records		integrated record can ensure better quality of support for the person as all professionals involved across the whole health and social care economy have access to the same personal record which is current and up to date as changes are made in 'real time' by anyone involved, including ambulances services. This should include history, care / support plan, end of life decisions as well as significant incidents and events. The record should include plans / action notes for foreseeable significant incidents given the progressive nature of the conditions. It should be owned by the person who will grant permission for professionals to access, maintain and update it. This can also keep long distance carers / relatives informed of the situation.	



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33	4.4	Social Policy Research Unit	<p>Key area for quality improvement 1</p> <p>Information about social care for people not eligible for local council funding (self-funders)</p>	<p>There is evidence that when people begin to struggle to live independently at home, they do not know what help they need or where to find out about it, they do not understand the social care system or what forms of help are available and, although information is available, they find information systems difficult to navigate.</p>	<p>The number of self-funders in England is large and increasing. The Care Act 2014 made provisions for self-funders, including a duty on councils to establish and maintain a service for providing people with information and advice about care and support. Other elements of the Care Act, including those delayed until 2020, make the provision of good quality, easily accessible information even more important. Each council is responsible for information and advice services in its area; variation in the commitment to and quality of these services is inevitable.</p>	<p>Please see Baxter and Glendinning (2015), People who fund their own social care, SSCR Scoping Review, NIHR School For Social Care Research, London for a review of research evidence about self-funders, including issues around information and advice.  <a href="http://www.york.ac.uk/inst/spru/publications/pdf/sscrSelfFundSR11.pdf">http://www.york.ac.uk/inst/spru/publications/pdf/sscrSelfFundSR11.pdf</a></p>
34	4.4	Royal College of Nursing	<p>Additional developmental areas of emergent practice: Much greater use of personal budgets; Much more effective joint</p>	<p>To encourage more individualised care and offer more control to older people in the care they receive</p>	<p>Due consideration to these areas of practice in the long term will improve outcomes for people with long term conditions (LTC), reduce pressure on the system and utilise the expertise of many third sector organisations</p>	

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			commissioning; Much greater use of the third sector		who are able to offer a more tailored approach or dovetail in with the statutory services to provide a more individualised package of care.	

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35	4.4	Independent Age	Information and advice provision for older people and their relatives	Information and advice for older people and their families is a vital part of supporting older people to choose residential care that meets their needs and offers a good quality of life.	<p>- Too often, older people and their families make decisions about care – particularly residential care – in crisis situations.</p> <p>But even when families attempt to plan ahead and choose residential care that works for them, they often find it very difficult to do so due to the difficulty in locating a single source of reliable, informative information about the comparative quality and fit of residential care options.</p> <p>A number of vital steps must be taken to ensure that providers of care, local authorities and other key actors in the care market, provide the information that older people and their families need, when they need it.</p> <p>These actions include: Ensuring all existing data is effectively shared in one</p>	<p>Commission on Residential Care, Demos, 2015 <a href="http://www.demos.co.uk/files/DemosCORCpubliccall.pdf">http://www.demos.co.uk/files/DemosCORCpubliccall.pdf</a></p> <p>Interviews with social care experts, older people and their families – due for future publication by Independent Age</p>

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					<p>place – for example on the ‘My NHS’ site;                      Increasing the coverage of available information to paint as full a picture as possible of care home quality; and                      Encouraging the use – and publication – of schemes such as ‘Your Care Rating’ among providers to provide a baseline of information about every home.</p>	

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36	4.4	Independent Age	Empowering older people and their families to ask the right questions when choosing a care home	Being empowered to ask for additional information about care homes is a vital component of older people and their families getting all the information they need to make an informed decision about which care home will best meet their needs.	<p>Too often older people and their families do not know which questions to ask to access quality information when looking for a care home. Further, people with little knowledge or experience of social care may not feel able to ask difficult or intrusive questions of potential care homes, even when it is vitally important that they do so.</p> <p>In order to address this issue, NICE should develop a quality standard for 'viewing a care home'. This standard should include guidance for providers setting out the kinds of questions managers/staff should be prepared to answer from older people and their relatives, what they should show to visitors, and what information and materials they should provide them with.</p>	
37	4.4	Independent	Understanding	In order for older people and	Currently most abuse	- Winterbourne View – the

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		Age	more about abuse and neglect in care homes	their families to have faith in the care system, they should be able to accurately gauge the scale of abuse within care homes, and understand how to protect themselves/their relatives against experiencing it.	<p>scandals are revealed as a result of whistle-blowers or covert hidden camera footage – this is clearly inadequate. Further, the nature of evidence of this nature is that it is sparse, and relates only to those cases where someone has been brave enough to come forwards.</p> <p>Instead of relying on these methods of detection, there should be an annual anonymous mandatory staff survey of all staff working in care homes across England. This would allow older people and their relatives, and the Government, to understand the true scale of care home abuse, and begin to show us how to tackle abuse that remains hidden.</p>	<p>Time for Change, NHS England  <a href="https://www.england.nhs.uk/wp-content/uploads/2014/11/transforming-commissioning-services.pdf">https://www.england.nhs.uk/wp-content/uploads/2014/11/transforming-commissioning-services.pdf</a></p> <p>Numerous examples of abuse, including:  <a href="http://www.independent.co.uk/news/uk/home-news/shocking-footage-shows-elderly-residents-being-taunted-and-abused-at-essex-care-home-9303888.html">http://www.independent.co.uk/news/uk/home-news/shocking-footage-shows-elderly-residents-being-taunted-and-abused-at-essex-care-home-9303888.html</a>  <a href="http://www.itv.com/goodmorningbritain/news/shocking-footage-shows-care-home-abuse">http://www.itv.com/goodmorningbritain/news/shocking-footage-shows-care-home-abuse</a></p>

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38	4.4	Skills for Care	Continuing professional development opportunities for Carers as well as for health and social care staff	To ensure up to date knowledge / skills in the wide range of long term conditions. To support carers in their role to be knowledgeable about the conditions and how they might interact with each other.	Without access to up to date information / treatments / responses, staff and carers are not able to provide quality services to those patients and people who access care and support.	<p>This could be provided in some kind of accessible repository for current new theories / solutions. Make further use of NHS choices webpages but also something more specialist for those who need to know about new research findings and possible changes in treatment /care.</p> <p>Some online learning programmes are available at Electronic learning for Health which is available to health and social care staff. Can this be made available to carers? <a href="http://www.e-lfh.org.uk/programmes/">http://www.e-lfh.org.uk/programmes/</a></p> <p>This range of online learning modules could be extended to include more learning on Long term conditions.</p>
39	4.4	SCM2	Key area for quality improvement 4 Delivering care	Information giving should be central to the work of care practitioners and reducing social isolation a target for those who deliver social care	Key to helping older people with multiple long term conditions to maintain their independence and quality of life	Guidelines Section 1.5
40	4.4	NHS England	Key area for quality improvement 4 Health and social care practitioners	This can help them maintain their independence and well being	This is an area that is underdeveloped and can have a significant impact on a persons social and emotional well being and	

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			should give people advice and information about social activities and opportunities that can help them maintain their social contacts, and build new contacts if they wish to.		consequently on their health.	



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41	4.5	Skills for Care	Supporting self – management: Greater understanding of the use of technology in supporting those with Long Term conditions	To ensure informal carers / staff are better equipped to support health and wellbeing of patients / people who access care and support.	Telecare is only one aspect of technology enabled care. Many other solutions are available, even in general DIY stores and do not need expensive products. There needs to be greater understanding /awareness of how these products can complement the telecare solutions normally offered through health and social care services. With the right knowledge patients / carers/ people who access care and support can self-care and support their own health and wellbeing without reliance on statutory services.	Number of Local Authorities in response to the Care Act legislation to provide advice and guidance offer information on technology enabled products both online and in paper format –some even have ready equipped ‘smarthouses’ that can be visited to raise awareness. E.g. <a href="http://www.moreindependent.co.uk/">http://www.moreindependent.co.uk/</a>
42	4.5	Housing Learning and Improvement Network	Housing, care and support for people with dementia	The prevalence of dementia is increasing as more people live into old age. Housing and related support services need to be designed so they can support this group of people effectively.	Comprehensive resources are available on a range of housing with care models, housing related support and use of new technology to support people with dementia at home	<a href="http://www.housinglin.org.uk/Topics/browse/HousingandDementia/Provision/">http://www.housinglin.org.uk/Topics/browse/HousingandDementia/Provision/</a>
43	4.6	SCM2	Key area for quality improvement 5 Training	Health and social care practitioners caring for older people with social care needs and multiple long-term	Training must be provided for all staff; it must be appropriate to the competencies of the role	Continuous professional development is essential if a high quality service is to be delivered sustainably.

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				conditions should have the necessary training. e.g. in managing medicines.	and it must be regularly reviewed and refreshed.	

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44	4.6	Alzheimer's Society	Key area for quality improvement 3 1.7 Training and social care practitioners	<p>There are around 850,000 people in the UK living with dementia (Prince et al, 2014), with over 42,000 developing the condition before they reach 65. It is believed that more than a third of people with dementia receive personal care from homecare workers, which would equate to almost 300,000 people (Alzheimer's Society, 2014). Homecare providers estimate that some 60% of people using their service have some form of dementia (UKHCA, 2013), many of whom do not have a formal diagnosis.</p> <p>People living with dementia often have complex needs related to the condition and the average number of other long-term health conditions a person with dementia lives with is just over four (Guthrie, Payne et al, 2012). It is important that home care workers are aware of the person's health conditions and how these interact with</p>	<p>Better training enables the person with dementia to receive care in a dignified and person centred way. If care is delivered correctly a person with dementia should be able to stay in their home for as long as possible and remain part of their community. This is beneficial for the person and also helps to avoid costly hospital or care home admissions.</p> <p>Dementia training has been prioritised in the Prime Ministers Challenge on Dementia 2020 which advocated for a better aware, educated and trained NHS and social care workforce. He stated that Tier 1 training opportunities will be provided to all NHS staff by the end of 2018. This will be supported by more in-depth (Tiers 2 and 3) training of expert leaders and staff working with people with dementia. As of</p>	<p>Prevalence rate: Prince M, Knapp M, et al (2014). Dementia UK: Update. London: Alzheimer's Society <a href="http://www.alzheimers.org.uk/dementiauk">http://www.alzheimers.org.uk/dementiauk</a></p> <p>Numbers of people receiving homecare in community Alzheimer's Society (2014a). Dementia 2014: Opportunity for change. London: Alzheimer's Society <a href="http://www.alzheimers.org.uk/site/scripts/download.php?fileID=2317">http://www.alzheimers.org.uk/site/scripts/download.php?fileID=2317</a></p> <p>Dementia and co-morbidities Adapting clinical guidelines to take account of multimorbidity. British Medical Journal, 345 (2004) <a href="http://eprints.gla.ac.uk/70694/1/70694.pdf">http://eprints.gla.ac.uk/70694/1/70694.pdf</a></p> <p>Percentage of people receiving home care who have dementia UK Homecare Association (2013). UKHCA Dementia Strategy and Plan, February 2013. Wallington: UK Homecare Association.</p>

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				<p>one another.</p> <p>At present there are three tiers of training for dementia which is delivered by Health Education England (HEE):</p> <p>Tier 1 training is to familiarise people with recognising and understanding dementia, interacting with those with dementia, and to be able to signpost patients and carers to appropriate support. This level is suitable for all staff working in health or social care; however, it does not provide sufficient information for staff who would be working regularly with people with dementia.</p> <p>Tier 2 dementia training should be aimed at staff in general healthcare settings or who are in regular contact with people with dementia. It can also be seen as a starting point for staff who will develop more specialist knowledge.</p> <p>Tier 3 is aimed at staff who</p>	<p>April 2015 Health Education England (HEE) had trained 515,967 people in the NHS in Tier 1 &amp; 2 dementia training. Going forward, there needs to be much greater focus on the roll out of tier 2 and 3 dementia training aims to further ensure that NHS staff continue to receive the most advanced support available.</p> <p>Furthermore, all undergraduate courses for health professionals would include education and training in dementia by September 2015 and all newly qualified staff who look after patients with dementia will receive Tier 1 training. This will undoubtedly include home care workers.</p> <p>The introduction of the Care Certificate for newly appointed healthcare assistants and social care workers on 1st April 2015,</p>	<p><a href="http://www.ukhca.co.uk/pdfs/UKHCADementiaStrategy201202final.pdf">http://www.ukhca.co.uk/pdfs/UKHCADementiaStrategy201202final.pdf</a></p> <p>Definitions of Tier training Guide to Dementia Training for Health and Social Care Staff in London (2014) <a href="http://www.slcsn.nhs.uk/scn/dementia/london-dementia-scn-core-elements-outcomes-training-062014.pdf">http://www.slcsn.nhs.uk/scn/dementia/london-dementia-scn-core-elements-outcomes-training-062014.pdf</a></p> <p>The Prime Ministers Dementia 2020 Challenge, (2015) <a href="https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-dementia2020.pdf">https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-dementia2020.pdf</a></p>

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				<p>will be working extensively with people with dementia and who are likely to be in a specialist or a decision making capacity.</p> <p>In accordance with these definitions home care workers should, at the very least, have received Tier 1 and Tier 2 training. It could also be argued that an investment in Tier 3 training would ensure people with dementia are receiving the very best care at home.</p> <p>Better training enables the person with dementia to receive care in a dignified and person centred way. If care is delivered correctly a person with dementia should be able to stay in their home for as long as possible and remain part of their community. This is beneficial for the person and also helps to avoid costly hospital or care home admissions.</p>	<p>includes training on dementia and cognitive issues.</p> <p>The challenge of having a health and social care workforce trained in dementia is starting to be addressed through the various methods outlined above. However, in order to build on this the NICE quality standards should reaffirm the importance of quality and dementia specific training so as to make it a priority for all health and social care providers.</p>	

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45	4.6	Alzheimer's Society	Key area for quality improvement 4 1.5 Delivering care Care in Care Homes	<p>One-third of people with dementia live in care homes (Alzheimer's Society, 2014). This amounts to 285,281 people. Around 70% of care home residents in the UK have dementia or significant memory problems (Alzheimer's Society, 2014).</p> <p>People with dementia living in care homes must be supported to live well. This can be enabled through well trained staff who recognise the importance of a person centred approach.</p>	<p>In 2013, Alzheimer's Society found that only 41% of family members of people with dementia living in care home thought that he or she had a good quality of life.</p> <p>Age UK's 2012 report Delivering Dignity found that the care home workforce is poorly regulated, poorly paid, has too little access to training and support and lacks professional status. Specifically in relation to dementia, in 2014 the CQC found variable or poor care regarding staff's understanding and knowledge of dementia care in about 27% of care homes. Some staff had received no training and where they had, it did not always improve dementia care. The CQC also found that people with dementia were affected when there were not enough staff. However, in some care</p>	<p>Age UK's 2012 report Delivering Dignity  <a href="http://www.ageuk.org.uk/Global/Delivering%20Dignity%20Report.pdf?dtrk=true">http://www.ageuk.org.uk/Global/Delivering%20Dignity%20Report.pdf?dtrk=true</a></p>

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					homes, the CQC did find lead roles in dementia care.	

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46	4.5	NHS England	<p>Key area for quality improvement 1</p> <p>Those responsible for contracting and providing care services should ensure health and social care practitioners caring for older people with social care needs and multiple long-term conditions are assessed as having the necessary training and competencies in managing medicines.</p>	<p>If staff are not adequately trained they cannot be expected to give quality care</p>	<p>Staff turnover in social care roles can frequently be high and it is essential that those providing care are able to do so effectively, without disadvantaging the service user.</p>	
47	4.4	NHS England	<p>Key area for quality improvement 2</p> <p>Make provision for more specialist support to be available to people who need it – for example, in response to complex long-term</p>	<p>If staff are not adequately trained they cannot be expected to give quality care. This will need to include training staff to recognise red flags and therefore enable them to refer appropriately or to maintain people in their home setting where appropriate.</p>	<p>It is important for the commissioning of training to be planned in advance, rather than in a crisis eg from the local NHS provider eg community nursing expertise, or specialist nurses providing training</p>	



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			health conditions – either by training practitioners directly involved in supporting people, or by ensuring partnerships are in place with specialist organisations .			

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48	4.6	NAT (National AIDS Trust)	Protection of confidentiality for people receiving care.	<p>In order to gain appropriate, high quality medical and social care, people living with HIV need to feel confident that they can disclose their HIV status without fear of their personal information being subject to further unnecessary disclosure.</p> <p>Confidentiality breaches, which often occur due to stigma and misinformation about levels of risk and duty of care, can go on to cause further stigma and discrimination for the person living with HIV.</p> <p>In a study conducted by Elford et al (2008), half of the people who reported experiencing HIV-related discrimination said this had involved a health care worker. This may affect how people living with HIV feel about disclosing their status to care providers.</p> <p>Care provider organisations</p>		

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				<p>need to establish confidentiality policies that are well understood by their staff to ensure that breaches do not occur, and by their clients so that people living with HIV are confident to share information they wish to disclose to support their health and social care provision.</p> <p>The Data Protection Act 1998 underpins requirements for confidentiality procedures in care settings.</p>		

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49	4.6	SCM3	1.Provision of Reablement for older people with social care needs and multiple long term conditions on discharge from hospital	The provision of reablement is a high priority for central and local government as evidence shows that reablement has positive outcomes for people who use services, providers and commissioners. Provision or reablement is recommended by NICE guidelines.	Evidence shows that flexibility is key to the success of reablement and therefore there needs to be an outcomes focused approach to commissioning reablement	NICE guidelines NG27 'Transition between inpatient hospital settings and community or care home settings for adults with social care needs' 1.6.1 NICE Dec 2015  Please see Social Care Institute for Excellence (2012) At a Glance 56: Making the move to delivering reablement, London, Social Care Institute for Excellence,
50	4.6	SCM3	2. It is crucial that people who provide reablement receive specialist training.	In order to ensure that reablement providers are trained in delivering specialised interventions as opposed to domicillary care.	Evidence shows that there needs to be a significant shift in the culture of working – which some care workers will adapt to more easily than others – for reablement to happen.	As above
51	4.6	SCM3	3.The provision of occupational therapy as a critical and essential part of the reablement pathway	The occupational therapist's strengths in assessment and goal planning are integral to service users achieving personalised outcomes. Rapid access to both occupational therapy skills and equipment is essential to avoid delays in people's progress. Occupational therapists have the skills and expertise to	Evidence from research and practice shows that occupational therapists have an important role in the delivery of reablement	As PI Please see; Social Care Institute for Excellence (2011) At a Glance 46: Reablement; A key role for occupational therapists, London, Social Care Institute for Excellence,

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				provide training to care workers delivering reablement. Advice on rehabilitation techniques from occupational therapists can assist the continuous reablement process for people with complex conditions		

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52	4.6	The Chartered Society of Physiotherapy	Key area for quality improvement 2 Access to reablement services	Reablement services that are well planned with integrated working can be effective at allowing earlier discharge, or preventing admission to hospital.	Currently there is variation across the country on the availability of reablement services, with many having arbitrary time periods rather than the needs of the patient. There is a need for a shift of rehabilitation from the acute setting to the community, which requires extensive integration between health and social care.	NHSIQ Unbundling recovery: Recovery, rehabilitation and reablement national audit report: <a href="http://www.nhsiq.nhs.uk/resource-search/publications/unbundling-recovery-recovery,-rehabilitation-and-reablement-national-audit-report.aspx">http://www.nhsiq.nhs.uk/resource-search/publications/unbundling-recovery-recovery,-rehabilitation-and-reablement-national-audit-report.aspx</a>
53	4.6	Royal College of Nursing	Key area for quality improvement 1: Access to rapid assessment and intervention	To ensure that frail older people are supported to remain in their usual place of residence.	Many older people are admitted to secondary care or care homes because of a lack of intensive, responsive community re-ablement and rehabilitation	<a href="http://www.nice.org.uk/guidance/ng27">NICE guideline NG27: Transition between inpatient hospital settings and community or care home settings for adults with social care needs</a> <a href="http://www.nice.org.uk/guidance/ng27">http://www.nice.org.uk/guidance/ng27</a>
54	4.6	SCM3	4.The integration of health and social care services to support early hospital discharge	Ensure that older people with identified social care needs are offered early supported discharge with a home care and rehabilitation package in order to maximise function and independence.	Evidence shows that Patients who are mentally alert, medically well and mobile postoperatively are most likely to benefit from a supported discharge scheme. Supported discharge schemes have also been shown to improve	Please see the following article; ‘ R Linertova, L Garcia-Perez, JR Vazquez-Diaz, A Lorenzo-Riera, and A Sarria-Santamera. (2014) Interventions to reduce hospital readmissions in the elderly: in-hospital or home care. A systematic review, University of York

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					patients' abilities to carry out activities of daily living. Evidence also shows that interventions that incorporate some component of home care were more likely to reduce hospital readmissions in elderly patients,	

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55	4.6	Royal Pharmaceutical Society	Key area for quality improvement 3 Transfer of care	When people are transferred between care settings there are often unintended changes to the medicines and miscommunication between care settings.	<p>If a person double doses, or doesn't take the new medicine they will not receive the health benefits from the medicine and are more likely to be readmitted to hospital</p> <p>Between 30 and 70% of patients have either an error or an unintentional change to their medicines when their care is transferred (National Patient Safety Agency and National Institute for Health and Clinical Excellence. Technical safety solutions, medicines reconciliation. 2007 guidance.nice.org.uk/PSG001)</p> <p>The correct information about a person's medicines needs to be transferred as the patient moves between care settings. Any changes to a person's medicines and the reasons for these changes needs to be made</p>	<p>The likelihood that an elderly medical patient will be discharged on the same medicines that they were admitted on is less than 10% (Relationship of in-hospital medication modifications of elderly patients to post discharge medications, adherence and mortality. Ann Pharmacotherapy 2008; 42: 783-9). Between 28-40% of medicines are discontinued during hospitalisation (Health care system vulnerabilities: understanding the root causes of patient harm. Am J Health Syst Pharm 2012; 69: 43-5) and 45% of medicines prescribed at discharge are new medicines (What happens to long-term medication when general practice patients are referred to hospital? Eur J Clin Pharmacol 1996; 50: 253-7) 60% of patients have 3 or more medicines changed during their hospital stay (Drug changes at the interface between primary and secondary care. Int J Clin Pharmacol Ther. 2004; 42:103-9).</p>



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					<p>clear. More information about the minimum data set that should be transferred can be found in our guidance 'Keeping patients safe when they transfer between care providers – getting the medicines right'.</p> <p>In addition the RPS referral toolkit ensures that a clinical handover occurs between hospital and community pharmacists further supporting the person as they move between care settings.</p>	

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56	4.6	Housing Learning and Improvement Network	Older People with social care needs and long term conditions living in extra care housing	Research funded by the NIHR SSCR, Adult Social Care Environments and Settings (ASSET), found that there is good evidence that appropriate and effective extra care housing can improve the quality of lives of people older people with social care needs.	<p>The research found that housing with care can support residents with widely different abilities, needs and care packages and offers significantly improved outcomes, including greater independence, when compared with remaining in mainstream housing.</p> <p>The evidence suggested housing with care effectively reduced the need for services, and that these settings can be cost-effective compared with mainstream community housing. The data confirms previous findings that housing with care residents are on average less dependent, both physically and cognitively, than those living in care homes.</p>	Please see the findings from the ASSET project at: <a href="http://www.housinglin.org.uk/Topics/browse/HousingExtraCare/Evaluation/?parent=3664&amp;child=9645">http://www.housinglin.org.uk/Topics/browse/HousingExtraCare/Evaluation/?parent=3664&amp;child=9645</a>
57	4.6	Housing Learning and Improvement Network	Extra care housing continued	Conducted by the PSSRU, this report provides the first comprehensive evaluation of the Department of Health	On average, people moving into extra care housing were found to be much more able,	Please see the evaluation report, executive summary and accompanying technical paper from the PSSRU research at:

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				extra care housing initiative. conducted by the PSSRU found that	both physically and mentally, than people moving into care homes (although residents in several schemes had high levels of physical disability).	<a href="http://www.housinglin.org.uk/Topics/browse/HousingExtraCare/Evaluation/?parent=3664&amp;child=8398">http://www.housinglin.org.uk/Topics/browse/HousingExtraCare/Evaluation/?parent=3664&amp;child=8398</a>

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58	4.6	Housing Learning and Improvement Network	Extra care housing continued	<p>Independent research by Aston University examined the total NHS savings across the NHS (primary and hospital care) for each participant in the study. This included the amount spent on nurses, GP appointments, and hospital admissions. Over a period of 12 months alone, the reduction equated to the NHS spending an average of £1,115 per person per year less on residents living in properties run by ExtraCare Charitable Trust than it would have done had the trust not provided the services, thereby reducing the NHS spend for residents by 38%</p>	<p>Research shows the Extra Care Charitable Trust (ECCT) saved the NHS money by successfully combining health, social care and housing services for older people, including employing a qualified nurse as well as providing informal drop-in sessions and advice services</p>	<p><a href="http://www.housinglin.org.uk/Topics/browse/HousingExtraCare/Commissioning/HousingHealthWellbeing/?parent=3662&amp;child=9605">http://www.housinglin.org.uk/Topics/browse/HousingExtraCare/Commissioning/HousingHealthWellbeing/?parent=3662&amp;child=9605</a></p>
59	4.6	Housing Learning and Improvement Network	Extra care housing continued	<p>This report by ILC-UK surveyed residents in retirement villages that offer extra care support to explore if: -It can promote greater independence and provide greater choice in planning for later life than would otherwise be available.</p>	<p>On all counts the experiences of older people demonstrated the positive contribution extra care housing made on their quality of life, reaffirming their decision to move and providing a higher degree of control; in particular, reporting lower levels of</p>	<p><a href="http://www.housinglin.org.uk/Topics/browse/HousingExtraCare/Commissioning/HousingHealthWellbeing/?parent=3662&amp;child=9688">http://www.housinglin.org.uk/Topics/browse/HousingExtraCare/Commissioning/HousingHealthWellbeing/?parent=3662&amp;child=9688</a></p>

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				<p>-The communal environment has the potential to reduce social isolation, particularly for residents who move from more rural or remote homes.</p> <p>-It can also promote residents' quality of life, enhancing it compared to what they would experience either in the general community or in another residential care setting.</p>	<p>loneliness than in the community</p>	

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60	4.6	Housing Learning and Improvement Network	Additional developmental areas of emergent practice	A selection of Housing LIN extra care housing case studies	The benefits of extra care housing on the quality of life of residents: The impact of living in Campbell Place, Fleet  'Blazing a trail: Extra Care Housing in Blandford Forum, Dorset' - Improving the quality of life for older people in extra care: Measuring outcomes using the ASCOT tool	<a href="http://www.housinglin.org.uk/Topics/browse/HousingExtraCare/Commissioning/HousingHealthWellbeing/?parent=3662&amp;child=9331">http://www.housinglin.org.uk/Topics/browse/HousingExtraCare/Commissioning/HousingHealthWellbeing/?parent=3662&amp;child=9331</a>  <a href="http://www.housinglin.org.uk/HousingRegions/SouthWest/?parent=1025&amp;child=9109">http://www.housinglin.org.uk/HousingRegions/SouthWest/?parent=1025&amp;child=9109</a>
61	4.6	Housing Learning and Improvement Network	Design for care	The accessibility and adaptability of housing is a key consideration in the way care can be delivered at home and/or facilitate self care	The way are housing and environments are designed can improved wellbeing, help reduce unnecessary hospital admissions and to help people stay in their own homes.	<a href="http://www.housinglin.org.uk/Topics/browse/Design_building/">http://www.housinglin.org.uk/Topics/browse/Design_building/</a>
62	4.6	Royal Pharmaceutical Society	Key area for quality improvement 1 Medicines review and medicines optimisation	People over 65 who have multiple LTCs are often on a variety of medicine and these need to be optimised for the individual person. Domiciliary Medicine Use Reviews MURs) should be undertaken by community pharmacists as a matter of course and these should	Research has shown that 30-50% of people do not take their medicines as intended.	Incidents of avoidable harm to patients can result in unnecessary readmissions and around four to five percent of hospital admissions are due to preventable problems with medicines (.Care Quality Commission. Managing patients' medicines after discharge from hospital. 2009 <a href="http://www.cqc.org.uk/_db/_documents/M">www.cqc.org.uk/_db/_documents/M</a>

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				become one of the target MUR groups.		anaging_patients_medicines_after_discharge_from_hospital.pdf).

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63	4.6	NAT (National AIDS Trust)	Additional developmental areas of emergent practice	<p>With the ageing of the population living with HIV, new research has begun to emerge on the impact of HIV on ageing, the side effects of long term treatment, and the interaction of HIV medication with other medications.</p> <p>As yet many questions remain unanswered, but we expect that there will be consequences for long term care in ways that have not yet become apparent. This needs to be kept in mind in relation to the future development of care standards.</p>		
64	4.6	Multiple System Atrophy Trust	Review criteria for definition of multiple long-term conditions to incorporate single conditions that have an impact on multiple functions of a person.	It is important because without this change, people with Multiple System Atrophy, despite having multiple problems and condition progression, will not be covered by this NICE guidance.	Multiple System Atrophy is a progressive neurological condition that leads to premature death. It affects both men and women and usually presents in people in their 50's and 60's. It is caused by atrophy of nerve cells in several areas of the brain and results in problems with a range of autonomic functions, such as bladder and bowel	



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					<p>control, blood pressure control and movement and communication issues. At advanced stage people may need 24hour care.</p> <p>People experience MSA in different ways individual to them but they are likely to require significant input and support for a range of Health and Care professionals in exactly the same way as required by many people with multiple conditions.</p> <p>To exclude these people from this Guideline may lead to differential treatment even though they still have similar or identical needs as those with multiple conditions.</p>	

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65	4.6	evidENT	Age related hearing loss. Specifically, the development of hearing pathways in older people with hearing loss.	<p>Hearing loss affects 10 million adults in the UK. This is anticipated to increase to 14.4 million people by 2031. Age related hearing loss (presbycusis) is the biggest cause of hearing loss and it is estimated that 70% of people above the age of 70 have hearing loss in the UK. The World Health Organisation has commented that age related hearing loss will be in the top ten disease burdens, above diabetes and cataracts by 2030. Moreover, the Global Burden of Disease study demonstrates that in the UK, age related hearing loss is the 8th most important contribution to 'Years Lived with Disability'.</p> <p>Age related hearing loss results in major personal, social and economic costs. It is thought that the UK economy loses £25 billion a year in productivity and unemployment mainly due to age related hearing loss. This is likely to worsen with</p>	<p>The development of successful hearing pathways for older people can work to address the challenges of age related hearing loss - specifically in terms of improving variations in access and quality of hearing services. Most people with age related hearing loss delay seeking help and live with their symptoms for an average of 10 years before appropriate referral. When they do seek help from primary care, there is considerable variation in the subsequent pathway with 11 fold variations in the rate of audiology assessments between hearing centres. This is reflected by 1 in 3 people with hearing loss reporting problems in accessing hearing rehabilitation. Moreover, once care is accessed, there is variation in service quality and provision. Hearing loss and its</p>	<p>Action Plan on Hearing Loss, NHS England, Department of Health. This identifies the variations in access and quality of hearing services  <a href="https://www.england.nhs.uk/wp-content/uploads/2015/03/act-plan-hearing-loss-upd.pdf">https://www.england.nhs.uk/wp-content/uploads/2015/03/act-plan-hearing-loss-upd.pdf</a>                      NHS adult hearing services in England: exploring how choice is working for patients. Monitor  <a href="https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/409273/Adult_hearing_services_-_Monitor_s_report.pdf">https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/409273/Adult_hearing_services_-_Monitor_s_report.pdf</a>                      Generate: The Research Agenda for ENT, Hearing and Balance Care A UK Partnership of Patients, Professionals and the Public. This is an evidence based research agenda for ENT, Hearing and Balance.  <a href="http://entuk.org/sites/default/files/files/Research%20Agenda%20ENT%20Hearing%20and%20Balance%2030%2011%2015.pdf">http://entuk.org/sites/default/files/files/Research%20Agenda%20ENT%20Hearing%20and%20Balance%2030%2011%2015.pdf</a>                      Action on Hearing Loss: Statistics. This provides statistics on age related hearing loss in the UK                      Lin FR, Yaffe K, Xia J et al. Hearing</p>

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				<p>estimates suggesting that by 2020 older people will account for over 30% of the working population. Older people with unmanaged hearing loss are more likely to require expensive care packages, such as a care home, than if their hearing loss was managed earlier in community based settings. This particularly important considering that by 2032, there will be around 620,000 older people living in care homes in England and of these, almost 500,000 will have hearing loss. Age related hearing loss is also associated with other conditions including dementia and poor mental health. Evidence suggests that older people with hearing loss are 2.5 times more likely to develop depression and up to five times more likely to develop dementia.</p>	<p>consequences become harder to manage the longer it is ignored. Timely diagnosis and management may improve social interaction, improve mental health and slow cognitive decline.</p> <p>The development of patient pathways can work to reduce this variation and improve patient care. Such pathways could include screening for age related hearing loss, patient education, patient assessment, social support and standardised evidence based management strategies.</p> <p>Both NHS England and Monitor have specifically highlighted variations in access and quality of hearing services for older people as an area of unmet need.</p> <p>In the recently launched UK</p>	<p>loss and cognitive decline in older adults. JAMA Intern Med. 2013 Feb 25;173(4):293-9. This provides evidence outlining the links between hearing loss and cognitive decline in older people.</p>

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					research agenda for ENT, Hearing and Balance, hearing screening for older people and its role in improving access to hearing services was identified as a research priority.	

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66	4.6	NHS England	<p>Key area for quality improvement 6</p> <p>Ensuring timely, accurate diagnosis of dementia</p>	<p>Diagnosis, memory assessment and care planning are included in NICE guidance.</p> <p>Memory assessment and care planning are also included in the NICE quality standard 2010.</p> <p>Care planning and disusing concerns are included in the NICE quality standard 2013.</p>	<p>As at November 2015 the national diagnosis rate for dementia is 67.1%. Whilst this meets our ambition for diagnosis there is still work to be done in terms of maintaining this rate and also addressing the underlying variation across geographies.</p>	
67	4.6	NHS England	<p>Key area for quality improvement 7</p> <p>Provision of safe, high quality health &amp; social care for people with dementia and their carers</p>	<p>There are approx. 620,000 living with dementia in England. A recent Alzheimer's Society survey found that 72 per cent of respondents were living with another medical condition or disability as well as dementia.</p> <p>Aspects of this are included in the NICE quality standard 2010 &amp; 2013, and also the NICE pathway for dementia.</p>	<p>Post diagnostic dementia support is a key priority for NHS England. Care standards vary across the country and it is important that best practice is disseminated.</p> <p>People with dementia are sometimes in hospital for conditions for which, were it not for the presence of dementia, they would not need to be admitted. An estimated 25 per cent of hospital beds are occupied by people with dement</p>	<p>A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function and Ageing Study I and II                      Matthews, Fiona E et al.                      The Lancet , Volume 382 , Issue 9902 , 1405 - 1412</p>

ID	Report Section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
68	4.6	NHS England	<p>Key area for quality improvement 8</p> <p>Supporting people with dementia to live normally in safe and accepting communities</p>	<p>There are approx. 620,000 living with dementia in England.</p> <p>Aspects of this are included in the NICE guidance, NICE quality standard 2010 &amp; 2013, and also the NICE pathway for dementia.</p>	<p>Two-thirds (£17.4 billion) of the cost of dementia is paid by people with dementia and their families, either in unpaid care (£11.6 billion) or in paying for private social care. This is in contrast to other conditions, such as heart disease and cancer, where the NHS provides care that is free at the point of use.</p>	<p><a href="https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=418">https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=418</a></p>
69	4.6	NHS England	<p>Key area for quality improvement 9</p> <p>Ensuring people with dementia die with dignity in the place of their choosing</p>	<p>Everyone deserves the right to die with dignity regardless of their health needs.</p> <p>Aspects of this are included in the NICE guidance, NICE quality standard 2010, and also the NICE pathway for dementia.</p>	<p>Dementia is now one of the top five underlying causes of death and one in three people who die after the age of 65 have dementia</p> <p>Nearly two-thirds of people with dementia are women, and dementia is a leading cause of death among women – higher than heart attack or stroke</p> <p>60,000 deaths a year are directly attributable to dementia.</p>	<p>Brayne C et al, Dementia before death in ageing societies – the promise of prevention and the reality, PLoS Med 2006;3; 10</p> <p>Dementia UK Update, second edition, Alzheimer’s Society, November 2014</p>

ID	Report Section	Stakeholder	Suggested key area for quality improvement	Why is this important?	Why is this a key area for quality improvement?	Supporting information
70	4.6	Social Policy Research Unit	<p>Key area for quality improvement 3</p> <p>Collection and collation of uniform data nationally and integrated with healthcare.</p>	<p>Currently there are limited/un-integrated recording systems about patient experience and service quality in social care (when compared to the NHS, for example). This makes it difficult to answer questions about whether service initiatives are effective, cost-effective and comparable.</p>	<p>Improving the collection and analysis of data and more uniform minimum datasets on user and service outcomes would make analysis of service improvements quicker and evaluations more responsive</p>	<p>Observation from research projects which have been and are being conducted.</p>