NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

DRAFT GUIDELINE

Social care of older people with complex care needs and multiple long-term conditions

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Contents

Introduction

A long-term condition is one that cannot be cured but can be managed with the use of medicines or other therapies. Long-term conditions may also be known as ‘chronic conditions’ and ‘life limiting conditions’.

The prevalence of long-term conditions is strongly linked to ageing and the number of people with multiple 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). Prevention, delaying onset and slowing the progression of long-term conditions are all important outcomes for older people. Other important outcomes include quality of life and positive experience related to independence, choice, dignity and control.

Despite recent policy focusing on integrated health and social care services, some people are still being treated as a collection of conditions or symptoms, rather than as a whole person (The mandate: a mandate from the government to the NHS Commissioning Board: April 2013 to March 2015 Department of Health). People with multiple long-term conditions want joined-up, coordinated services but often find they are hard to access and fragmented (Integrated care and support: our shared commitment Department of Health). Poor mental health can be associated with both social isolation and poor physical health, and can go unnoticed. The issue of delivering integrated support to people with long-term conditions who live in nursing and care homes has also been neglected (A quest for quality in care homes British Geriatrics Society; Health care in care homes Care Quality Commission).

The Department of Health asked NICE to develop an evidence-based guideline to help address these issues (see the scope). The guideline was developed by a Guideline Committee following a detailed review of the evidence. The guideline focuses on older people with multiple long-term conditions and their carers. It does not cover younger adults (although many of the recommendations may also be relevant to younger adults). This is because the largest group of people affected by multiple long-term conditions is older people and because older people can experience inequalities in terms of resource allocation which is in the context of decreasing resources available to them overall (Older people's vision for long term care Joseph Rowntree Foundation, What is social care, and how can health services better integrate with it? British Medical Association).

This guideline considers how person-centred social care and support for older people with multiple long-term conditions should be planned and delivered. It addresses how those responsible for commissioning, managing and providing care for people with multiple long-term conditions should work together to deliver safe, high-quality services that promote independence, choice and control.

This guideline has been developed in the context of a complex and rapidly evolving landscape of guidance and legislation, most notably the Care Act 2014. While the Care Act and other legislation describe what organisations must do, this guideline is focused on ‘what works’ in terms of how to fulfil those duties, and deliver support to older people with complex care needs and multiple long term conditions.

Context

Legislation, policy and guidance

This guideline has been developed in the context of a complex and rapidly evolving landscape of guidance and legislation, most notably the Care Act 2014 which has a significant impact on people with complex care needs and multiple long-term conditions and their carers. The majority of the Care Act took effect from April 2015, with specific financial provisions coming into force from April 2016. This legislation places a duty on local authorities to promote wellbeing and meet needs (rather than requiring them simply to provide services).

The Care Act also recognises the important role played by carers and the fact that many carers are themselves older people with complex needs. It requires local authorities to assess and offer support to address the needs of carers, independently of the person they care for. This is aligned with a range of other carer-specific policies. For example: Department of Health (2014) Carers strategy: the second national action plan 2014-2016 and NHS England (2014) NHS England's Commitment to Carers which emphasise the value of carers, and the importance of enabling them to have 'a life alongside caring' (Department of Health 2014 p40).

Under the Act, local authorities have 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. They also have a duty to provide information and advice for the whole population, not just those who are receiving services that they fund. This means that people funding their own care and support are entitled to guidance from the local authority, including on financial matters. The Care Act 2014 requires local authorities to stimulate and manage their local market to benefit the whole population, again, not just those in receipt of local authority funded support.

While the Care Act and other legislation describes what organisations must do, this guideline is focused on 'what works' in terms of how they fulfil those duties, and deliver support to older people with multiple long-term conditions and their carers.

In focusing on wider wellbeing and person-centred support, the Care Act also encourages more integrated working and coordinated engagement between Clinical Commissioning Groups, local authorities, providers and national bodies, including voluntary and community sector organisations. This consolidates a shift towards more holistic, coherent provision of support which has been evident in health and social care policy for some time. For example, the 2013 NHS Mandate aims to focus on quality of life for people with long-term conditions and on ‘the person as a whole, rather than on specific conditions’ (Department of Health p11). The Mandate also aimed to improve people's self-management skills, functional ability and quality of life, as well as helping them to stay out of hospital and to address their emotional and mental health needs.

The ‘whole person’ approach in policy is supported by recognition of the association between long-term conditions and mental ill-health which can sometimes go unnoticed. No Health without Mental Health strategy, for example links to The Adult Social Care Outcomes Framework and aims to improve mental health outcomes and embed consideration of wellbeing into frontline social care practice.

Current Practice

As the incidence of long-term conditions increases with age, many older people have a variety of physical and mental health and social care needs for which they require support. There is evidence that depression is 7 times higher in those with two or more long term conditions or chronic health complaints (The Kings Fund 2012) and that these depressive symptoms can often go untreated and affect the abilities of older people to manage their own conditions (National Development Team for Inclusion 2011).

People with multiple long-term conditions want joined-up, coordinated services (National Voices 2012). The need to deliver integrated support to people with long-term conditions who live in nursing and care homes has been particularly neglected (British Geriatrics Society 2011). 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. There are also well-documented problems related to the sometimes limited amount of time care workers have to build relationships with older people, or to address their support needs fully. As well as training and resourcing issues the workforce is also challenged by a lack of joined up and integrated service, that can mean that services for older people with complex needs can become fragmented (National Collaboration for Integrated Care and Support 2013).

Older people with long term conditions are vulnerable to hospital admission, sometimes for routine complaints. If social care staff were skilled up to detect problems early and manage conditions better, hospital admissions may be avoided (The Kings Fund 2010). Older people may have long term conditions that need routine monitoring or they themselves may need regular practical support to manage their conditions.

Communication

A person-centred approach is one in which people are supported to communicate their needs and preferences, exercise control over their care and live the lives they choose, so far as possible. However, this can be particularly challenging for some older people. Older people are disproportionately affected by dementia and other conditions (Alzheimer's Disease International 2011) which can limit their capacity to make decisions about their care. Those affected by long-term multiple conditions may also have disabilities which impede communication, such as sensory impairments (Department of Health 2012). Lack of capacity can be compounded by having limited (or no) information about what services are available (Department of Health, Social Services and Public Safety 2012).

Funding and funding mechanisms

A significant proportion (70 per cent) of government health and social care spending is attributed to the care of older people with long-term conditions (Department of Health 2012) 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 one long term condition is £3000, three times the bill for a person without a long term condition. This figure rises to £6000 for a person with two conditions and approximately £7800 for a person with three (Department of Health 2012). These figures need to be taken in the context of large cuts to the social care budget of local authorities over last 5 years (Local Government Association 2014). 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 self-funders and individual budget holders can be complicated and people may not be aware how to fund residential care if their conditions worsen.

Person-centred care

This guideline assumes that the practitioners using it will read it alongside the Care Act 2014 and other relevant legislation and statutory guidance It is also written to reflect the rights and responsibilities that people and practitioners have as set out in the NHS Constitution for England.

Care and support should take into account individual needs and preferences. People should have the opportunity to make informed decisions about their care, in partnership with health and social care practitioners. Practitioners should recognise that each person is an individual, with their own needs, wishes and priorities. They should treat everyone they care for with dignity, respect and sensitivity.

If someone does not have capacity to make decisions, health and social care practitioners should follow the code of practice that accompanies the Mental Capacity Act and the supplementary code of practice on deprivation of liberty safeguards.

If the person using the service agrees, families and carers should have the opportunity to be involved in decisions about care and support. Families and carers should also be given the information and support they need in their own right.

Recommendation wording

The Guideline Committee makes recommendations based on an evaluation of the evidence, taking into account the quality of the evidence and cost effectiveness.

In general, recommendations that an action 'must' or 'must not' be taken are usually included only if there is a legal duty (for example, to comply with the Care Act or health and safety regulations), or if the consequences of not following it could be extremely serious or life threatening.

Recommendations for actions that should (or should not) be taken use directive language such as 'agree', ‘offer’ 'assess', 'record’ and ‘ensure’.

Recommendations for which the quality of the evidence is poorer, or where there is a closer balance between benefits and risks, use 'consider'.

1 Recommendations

The wording used in the recommendations in this guideline (for example words such as 'offer' and 'consider') denotes the certainty with which the recommendation is made (the strength of the recommendation). See 'recommendation wording' for details.

1.1 Identifying and assessing social care needs

Older people with multiple long-term conditions

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.

1.1.2 Consider referral for a one-time assessment by a geriatrician or old-age psychiatrist to guide social care planning for older people with multiple long-term conditions:

- whose social care needs are likely to increase to the point where they are assessed as ‘substantial’ or ‘critical’
- who may need to go into a nursing or care home.

All older people, including those with multiple long-term conditions

1.1.3 When planning and undertaking assessments, health and social care practitioners should:

- always involve the person and their carer (if appropriate)
- take into account the person's strengths, needs and preferences
- involve all relevant practitioners, to address all of the person's needs (including emotional, psychological, social, personal, sensory, communication and environmental care needs, as well as health 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 via an advocate
- give people information about the options for services available to them, the cost of services and how they can be paid for.

1.1.4 If the person's carer has specific social care needs of their own, refer them to the local authority for a needs assessment in their own right.

1.1.5 Ask the person if they have caring responsibilities and, if so, ensure they are offered a carer's assessment.

Telecare to support older people with multiple long-term conditions

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 manage their conditions, potential benefits, risks and costs.

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.

1.2 Care planning

Named care coordinator

Older people with multiple long-term conditions

1.2.1 Ensure that older people with multiple long-term conditions have a single, named care coordinator who acts as their first point of contact. The named care coordinator should:

- be involved in the assessment process

1.2.2 liaise and work with all health and social care services, including those provided by the voluntary and community sector. Ensure care plans are tailored to the individual and focused on ensuring the person has choice and control. Offer the person the opportunity to:

- have a range of needs addressed (including emotional, psychological, social, personal, sensory, communication and environmental care needs, as well as health needs)
- be supported to minimise the impact of health problems, including continence needs, if appropriate
- identify how they can be helped to manage their own care and support, which may include information and support to manage their condition/s, taking part in their preferred activities, hobbies and interests (see also section 1.5)
- ensure that care plans cover leisure and social activities outside and inside the home, mobility and transport needs, adaptations to the home and any support needed to use them.

1.2.3 Discuss medicines management as part of care planning.

1.2.4 Write any medicines management requirements into the care plan including:

- The purpose of, and information on, medicines
- The importance of timing and implications of non-adherence.[1]

For more information on medicines management see the NICE guideline on Medicines optimisation.

1.2.5 Develop care plans in collaboration with GPs and representatives from other agencies that will be providing support to the person in the care planning process.

1.2.6 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 multiple long-term conditions.

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[1] This recommendation is taken from NICE's draft home care guideline.

1.2.7 Ensure older people with 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 the different mechanisms they can use to manage the budget available to them, including information about any impact different funding mechanisms may have on carers
- 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 those whose care is publicly funded
- ensuring that carers' needs are taken fully into account.

All older people, including those with multiple long-term conditions

1.2.8 Named care coordinators should offer the older 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, to recognise that people want to do different things with their lives at different times. (see also section 1.5)

1.2.9 Ensure that care plans enable people 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.

1.2.10 Ensure that care plans include ordinary activities outside the home (whether that is a care home or the person's own home) that reduce isolation, for example, shopping or visiting public gardens and build confidence by being involved in their wider community, as well as with family and friends (see also section 1.6).

1.2.11 Named care coordinators should ensure the person, their carers or advocate and the care practitioners jointly own the care plan and sign it to indicate they agree with it.

1.2.12 Named care coordinators should review and update care plans regularly to reflect changing needs, and at least annually (in line with the Care Act). Record the results of the review in the care plan, along with any changes made.

1.3 Supporting carers

All older people, including those with multiple long-term conditions

1.3.1 In line with the Care Act local authorities must offer carers an individual assessment of their needs. Ensure this assessment:

- takes into account carers' views about services that could help them maintain their caring role and live the life they choose
- involves cross-checking any assumptions the person has made about the support their carer will provide.

1.3.2 Check what impact the carer's assessment is likely to have on the person’s care plan.

1.3.3 Support carers to explore the possible benefits of personal budgets and direct payments, and how they might be used for themselves and for the person they care for. Help them to administer their budget, so that their ability to support the person's care is not undermined by anxiety about managing the process.

1.3.4 Consider helping carers access support services and interventions, such as carer breaks.

1.4 Integrating health and social care planning

Older people with multiple long-term conditions

1.4.1 Commissioners should build into service specifications and contracts the need:

- to direct older people with multiple long-term conditions to different services
- for seamless referrals between practitioners.

1.4.2 Make provision for community-based multidisciplinary support for older people with multiple long-term conditions. The health and social care practitioners involved in the team might include, for example, a community pharmacist, physical or occupational therapist, a mental health social worker or psychiatrist, and a community-based services liaison.

1.4.3 Health and social care practitioners should inform the named care coordinator if the person has needs that they cannot meet.

1.4.4 Named care coordinators should record any needs the person has that health and social care practitioners cannot meet. Discuss and agree a plan of action to address these needs with the person and their carer.

1.5 Delivering care

Older people with multiple long-term conditions

Care in care homes

These recommendations for care home providers are about ensuring that care and support addresses the specific needs of older people with multiple long term conditions.

1.5.1 Identify ways to address particular nutritional and hydration requirements and ensure people have a choice of things to eat and drink and varied snacks throughout the day (including outside regular meal times).

1.5.2 Identify how the care home environment and layout can encourage social interaction, activity and peer support.

1.5.3 Ensure people are physically comfortable, for example, by allowing them control over the heating in their rooms.

1.5.4 Encourage social contact and provide opportunities for education and entertainment by:

- making it easier for people to communicate and interact with others, for example reducing background noise, providing face-to-face contact with other people, using accessible signage and lighting
- using a range of technologies such as IT platforms and wifi, hearing loops and TV listeners
- involving the wider community in the life of the care home through befriending schemes and intergenerational projects.

When providing care for older people with long-term conditions, care home providers should:

1.5.5 Make publicly available information about:

- tariffs for self-funded and publicly-funded care
- what residents are entitled to and whether this could change if their funding status or ability to pay changes.

1.5.6 Make available a statement for each person using their services about what their funding pays for.

1.5.7 Build links with local communities, and encourage interaction between residents and local people of all ages and backgrounds.

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

Needs and preferences

1.5.9 Health and social care practitioners should offer older people with multiple long-term conditions:

- opportunities to interact with other people with similar conditions
- help to access one-to-one or group support, social media and other activities, such as dementia cafes, walking groups and specialist support groups, exercise and dance.

Self-management and support

1.5.10 Health and social care practitioners should review recorded information about medicines and therapies regularly and follow up any issues related to medicines management. This includes making sure information on changes to medicine is made available to relevant agencies.

1.5.11 Social care practitioners should contact the person’s healthcare practitioners with any concerns about prescribed medicines.

1.5.12 Social care practitioners should tell the named care coordinator if any prescribed medicines are affecting the person's wellbeing. This could include known side effects or reluctance to take medicines.

1.5.13 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.

1.5.14 Health and social care providers should give information and advice about continence to older people. Make a range of continence products available, paying full attention to people's dignity and respect.

1.5.15 Give people information about how your service can help them manage their lives. This should be given:

- at the first point of contact and when new problems or issues arise
- in different formats which should be accessible (including through interpreters).

1.5.16 Health and social care providers should ensure that care is person-centred and that the person is supported in a way that is respectful and promotes dignity and trust.

All older people, including those with multiple long-term conditions

Provision of information

1.5.17 Named care coordinators should review information needs regularly, recognising that people may not take in information when they receive a new diagnosis.

1.5.18 Consider continuing to offer information and support to people and their family members or carers even if they have declined it previously.

Continuity of care

1.5.19 Named care coordinators should take responsibility for:

- giving older people and their carers information about what to do and who to contact in times of crisis, at any time of day and 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 older people and their carers have information about their particular condition, and how to manage it
- knowing where to access specialist knowledge and support, about particular health conditions
- involving carers and advocates.

1.6 Preventing social isolation

All older people, including those with multiple long-term conditions

1.6.1 Health and social care practitioners should support older people with multiple long-term conditions to maintain links with their friends, family and community, and identify if people are lonely or isolated.

1.6.2 Named care coordinators and advocates should 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.

1.6.3 Health and social care practitioners should give advice and information about social activities and opportunities that can help people have more diverse social contacts.

1.6.4 Commissioners should consider funding and collaborating with community enterprises and services to help people to remain active in the home and engaged in the community, including when people are in care homes.

1.6.5 Voluntary and community sector providers should consider collaborating with local authorities to develop new ways to help people to remain active and engaged in their communities, including when people are in care homes.

1.7 Training health and social care practitioners

Older people with multiple long-term conditions

1.7.1 Commissioners and providers should ensure health and social care practitioners caring for people with multiple long-term conditions have the necessary training and are assessed as competent in medicines management.

1.7.2 Ensure health and social care practitioners are able to recognise:

- common conditions, such as dementia and sensory loss, and
- common care needs, such as nutrition, hydration and skin integrity, and
- common support needs, such as dealing with bereavement and end-of-life, and
- deterioration in someone's health or circumstances[2].

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[2] This recommendation is taken from NICE's draft home care guideline.

2 Research recommendations

The Guideline Committee made the following research recommendations in response to gaps and uncertainties in the evidence identified from the evidence reviews. The GDG selected the key research recommendations that they think will have the greatest impact on people's care and support

2.1 Older people’s experiences

What is the lived experience of older people with multiple long-term conditions?

Why this is important

While there was some evidence on the experiences of older people with multiple long-term conditions, there were gaps in relation to people’s experience of:

- the effect of multiple conditions on each other, and on the person, as their lives and conditions progress over time
- the impact of living with multiple conditions on people’s independence, activities, participation, communication as their conditions progress
- the impact of living with multiple conditions at different stages of a person’s life.
- the priorities, meanings and preferences of older people living with multiple long term conditions

Surveys and qualitative studies are needed to ascertain the views and experiences of older people views and experiences of living with multiple long term conditions from their point of view.

2.2 Service delivery models

Which models of service delivery are effective and cost-effective for older people with multiple long-term conditions?

Why this is important

There was lack of evidence about different models of support provision for older people with multiple long-term conditions. There is a need, therefore, for robust evaluations of different approaches, for example, studies which compare:

- models led by different professionals
- different team structures.
- the components and configurations of effective and cost effective models of service delivery?
- the barriers and facilitators to implementation of effective and cost effective service delivery models

Studies of comparative design are needed to evaluate the effectiveness and cost effectives' of different models of service delivery. Surveys and qualitative studies of the views of service users, their carers and practitioners could illustrate the barriers and facilitators to effective models of service delivery and how this compares to the services available and being delivered.

2.3 Reablement

What is the impact of reablement interventions on outcomes for older people with multiple long-term conditions?

Why this is important

There is a need to determine the impact of reablement interventions on this particular group of older people. The Guideline Committee noted the particular importance of identifying whether reablement interventions or approaches have any preventative effects.

Studies of comparative design are needed to evaluate the effectiveness and cost effectiveness of different reablement interventions. Surveys and qualitative studies of the views of service users, their carers and practitioners could illustrate the feasibility and acceptability of reablement interventions.

2.4 Supporting people in care homes to stay active

What is the most effective and cost-effective way of supporting older people with multiple long in care homes to live as independently as possible?

Why this is important

There is a need for robust evaluation of different interventions for supporting older people with long-term conditions in care homes. The Guideline Committee thought it particularly important to ensure that future studies evaluate how people living in care homes can best be supported to participate in social and leisure activities.

Future research could involve comparative study designs that evaluated the impact of different interventions to support older people stay active in care homes. Outcomes could include measures of both physical and mental health wellbeing.

2.5 Developing a 'risk positive' approach in care homes

What is the effectiveness and acceptability of different strategies to enable positive risk-taking in care homes?

Why this is important

The Guideline Committee noted that informed risk-taking is a normal part of everyday life and that helping older people exercise choice and control relies on a 'risk positive' approach. They identified a gap in the literature about what works well in care homes in this respect and suggested future studies could usefully include:

- a systematic review of the literature on perceptions of and approaches to risk-taking in care homes
- organisational, operational and individual-level approaches to risk-taking in care homes
- the views and experiences of people using care home services and their carers
- the barriers and facilitators to risk-positive approaches in care homes.

Studies of comparative design are needed to evaluate the effectiveness and cost effectives' of different approaches to ensuring older people with multiple long term conditions are enabled to exercise their choice and control within an acceptable risk framework.   Surveys and qualitative studies of the views of practitioners could identify barriers and facilitators to risk-positive approaches in care homes.

2.6 Self-management

What is the impact of different early intervention-focused approaches to self-management on outcomes for older people?

Why this is important

The Guideline Committee highlighted lack of evidence on the impact of different approaches to self-management, particularly those aimed at helping older people with multiple long-term conditions to continue living independently for as long as possible. They highlighted the need to understand better the type of interventions and strategies available, and then to evaluate their effectiveness in terms of the impacts on outcomes for older people and their carers.

Future research should compare different approaches to self-management and their impact on social care-related quality of life and wellbeing in addition to physical health, acceptability and accessibility as well as the views, experiences and potential impact on carers.

3 Evidence review and recommendations

Introduction

When this guideline was started, we used the methods and processes described in the Social Care Guidance Manual (2013). From January 2015 we used the methods and processes in Developing NICE Guidelines: The Manual (2014). The included studies were critically appraised using tools in the manuals and the results tabulated (see Appendix B for tables). Minor amendments were made to some of the checklists to reflect the range of evidence and types of study design considered in the evidence reviews. For more information on how this guideline was developed, see appendix A.

Rating the included studies was complex as the 'best available' evidence was often only of moderate quality. Studies were rated for internal and external validity using ++/+/- (meaning very good, good to moderate, and poor). Where there are two ratings (for example +/-), the first rating applies to internal validity (how convincing the findings of the study are in relation to its methodology and conduct). The second rating concerns external validity (whether it is likely that the findings can be applied to similar contexts elsewhere). Qualitative evidence is (largely) only rated for internal validity, and some surveys with a relatively high response rate within a well-defined population (for example, DHSSPS, 2010, a survey of providers in Northern Ireland) may also have a single rating for internal validity if it is unclear how well the context matches the English context. Hence some studies have a single rating (e.g. ++) and others have two ratings (e.g. +/+).

The quality of economic evaluations are described on the basis of their limitations and therefore applicability in answering whether the intervention is cost-effective from the NHS and personal social services perspective, described as having very serious, potentially serious, or minor limitations, accompanied with further detail. Methodological appraisal detailing the limitations of these studies is fully described in Appendix C.

The critical appraisal of each study takes into account methodological factors such as:

- whether the method used is suitable to the aims of the study
- whether random allocation (if used) was carried out competently
- sample size and method of recruitment
- whether samples are representative of the population we are interested in
- transparency of reporting and limitations that are acknowledged by the research team.

Evidence rated as of only moderate or poor quality may be included in evidence statements, and taken into account in recommendations, because the Guideline Committee independently and by consensus supported its conclusions and thought a recommendation was needed. In the evidence statements, evidence from more than one study rated as good and poor may be described as 'moderate'. Where evidence is described as 'very good', it suggests that several well-conducted studies support the same or similar conclusions.

For full critical appraisal and findings tables see appendix B.

3.1 Assessment and care planning

Introduction to the review questions

The focus for these review questions were on personalised and integrated care planning and assessment for older people with multiple long-term condition.

Review question(s)

Q.2.1.1 What are the effects (benefits and harms) of different types of assessment and planning of personalised care on outcomes for older people with multiple long-term conditions and their carers?

Q.1.1.1 What are the views and experiences of older people with multiple long-term conditions and their carers, of assessment and care planning?

Q.1.1.2 What do they think works well and what needs to change?

Q.1.2.1 What are the views and experiences of practitioners, managers and commissioners in health and social care who procure, manage or deliver care to older people with multiple long-term conditions, in community and care home settings of assessment and care planning?

Q.1.2.2 What do they think works well and what needs to change?

Summary of review protocols

The protocols sought to identify studies which would:

- Identify models of care assessment and care planning, and associated outcomes
- Identify and evaluate the effects of different models and processes for holistic assessment of (mental, physical and social) care needs and care planning
- Identify and evaluate the support services, including information and advocacy, of people with multiple long-term conditions who use services

and their carers, which will promote participation in care planning and review.

Population: Older people, aged 65 years and older, with multiple long-term conditions that use social care services, and their families, partners and carers. Self-funders and people who organise their own care are included.

Intervention: Personalised and integrated assessment and care planning, including carer assessment where this is carried out simultaneously. Established and emerging models (which may show promise but are not well evidenced) may be considered.

Comparator: Different approaches to care planning, usual care.

Outcomes: Includes service user focused outcomes such as:

Setting: Service users' homes, including sheltered housing accommodation; care (residential and nursing) homes (not hospital settings).

User satisfaction: Quality and continuity of care; empowerment, choice and control; involvement in decision-making; dignity and independence; quality of life; health status; safety and safeguarding, preventative effects, impact on unplanned hospital admissions and delayed discharges, mortality. (4.4 Scope). Sub-group analysis (see EIA) may be of interest.

The study designs relevant to these questions were expected to include:

- Systematic reviews of studies of different models of assessment and care planning;
- Randomised controlled trials of different approaches to assessment and care planning (e.g. outcomes-focused vs task-focused);
- Quantitative and qualitative evaluations of different approaches;
- Observational & descriptive studies of process;
- Cohort studies, case control and before and after studies;
- Mixed methods studies
- Grey literature which includes the views of people who use services and their carers (possibly as part of an evaluation) may be identified.

- Findings from surveys undertaken by organisations representing service users, patients and carers which are not published in research journals may also be considered.

Full protocols can be found in Appendix A.

How the literature was searched

The evidence reviews used to develop the guideline recommendations were underpinned by systematic literature searches. The aim of the systematic searches was to comprehensively identify the published evidence to answer the review questions developed by the Guideline Committee and the NICE Collaborating Centre for Social Care.

The search strategies for the review questions (based on the scope) were developed by the NICE Collaborating Centre for Social Care in order to identify empirical research. The search strategies are listed at the end of this appendix.

Searches were based upon retrieving items for the population groups ‘older people’, ‘carers’, ‘long-term conditions’, ‘workforce/social care organisation’ in the settings of ‘residential care’, ‘nursing/care homes’, ‘intermediate care’ or ‘community care. Searches were developed using subject heading and free text terms, aiming to balance sensitivity and precision, and the strategy was run across a number of databases. The searches limited results to studies published from 2004 onwards. The database searches were not restricted to specific geographical areas; however, in selecting the websites to search, research on people's views was focused on the UK. The sources searched are listed below. Forward and backwards citation searches using Google Scholar was undertaken in January 2015 for all of the included studies.

The Guideline Committee members were also asked to alert the NICE Collaborating Centre for Social Care to any additional evidence, published, unpublished or in press, that met the inclusion criteria.

Full details of the search can be found in Appendix A.

How studies were selected

Search outputs (title and abstract only) were stored in EPPI Reviewer 4 - a software programme developed for systematic review of large search outputs - and screened against an exclusion tool informed by the parameters of the scope. Formal exclusion criteria were developed and applied to each item in the search output, as follows:

- Language (must be in English).
- Population (must be older people with multiple long-term conditions, with a social care need).
- Intervention (must be identification/assessment of social care needs; personalised care planning; support to self-manage; integration of social & health care; training of staff to recognise/manage common LTCs; support for carers to care; interventions to support involvement & participation, including information for users and carers.
- Setting (must be in the person's home or care home).
- Workforce (must involve people who work in social care, are integrated with social care or act as gatekeepers to social care).
- Country (must be UK, European Union, Denmark, Norway, Sweden, Canada, USA, Australia and New Zealand).
- Date (not published before 2004).
- Type of evidence (must be research).
- Relevance to (one or more) review questions.

Title and abstract of all research outputs were screened against these exclusion criteria. Those included at this stage were marked for relevance to particular review questions and retrieved as full texts.

Full texts were again reviewed for relevance and research design. If still included, critical appraisal (against NICE tools) and data extraction (against a coding set developed to reflect the review questions) was carried out. The coding was all conducted within EPPI Reviewer 4, and formed the basis of the analysis and evidence tables. All processes were quality assured by double coding of queries, and of a random sample of 10%.

In our initial screen (on title and abstract), we found 75 studies which appeared relevant to the review questions. We ordered full texts of 23 papers, prioritizing views and experiences studies from the UK, and those that were of acceptable methodological quality. On receiving and reviewing the full texts, we identified 11 which fulfilled these criteria (see included studies below). Of these, 4 were qualitative views research studies, and 7 were quantitative, impact studies. The included studies (see below) were critically appraised using NICE tools for appraising different study types, and the results tabulated. Further information on critical appraisal is given in the introduction at the beginning of Section 3. Study findings were extracted into findings tables. For full critical appraisal and findings tables, see Appendix B.

Narrative summary of the evidence: Implementation of multidisciplinary single assessment

Only one mixed methods UK study directly considered the assessment processes (Challis et al, 2010a +/+), and it was based on material from 2005-2006. The purpose of the survey was to consider whether and how Single Assessment Processes (SAP) with real multidisciplinary input were being implemented by staff, in the wake of policy, guidance and implementation tools published by the Department of Health in 2002. Four types of assessment are identified in the SAP guidance (contact, overview, specialist and comprehensive), each being triggered by the specific circumstances and needs of an individual.

The policy recommendation is more prescriptive for people being considered for residential and nursing care: a comprehensive assessment should have involved the input of a range of professionals, with geriatricians, old-age psychiatrists, other consultants working with older people, registered nurses, social workers and therapists playing a prominent role. Medical consultants were most frequently involved (but only in 40 per cent of the authorities) in assessments for placement in a care-home-with-nursing. Occupational therapists were most likely to be involved in assessments for intermediate care (25 per cent). Social workers/care managers were involved in the majority of local authorities for placements in care homes or care homes-with-nursing and for intensive domiciliary care, but less so for intermediate care. If multi-disciplinary is defined (as the authors do) as three or more professionals involved in an assessment, it is notable that it occurred in only one sector: placements in care home, with nursing.

There was little evidence of multi-disciplinary team working; rather, single, then two-person assessments were most common. A feature of this survey is that respondents seemed to anticipate the outcome of the assessment, which seems to support a service user comment (Granville 2010, +) about choice being constrained when others thought residential care was the appropriate intervention.

Record-sharing

A qualitative UK study of high (++) quality (King 2012) considered the issues of information boundaries between health and social care agencies and personnel, and the extent to which they impact on the feasibility of implementing a Single Shared Assessment across health and social care. Progress in effectively sharing electronic data was found to be slow and uneven.

One cause was the presence of established structural boundaries which led to competing priorities, incompatible IT systems and infrastructure, and poor cooperation. A second cause was the presence of established professional boundaries, which affect staffs' understanding and acceptance of data sharing and their information requirements. Geographical boundaries featured, but less prominently than agency boundaries. Successful integration needs practices such as good project management and governance, ensuring system interoperability, leadership, good training and support, together with clear efforts to improve working relations across professional boundaries and communication of a clear project vision.

Assessment functions within case management

Reilly et al (2010; (-/+) was a systematic review that focused on the implementation of case management which, as is common in populations with major health conditions, was predominantly nurse led, selecting (using uncertain criteria) citations from previous research papers. All 29 studies identify assessment, planning and implementation of care plans as core tasks of case management. Some studies specified the importance of assessment including professionals with training in geriatric care; shared assessment documentation and joint visits (by different, mainly health professionals). Almost 50% of the studies did not report information about the continuity of assessment with other tasks of case management, e.g. through the same professional taking responsibility.

Case managers in many programmes relied on making referrals to other services, so the availability of services would affect what was delivered, and the continuity of assessment with service provision would be very limited. In such cases, the case manager is merely a broker, with no role in ensuring the quality of delivery. Nurses adopting the Community Matron role without community training were likely to under-estimate the impact of social and environmental factors in improving the health of patients, and case managers were also found to be constrained by the shortage of services to deliver personal care and household support (social care services). In just 3 of the 29 studies, social workers could also be case managers, and there was evidence of financial and benefits advice being part of the assessment in these contexts.

Models of interdisciplinary working

The systematic review of literature on Inter-Professional Working (IPW) by Trivedi et al (2013 +/-, linked to Goodman et al, 2011 +/+) found that none of the models of IPW identified (case management, collaboration and integrated team working) were shown by the literature to be more effective than any other. There was weak evidence from the 37 included RCTs of effectiveness and cost-effectiveness for IPW as a whole, although well-integrated and shared care models improved processes of care and have the potential to reduce acute and hospital services or nursing/care home use. The material is relatively old, not focused on care planning and assessment, and the professionals working together are not health and social care professionals, but clinical care providers. The range of interventions (e.g. palliative care and discharge planning services) is very broad, and the outcomes for patients are inconsistently measured and very variable. The origin (largely US), context (largely clinical) and age of the studies suggest that this review is not generalizable to UK settings.

Goodman et al (2011) was a UK study of moderate quality (+/+) using a multi-method approach (in this case, a literature review, survey of professionals, interviews with older people and consensus events). The focus was on inter-professional working (IPW) at all stages of care planning and delivery. The study concluded that older people and their carers define effectiveness in IPW through the processes of care and delivery as much as through outcomes: timeliness, completion of actions as promised and perceived expertise, as well as the quality of relationships was considered important. The accompanying literature review on IPW (Trivedi 2013 +/-, discussed above) included studies that measured some patient-related outcomes, but the interventions (case management, collaboration and integrated team working in clinical settings), quality of the studies, and outcomes measured were too varied to draw general conclusions about what works for service users.

Aspects of the care and support process that are important to older people and carers. What older people want from care and support

One selected UK qualitative study of moderate (+) quality and relevance to care planning (Granville, 2010, +) highlighted the concerns of older people living either in the community or in care homes. As with Goodman et al (2011 +/+), data were not collected on specific processes such as assessment and planning so much as on the issues which mattered to people, and how these related to personalised care. Older people in both settings identified the importance of living a ‘normal’ life, maintaining social contact with people of all generations, having money and knowing their rights, and the ability to choose meaningful activities.

Older people’s experience of choice and control in care homes and carers. What older people want from care and support

One selected UK qualitative study of moderate (+) quality and relevance to care planning (Granville, 2010. +). Older people living in care homes felt that ‘the need to fit in’ could compromise their agency and ability to maintain personal identity, while those in the community felt they lacked choice and control over the amount and content of home care services they could have, particularly when other stakeholders clearly felt that the residential option was preferable.

Areas of support that older people and carers think need improving. Importance of continuity of care to older people and carers

Goodman et al (2011, +/+) (also discussed above) a UK mixed methods study, found that older people wanted continuity of care through having a named key person; relationship styles which fostered co-production with the older person, for instance in planning; ongoing shared review; functioning links across the wider primary care network (regarded as the foundation of care for this group); and evidence that the system can respond effectively at times of crisis.

Importance of support that extends beyond personal care

Challis (2010b, +/-), a UK mixed methods study, found that older people emphasised the importance of practical help with housework, shopping and banking: “There are all sorts of basic needs that aren’t being met for people who live by themselves” (interviewee 1, p180).

Health & social care inputs into health care assessment & planning.

There is one well-designed, non-UK randomised controlled trial (reporting on two different outcomes) (Keeler 1999; Reuben 1999, +/+) focusing on community dwelling older people above age 65 (mean age 76, SD=6) at risk for decline in one of four conditions (falls, urinary incontinence, depressive symptoms, or functional impairment) and are at risk for functional or health related decline. The sample was predominantly female (80%), the proportion living alone was 60%, and it was not reported whether individuals had informal care and whether they had multiple long-term conditions.

The intervention comprised the integration of health and social care professional input through a one-off comprehensive geriatric assessment from an external geriatric team (social worker, gerontology nurse practitioner/geriatric team (plus physical therapist) when indicated (by falls or impaired mobility) to advise the GP on health care planning coupled with a patient education intervention from a health educator plus information booklet “how to talk to your GP” prior to the individual’s GP appointment. This study was identified through additional searches of the literature by the NCCSC economist.

Findings from the evaluation indicate that older people showed improvements at 64 weeks follow-up. Statistically significant improvements were found favouring the intervention group in physical functioning, mortality, and health-related quality of life summary scales for physical and mental health and measures of restricted activity days and bed days. All other outcomes were not statistically different for patient satisfaction in general or satisfaction with their GP or patient’s perceived self-efficacy in interacting with their GP.

Changes in service-level outcomes included a statistically significant increase in the intervention’s use of community health care services (the addition of one extra visit to the psychologist and physical therapist) however there were no statistically significant differences in use of A&E visits or inpatient stays. The authors did not measure the impact on admissions to nursing or care homes.

This economic evaluation has potentially serious limitations in the collection of resource use as only healthcare and not social care services were measured. However, the quality of reporting of results and calculations was good. Whether this intervention is cost-effective in the UK context is unclear without further analysis due to differences in institutional context and unit costs and there are issues of relevancy as findings are based on older data. The authors report that the intervention costs an average of $237 per person and is associated with an additional average health care cost of $184 per person (standard error = $98) as measured over a 64-week follow-up period. Price year is not clearly reported, but may be between 1997/1998.

The applicability of the economic evaluation to the UK context is partially limited due to differences in institutional context (baseline patterns of service use) and differences in unit costs. For this reason, relying on the findings of changes in net costs from non-UK studies (assuming that all relevant health and social care resource use are included) cannot completely answer whether the intervention is cost-effective in the UK context but can provide an indication of likely cost-effectiveness. Furthermore, some studies are further limited if they do not comprehensively measure all relevant health and social care resource use, and therefore cost-effectiveness may be based on incomplete information. For both reasons, we present a summary of the findings in terms of net costs and in terms of the impact on the change of community and institutional health and social care resource use in order to make the findings more useful to the UK perspective. Overall, the results indicate that, from the perspective of community and acute health care services, the intervention is associated with additional costs and additional benefits.

Health & social care inputs into social care assessment & planning.

Community-dwelling older adults

There is one good quality UK mixed methods study (Challis 2004, +/++) focusing on older people living in the community, over age 60 (mean age 82, SD=7.2) who may have ‘substantial’ or ‘critical’ social care needs or be at risk of nursing or care home placement, as identified by a social care manager. It is unclear whether individuals had multiple long-term conditions although it is known that they had at least one chronic condition. The intervention consists of a one-time assessment by a geriatrician or old age psychiatrist to guide social care managers in social care planning. Standard care was defined as standard GP and social care services. This study was identified through additional searches of the literature by the NCCSC economist.

Finding from the evaluation found statistically significant improvements favouring the intervention in for individual’s functioning and social network scores and carers experienced reductions in stress. When considering service-level outcomes, the intervention was also associated with statistically significant lower mean usage of Accident & Emergency (A&E) visits (p=0.02) and nursing home admissions (p=0.005) and for all other community and social care services, net costs were not different between groups as measured at the end of a 6-month follow up.

This was a very good quality economic evaluation with a high level of reporting. It collected a comprehensive range of costs (health and social care perspective and individual private costs) and included individual and carer outcomes. The results were presented as a cost-consequence analysis (presenting changes in costs alongside changes in outcomes). The intervention is cost-effective from the perspective of the NHS and PSS and also from the perspective of individual private costs as measured over a 6-month period as it produces improvements in patient and carer outcomes with no differences in net costs (lower use of services in the intervention group offset increased costs of the intervention). Total mean weekly costs alive for the intervention and control groups were, respectively, £359 and £368 (p-value, not statistically different, using prices from 2000/01).

Of total costs, mean weekly NHS costs were lower for the intervention group compared to control group, (£73 vs. £83, p=0.03). When looking at net costs from the view of personal social services, while there was a significant reduction in nursing home admissions (p=0.05), this did not result in significant differences in total social care costs (intervention vs. control, £175 vs. £190) and were not different from the view of private costs (intervention vs. control, £110 vs. £95). There is some concern about the relevance of these results as a whole and whether they may be less relevant today since the study seems to have been conducted between 1998/2000.

Health & social care inputs into social care assessment & planning.

Older adults in residential care

One high quality Dutch RCT focused on the assessment of older people in residential care for depression and anxiety (Dozeman, 2012, ++/++), followed by a cluster randomised trial of stepped care for depression. Participants did not meet the diagnostic threshold for depressive or anxiety disorder, but met a minimum score of 8 on the Centre for Epidemiological Studies Depression Scale, suggesting they were at risk of developing depression, which is commonly associated with anxiety. The assessment was followed in the intervention group by a stepped-care approach in which participants sequentially underwent watchful waiting, a self-help intervention, life review, and a consultation with a GP. Primary outcome measure was the incidence of a major depressive disorder or anxiety disorder during a period of one year. The intervention group showed improvement in depressive symptoms, but 30% of them showed more anxiety disorders at follow up than did those in the control group. The rate of attrition was also higher in the treatment group which could indicate the intervention was not acceptable to the participants. Due to the mixed, potentially harmful results from this evaluation, no evidence statements could be determined.

Evidence statements

ES1	**Implementation of multidisciplinary single assessment** A good quality survey study (Challis, 2010a, +/+) concluded that, despite policy recommendations, a Multidisciplinary single assessment of health and social care needs is not widely implemented, with one then two persons undertaking the assessment most common A more comprehensive assessment involving at least a social worker if transfer to residential care or intensive domiciliary care was being considered, and a geriatrician was more likely to be involved if the person at the centre was being considered for nursing home care.
ES2	**Record sharing** A high quality qualitative study drawing on the views and experiences of UK health and social care practitioners (King, 2012, ++) concluded integrated working between health and social care and other professionals required shared records, although records were currently separate and accessed through different IT systems and staff understanding and acceptance of data sharing requirements

ES3	**Assessment functions within case management** There is good evidence (King (2012, ++) and Challis (2010b, +/+), and evidence of uncertain quality (Reilly et al, 2010, uncertain selection of studies) that assessment functions within case management might involve little continuity with care delivery and review of care plans; that nurses are overwhelmingly likely to be case managers, with little support from social workers; and that nurses without community training were likely to under-estimate the impact of social and environmental factors in improving the health of patients, and be constrained by the shortage of services to support social care needs. Assessment records were unlikely to detail the contribution and responsibilities of different practitioners. Nurse case managers were likely to act as brokers, but found it difficult to refer people onto social care services.
ES4	**Models of interdisciplinary working** There is moderate quality evidence (Trivedi, 2013, +/-, Goodman, 2012, +/+) that inter-professional working (IPW) may be cost-effective but does not show clearly that any particular model (e.g. care management, collaborative working or integrated teams) delivers better outcomes. User and carers consistently value aspects of integrated service delivery which foster confidence in the reliability of services, continuity of paid carers, user and carer involvement in planning and reviewing care, services to support carers and the ability of services to respond effectively at times of crisis. There is also qualitative evidence that inter-professional working can reduce carer burden.
ES5	**Aspects of the care and support process that are important to older people and carers** There is good evidence from two studies (Goodman et al, 2012, +/+; Granville et al, 2010,+) that, for older people and their carers, the process of care is as important as the outcomes. Older people want continuity of care in order to develop relationships with paid carers, a named key person to coordinate care, co-production of care with users and carers, and good links with the wider system of health and social care, allowing effective response at times of crisis.
ES6	**What older people want from care and support** There is good evidence from one qualitative study (Granville et al, 2010,+) that older people value the importance of living a ‘normal’ life, maintaining social contact with people of all generations, having money and knowing their rights, and the ability to choose meaningful activities.
ES7	**Older people’s experience of choice and control in care homes** There is good evidence from one qualitative study (Granville et al, 2010,+) that older people living in care homes feel they are required ‘to fit in’ at the expense of their choice and control, personal identity and preferences, while those in the community felt they lacked choice and control over the amount and content of homecare services they could have, particularly when other stakeholders clearly felt that the residential option was preferable.

ES8	**Areas of support that older people and carers think need improving** There is good evidence (Goodman, 2012, +/+) that service users and carers want improvement in, areas of care assessment and delivery that concern the integration of health and social care practitioners, including discharge planning, GP involvement in the care delivery team, and the inability and/or unwillingness of health and social care assessors and providers to access or refer into these complementary care agencies..
ES9	**Importance of continuity of care to older people and carers** There is good evidence (Goodman, 2012, +/+) that service users and carers want more continuity of staff, as they are otherwise liable to experience care of a lower quality, plus embarrassment and loss of dignity in receiving personal care. They also want a designated person with a remit across all care services who is accessible in a crisis.
ES10	**Importance of support that extends beyond personal care** There is moderately good evidence (Challis, 2010b, +/-) that service users, especially those living alone without an unpaid carer, want services, whether organised by care management or not, to deliver different types of essential support, prioritising the basic needs for shopping, laundry, housework and other practical needs over personal care.
ES11	**Health & Social Care inputs into health care assessment & planning**. There is one good quality [+/+] US study (Keeler 1999; Reuben 1999) that community dwelling older people at risk for functional or health related decline, may benefit from the integration of health and social care professional input through a one-off comprehensive geriatric assessment from an external geriatric team (social worker, gerontological nurse practitioner/geriatric team (plus physical therapist) when indicated by falls or impaired mobility) to advise the GP on health care planning coupled with a patient education intervention and pre-appointment information. The study is limited by its non-UK context, and limited collection of resource use data (only healthcare data were captured), however, the quality of reporting of results and calculations was good. Whether this intervention is cost-effective in the UK context is unclear without further analysis.
ES12	**Health and social care inputs into social care assessment and planning** This evidence statement is based on one good quality UK study measured over a 6-month period (Challis 2004) [+/++]. Findings from this study indicate that from the perspective of the NHS, personal social services, and individuals' private costs, the intervention is cost-effective, from the perspective of NHS, social services and individuals, for community-dwelling older people who may have 'substantial' or 'critical' social care needs or be at risk of nursing or care home placement.. The intervention is a one-time healthcare assessment by a geriatrician or old age psychiatrist to guide the social care manager in social care planning.

Included studies for these review questions

Challis D, Abendstern M, Clarkson P et al (2010a) comprehensive assessment of older people with complex care needs: The multi-discipliniarity of the Single Assessment Process in England. Ageing and Society. 30 (7): 1115-34.

Challis DJ, Clarkson P, Williamson J, et al (2004). The value of specialist clinical assessment of older people prior to entry to care homes. Age and Ageing, 33, 25-34.

Challis D, Hughes J, Berzins K, et al (2010b) Self-care and Case Management in Long-term Conditions: The Effective Management of Critical Interfaces. Report for the National Institute for Health Research Service Delivery and Organisation programme. : Personal Social Services Research Unit. http://www.pssru.ac.uk/pdf/MCpdfs/SCCMfr.pdf

Dozeman E, van Marwijk H, van Schaik DJF, et al (2012) Contradictory effects for prevention of depression and anxiety in residents in homes for the elderly: a pragmatic randomized controlled trial. International Psychogeriatrics. 24(8): 1242-1251.

Fenlon D, Frankland J, Foster CL, et al (2013) Living into old age with the consequences of breast cancer. European Journal of Oncology Nursing. Jun; 17(3):311-6.

Goodman C, Drennan V, Manthorpe J, et al (2012) A study of the effectiveness of interprofessional working for community-dwelling older people - Final Report. National Institute for Health Research (NIHR).

Granville G, Runnicles J, Barker S; et al (2010) Increasing the Voice, Choice and Control of Older People with High Support Needs: A Research Findings Paper from the South East Regional Initiative (SERI). National Development Team for Inclusion. HM Government Office for Disability Issues.

Keeler EB, Robalino DA, Frank JC, Hirsch SH, Maly RC and Reuben DB. (1999). Cost-Effectiveness of Outpatient Geriatric Assessment with an

Intervention to Increase Adherence. Medical Care, Vol. 37, No. 12 (Dec), pp. 1199-1206.

King G, O’Donnell C, Boddy D, et al (2012) Boundaries and e-health implementation in health and social care. BMC Medical Informatics and Decision Making. 12: 100.

Reilly S, Hughes J, Challis D (2010) Case management for long-term conditions: implementation and processes. Ageing and Society. 30(1): 125-155.

Reuben DB, Frank JC, Hirsch SH, McGuigan KA, Maly RC. (1999). A randomized clinical trial of outpatient comprehensive geriatric assessment coupled with an intervention to increase adherence to recommendations. Journal of American Geriatric Society. 47:269-276.

Trivedi D, Goodman C, Gage H, et al (2013) The effectiveness of inter-professional working for older people living in the community: a systematic review. Health & Social Care in the Community. 21(2): 113-28.

3.2 Service Delivery models and frameworks

Introduction to the review question

The purpose of the review questions on service delivery models and frameworks was to seek evidence which would guide recommendations about the different ways in which services for older people with multiple long- term conditions can be delivered. The reviews sought evidence from effectiveness studies and views and experiences of service users and their families and/or carers as well as views and experiences of service practitioners.

Review question(s)

Q.2.1.2. What are the existing frameworks, models and components of care packages for managing multiple long-term conditions and what outcomes do they deliver?

Q.1.1.1. What are the views and experiences of older people with multiple long-term conditions and their carers, of the social care services they receive?

Q.1.1.2. Do service users and carers consider that their care is (a) personalised; (b) integrated or coordinated with healthcare?

Q.1.1.2. What do they think works well and what needs to change?

Q.1.2.1. What are the views and experiences of practitioners, managers and commissioners in health and social care who procure, manage or deliver care to older people with multiple long-term conditions, in community and care home settings?

Q.1.2.2. What do they think works well, and what needs to change?

Q 2.1.3 What are the barriers to the delivery of effective, personalised, integrated care for people with multiple long-term conditions in community settings; in care home settings?

Q 2.1.4 What are the facilitators to the delivery of effective, personalised, integrated care for people with multiple long-term conditions in community settings; in care home settings?

Summary of review protocols

The protocols sought to identify studies which would:

- Identify frameworks and models of care delivery and associated outcomes
- Identify the components of effective care for people with long-term conditions, including those relating to structure and culture, with reference to the specific community and residential settings involved
- Consider the outcomes of care organised and delivered outside the statutory sector.

Population: Older people, age 65 years and over, with multiple long-term conditions who use social care services, and their families, partners and carers. Self-funders and people who organise their own care are included.

Intervention: Different frameworks, models and approaches for managing and delivering personalised and integrated care for older people with multiple long-term conditions

Comparator: Comparative studies could compare different service delivery models, or before/after designs.

Outcomes: Effective and safe management of multiple long-term conditions; measures of choice, control and independence; service user and carer satisfaction and quality of life; reduced emergency hospital admissions; reduction in inappropriate admissions to residential care; mortality; cost effectiveness.

Setting: Service users' home, including sheltered housing accommodation; care (residential and nursing) homes (not hospital settings).

The study designs relevant to these questions were expected to include:

- Systematic reviews of studies which evaluate different models, frameworks and components of care;

- Randomised controlled trials of different approaches;

- Quantitative and qualitative evaluations of different approaches;
- Observational & descriptive studies of process;
- Cohort studies, case control and before and after studies;
- Mixed methods studies.

Full protocols can be found in Appendix A.

How the literature was searched

The evidence reviews used to develop the guideline recommendations were underpinned by systematic literature searches. The aim of the systematic searches was to comprehensively identify the published evidence to answer the review questions developed by the Guideline Committee and NICE Collaborating Centre for Social Care.

The search strategies for the review questions (based on the scope) were developed by the NICE Collaborating Centre for Social Care in order to identify empirical research. The search strategies are listed at the end of this appendix.

Searches were based upon retrieving items for the population groups: ‘older people’, ‘carers’, ‘long-term conditions’, ‘workforce/social care organisation’ in the settings of ‘residential care’, ‘nursing/care homes’, ‘intermediate care’ or ‘community care . Searches were developed using subject heading and free text terms, aiming to balance sensitivity and precision, and the strategy was run across a number of databases. The searches limited results to studies published from 2004 onwards. The database searches were not restricted to specific geographical areas; however, in selecting the websites to search, research on people's views was focused on the UK. The sources searched are listed below. Forward and backwards citation searches using Google Scholar was undertaken in January 2015 for all of the included studies.

The Guideline Committee members were also asked to alert the NICE Collaborating Centre for Social Care to any additional evidence, published, unpublished or in press, that met the inclusion criteria.

Full details of the search can be found in Appendix A.

How studies were selected

Search outputs (title and abstract only) were stored in EPPI Reviewer 4 - a software programme developed for systematic review of large search outputs - and screened against an exclusion tool informed by the parameters of the scope. Formal exclusion criteria were developed and applied to each item in the search output, as follows:

- Language (must be in English).
- Population (must be older people with multiple long-term conditions, with a social care need).
- Intervention (must be identification/assessment of social care needs; personalised care planning; support to self-manage; integration of social & health care; training of staff to recognise/manage common LTCs; support for carers to care; interventions to support involvement & participation, including information for users and carers.
- Setting (must be in the person’s home or care home).
- Workforce (must involve people who work in social care, are integrated with social care or act as gatekeepers to social care).
- Country (must be UK, European Union, Denmark, Norway, Sweden, Canada, USA, Australia and New Zealand).
- Date (not published before 2004).
- Type of evidence (must be research).
- Relevance to (one or more) review questions.

Title and abstract of all research outputs were screened against these exclusion criteria. Those included at this stage were marked for relevance to particular review questions and retrieved as full texts.

Full texts were again reviewed for relevance and research design. If still included, critical appraisal (against NICE tools) and data extraction (against a coding set developed to reflect the review questions) was carried out. The coding was all conducted within EPPI Reviewer 4, and formed the basis of the analysis and evidence tables. All processes were quality assured by double coding of queries, and of a random sample of 10%.

From 46 studies which appeared relevant (by title and abstract), we ordered full texts of those which appeared to concern either evaluations of service delivery models and frameworks (prioritising systematic reviews and controlled studies) or which reported older people's and/or their carers' views on service delivery models and frameworks. On receiving and reviewing the full texts, we identified 13 which fulfilled these criteria. These were numbered according to appearance in the accompanying tables. We divided them according to whether they primarily reported views of users and carers, or primarily concerned effectiveness and outcomes. Where applicable, the evidence statements reflect the findings from both views and impact studies.

The included studies were critically appraised using NICE tools for appraising different study types, and the results tabulated. Further information on critical appraisal is given in the introduction at the beginning of Section 3. Study findings were extracted into findings tables. For full critical appraisal and findings tables, see Appendix B.

Narrative summary

Primary care practitioners' perceptions of the impact of complex health needs on older people's social care needs

Keefe (2009) (++) is a small exploratory study using focus groups to explore the views of Non-UK primary care physicians (n=13), nurses (n=11) and a nurse practitioner on the challenges of providing integrated care to older patients, and the potential benefits of introducing a social worker into the practice. Grounded theory was used to identify and extract themes from the group discussions.

Problems reported included social isolation and depression, poor access to community resources, including transport (which limited access to healthcare appointments), and inability to deal with financial pressures. Healthcare staff found that limited consultation time was taken up with issues they could not address, although they were aware that patients probably did not divulge the extent of these social problems, in case they might be forced into residential care.

It was thought that a social worker could help address these psycho-social problems, and investigate home circumstances. However, there was disagreement between physicians about the merits of hosting the social worker in the practice, with some concerned that they would be expected to take part in time-consuming discussions and briefings, while others, including one with experience of co-location, felt that having the social worker integrated in the team would be essential.

This is a relatively small study from the US, but the model of placing a social worker in a primary care practice is not widespread in the UK, and we did not find any similar material focused on the needs of older people.

User and practitioner perspectives on community-based case management

Challis (2010b) (+/-) is a UK mixed methods study on case management, with separate sections on self-management. The study is not very clearly reported. This study is about case management in primary care by nurses. It is only assessed here for that part which is relevant to case management for older people with multiple long-term conditions (as it concerns all adults with LTCs). Methods included a survey of case managers (with a poor response rate of 56), qualitative ‘case studies’ with practitioners and a ‘focus group consultation’ with users and carers. The aims of the study are very broad, and findings – which do not concern impact – are not clearly related to different methodologies.

As a scoping study, it has some use in defining the problems of integrated services in case management which is itself a poorly defined construct. These problems include the domination of case management by healthcare practitioners (mostly primary care nurses in community settings); inability of these case managers to access social services except by referral (and then often with very slow response rates); and ineffective case funding where patients were 'allocated on the basis of staff qualification or the predicted intensity of involvement' (p187), so that they ended up in disease specific care – rather than holistic care – services.

Service users and carers involved in the focus groups recognised the gaps in care, many of which related to help with housework, finances, and day to day living, i.e. those services that might be addressed through social services involvement. The authors conclude that: ‘Participants felt the key priorities for a case management service should be to improve the range of services available to care for people at home and to provide more intensive long-term support. Service users clearly placed more import on the meeting of basic needs first, before self-care could be supported.’ (p181)

Older people’s perceptions of the Community Matron Service

Sargent (2007) (+) explored patient and carer perceptions of case management for (mostly older) people with long-term conditions, implemented through the introduction of community matrons in the UK. In-depth interviews with a ‘purposive’ sample of 72 patients receiving case management through a community matron, and 52 carers, across 6 Primary Care Trusts. This is a relatively large sample for a qualitative study, but participants were recruited by the Community Matrons (which may introduce bias to the sample). The role of Community Matrons combines clinical care, care co-ordination, education, advocacy and psychosocial support, and is targeted at people with complex needs. Unfortunately, this is not a comparative study, so the impact of the Community Matron (CM) service is not entirely clear.

In general, service users reported that their health and practical needs were well monitored and addressed, and they reported improvements in mood and wellbeing. Patients felt better ‘cared for’, reassured because they had regular reviews of blood pressure and other vital signs, and particularly welcomed the Matron’s ability to manage and advise on complex medication regimes. As case managers, the Matrons could advocate effectively with other services, for example organising the provision of necessary equipment and repeat prescriptions.

Carers in the sample felt that the Matrons ‘took the pressure off’ them, by providing a welcome source of 'advice, practical and emotional support' (517), thereby reducing their sense of isolation. Both service users and carers appreciated the social aspect of the Matrons’ visits, and felt confident that they could access advice and support. While the authors comment that the ‘psychosocial’ impact of the Community Matrons was not anticipated, there was little evidence from this paper that users and carers had been referred to other community services for practical (e.g. financial) or social support.

Brown (2008) (+) is a similar UK qualitative study, interviewing a ‘purposive’ sample of 24 people with complex needs and multiple LTCs from two primary care trusts who were receiving the services of a Community Matron. Matrons are described as: 'Highly trained nurses, able to diagnose, prescribe and manage patients with long-term conditions within primary care' (409). As in Sargent (2007, +), patients commented on the impact of the Matron as a friend; as a provider of personal care and clinical skills, and on the specific outcomes for themselves and other service use. Although one patient felt initially that they had been offered the service as a lesser substitute for the GP, others were also aware that they had less need of GP services (which they perceived as overloaded), and some felt that the support of the Matron had been more effective in keeping them out of hospital or residential care.

Patients reported an improved quality of life and better medication and self-management skills as a result of the service, and that it had reduced their need for social and psychological support, and given better support to family carers. The Matrons were said to be a reliable and flexible source of medical and social support. Participants felt that they filled a gap where GPs could no longer give support.

Potential benefits of multi-disciplinary working, and potential barriers to implementation.

Johansson, G. (2010) (++/+) is a systematic review (of international studies) that explores the literature concerning multidisciplinary teams that work with elderly persons living in the community. The review included a wide range of study designs including randomised controlled studies, qualitative designs, non-experimental designs and examples of practice. Studies were too heterogeneous for a meta-analysis and a narrative synthesis was presented. Few of the included studies were within our date range and only one study explicitly targeted older people with multiple long-term conditions (Nikolaus 2003).

This review found that the responsibility to develop teamwork lies both with the individual team member, the team as a group and with the management, organisation or society within which the team works. Team work requires more than the simple organization of professionals and naming them as a "team" (p108). Obstacles to teamwork included differences in attitudes, knowledge, documentation and management. Implementation of change was affected by power, culture and structure. Professionals acted to enhance or defend their own interests and perspectives. On the other hand, client involvement, and opportunities to discuss the needs of elderly persons within a group of different professionals, was conducive to greater understanding of the potential of teamwork to deliver good outcomes.

Clinical outcomes cited in the review were comprehensive multidisciplinary geriatric assessment combined with appropriate interventions: these were reported as beneficial in promoting improved capacity. Other outcomes widely used were those relating to service use: change in hospital admission rates, plus reduced readmissions and reduced length of hospital stay.

Models and impact of inter-professional working

Trivedi (2013) (+/-) is a systematic review of international evidence on the effectiveness of inter professional working (IPW) for community dwelling older people with multiple health and social care needs. (Note that Beland 2006, see below, is also included in this review.) This study is the systematic review part of a larger study that also included a survey of UK practitioners and service provision and a study of the views of UK service users, carers and their representatives (see Goodman, 2012 +/+). The reviewers classified included studies into 3 categories: case management, collaboration, integrated teams.

- Case management: No evidence of reduced mortality was found; poor quality studies showed no significant health outcomes or reduced depression in Geriatric Care Management model. Two low quality studies delivered case management with integrated care and included participants recently discharged from hospital with good social support. The SWING (South Winnipeg Integrated programme) showed no overall improvement in ADL⁄EADL but improved MMSE scores, increased prescriptions and did not add to caregiver strain.
- Collaboration model: Leaving aside acute care, one high quality study showed reduced admissions and improved physical functioning, but no cost reduction. Discharge planning improved patient satisfaction, quality of care and collaboration.
- Integrated teams: Evidence about service use and costs was mixed but around half the studies showed reduced hospital or nursing⁄care home use. Two studies reported a significant reduction in caregiver strain with most participants' co-resident with caregivers.

The authors concluded there was weak evidence of effectiveness and cost-effectiveness for IPW, although well-integrated and shared care models improved processes of care and have the potential to reduce hospital or nursing⁄care home use. One study in the review (Reeves et al.'s 2010a) observed that IPW is too often represented as the outcome without discriminating between the process of IPW and its effectiveness. Study quality varied considerably and high quality evaluations as well as observational studies are needed to identify the key components of effective IPW in relation to user-defined outcomes. Differences in local contexts raise questions about the applicability of the findings and their implications for practice.

The review says little about social care organisation and delivery in relation to IPW. The material is largely not contemporary, and not from UK settings. Some of the populations included are very specific to particular circumstances - e.g. rehabilitation after hospital discharge, palliative care at end of life - and others may be targeted at a mixed population, while only some of that population will benefit. Insufficient evidence on context is available. Not all of the studies quality ratings were used in the narrative synthesis, so the strength of the evidence in the review findings was at times unclear.

Goodman, C. (2012) (+/+) is a mixed methods study, which included the systematic review outlined above (Trivedi, 2013 +/-). It aimed to identify the effectiveness of inter-professional working (IPW) in primary and community care for older people with multiple health and social care needs. It aimed to identify appropriate measures of effectiveness from user, professional and organisational perspectives for IPW and to investigate the extent to which contextual factors influence the sustainability and effectiveness of IPW and patient, carer and professional outcomes.

Exploratory interviews with older people, carers and health and social care providers were undertaken; a national survey of how IPW is structured was held; along with a consensus event with stakeholders that reviewed key findings. The second phase of the project involved analysis that focused on the older person's experience of IPW and comparison of the processes of care, resource use and outcomes in three case studies.

Conclusions are credible, and come from a service user perspective. However, they are also somewhat limited, as no evidence was found to support organisational effectiveness, which was one aim of the study.

The social care outcomes specified by users & carers as important outcomes of good IPW were:

- Service recipient is relaxed and is not made more anxious by the services or service personnel.
- Users and carers are involved in decision making and specific requests are met (e.g. ability to die at home).
- Carers are acknowledged and supported by services, and their needs are assessed and provided for.

The study concluded that older people and their carers define effectiveness of IPW through the processes of assessment, care and delivery as much as through outcomes. Timeliness, completion of actions as promised and perceived expertise, as well as quality of relationships are important. No model of IPW was identified as being more effective (see also Trivedi 2013 – a systematic review - for detail).

Effectiveness in relation to processes of assessment, planning and care was agreed by service users and carers to be that which promoted: continuity of care through a named key person; relationship styles which fostered co-production with the older person, e.g. in planning; evidence that the system can respond effectively at times of crisis. These values do not relate specifically to care assessment and planning, but to the whole process of care planning and delivery.

Outpatient geriatric multidisciplinary evaluation and management plus case management

Beland (2006) (++/+) is a non-UK trial of the 'SIPA'[3] model of integrated care, including 1230 frail elderly participants living in the community with 'a complex mixture of service needs' (27). The purpose of the trial was to evaluate the impact of the service on admissions to hospital or other forms of institutional care. This included hospital admission, potentially going into a nursing home, or receiving intensive home bed services. Another expected outcome was increased use of community services for those using the SIPA intervention. The evaluation aimed to demonstrate that cost savings could be achieved by improved integrated and inter-professional working, and this explicitly included social and personal services such as home care. The integrated service model in the SIPA is based on 'community services, a multidisciplinary team, case management that retains clinical responsibility for all the health and social service required and the capacity to mobilise resources as required' (abstract).

Overall the SIPA achieved its expected outcomes. '$4,000 of institutional based services per person was transferred to community based services', (p38) although the intervention was also successful in reducing the use of

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[3] SIPA is an abbreviation for the French language title of the programme: 'Système de soins Intégrés pour Personnes Âgées fragiles' translated as 'integrated care system for frail older people'.

institution-based services. A&E visits and permanent nursing home admission was reduced by 10%, and there was a reduction in waiting times for hospital admission or nursing home placement. SIPA had different impacts on individuals with different levels of need, so although this is an encouraging outcome for a model of inter-professional working, sub-group analysis would be helpful, as would more information on the views and quality of life impacts on participants.

Counsell (2009) (++/+) is a cluster randomised trial of older (65+, mean age 72) patients of 164 primary care physician practices in Indiana, USA to test the effectiveness of a geriatric care management model (GRACE) on improving the quality of care for low-income seniors in primary care. Participating physicians were randomised, so that all eligible patients in each practice had either the intervention (474 patients, 78 physicians) or usual care (477 patients, 86 physicians). Nearly 1 in 4 study participants were at high risk of hospitalisation and the whole sample (N=951), which includes the subgroup of individuals with lower risk of hospital admissions (N=725) had an average of 2+ multiple long-term conditions, and for the subgroup with higher risk of hospitalisation (N=224), the average was 3.5 multiple long term conditions (Counsell et al 2009).

The intervention comprised home-based care management for 2 years by a nurse practitioner and social worker who collaborated with the primary care physician and a geriatrics interdisciplinary team and were guided by 12 care protocols for common geriatric conditions (described in Counsell 2006, ++/+: advance care planning; health maintenance; medication management; difficulty walking/falls; chronic pain; urinary incontinence; depression; visual impairment; hearing impairment; malnutrition/weight loss; dementia and caregiver burden). These protocols are included here as important aspects of care for older people with LTCs, which might also be relevant to social care.

Features of the model included: ‘In-home assessment and care management provided by a nurse practitioner and social worker team; extensive use of specific care protocols for evaluation and management of common geriatric conditions; utilisation of an integrated electronic medical record and a Webbased care management tracking tool; and integration with affiliated pharmacy, mental health, home health, and community-based and inpatient geriatric care services.' (p2624)

The GRACE patients made significant improvements compared with usual care patients at 24 months in 4 of 8 SF-36 scales: general health, vitality, social functioning and mental health. No group differences were found for Activities of Daily Living or death, and although Accident & Emergency (A&E) service usage was lower in the intervention group, admissions did not vary. No significant differences were found between patient satisfaction at 24 months, and mortality and time to death was not significantly different.

Mortality at 24 months - 33 intervention patients vs 37 usual care patients – and time to death were similar between groups. (2628). In sub-group analysis of a predefined group at high risk of hospitalisation (comprising 112 intervention and 114 usual-care patients), emergency department visits and hospital admission rates were lower for intervention patients in the second year.

Conclusions from this study suggest that integrated care, planned by a nurse and social worker, may have positive impacts on general health, vitality, social functioning and mental health.

Economic studies narrative summaries statements

We found six non-UK economic evaluations of mixed quality. Of these six studies, two came from the systematic search (two excellent quality controlled trials from Canada (Beland 2006 ++/+) (N=1,270) and the US (Counsell 2007 ++,/+) (N=951). The other four were identified through additional searches carried out by the NCCSC economist (three good quality controlled trials (+/+) two of which were from the US (Boult 2001, N=568); Toseland 1997, N=160) and one from Italy (Bernabei 1998, N=226), and one low quality (-/+) before and after cohort study from Italy (Landi 1999, N=115). A possible limitation of these four studies is the age of the research and whether the results are relevant and generalizable to inform current practice.

These studies were broadly similar in the intervention model: outpatient geriatric multidisciplinary evaluation and management plus case management. They were compared to some variation of ‘usual care’; which might be considered as some degree of fragmented health care services. The population covered community-dwelling individuals over the age of 65 years old with the exception of one study focusing on US military veterans over the age of 55; and the range of mean ages across all studies was between 72 to 82 years old. Mean chronic conditions ranged from 1+ to 5 chronic conditions. The proportion of individuals living alone was not reported in half of the studies, although in the other studies, the range was 44% to 58% (Counsell 2007, ++,/+, N=951; Bernabei 1998, +/+, N=226, Beland 2006, ++/+, N=1,270). Likewise, the proportion with an informal carer was not reported in three studies, but in the other studies, the range was 25% to 76% (Counsell 2007, ++,/+, N=951; Landi 1999, -/+, N=115; Bernabei 1998, +/+, N=226).

Findings from all economic evaluations were presented as cost-consequence analyses (costs were presented alongside changes in outcomes). The applicability of the economic evaluations to the UK context is partially limited due to differences in institutional context (baseline patterns of service use) and differences in unit costs. For this reason, relying on the findings of changes in net costs from international studies (assuming that all relevant health and social care resource use are included) cannot completely answer whether the intervention is cost-effective in the UK context but can provide an indication of likely cost-effectiveness. Furthermore, some studies are further limited if they do not comprehensively measure all relevant health and social care resource use. For both reasons, we present a summary of the findings not in terms of net costs, but in terms of the impact on the change of community and institutional health and social care resource use.

Taken together, these studies found improvements in a range of patient health and social care outcomes. It is important to note that not all of the same outcomes were measured, and where there were overlaps, in some cases, findings were mixed (improvements or no differences) but none of the findings indicated worse outcomes. These individual-level outcomes are listed further below.

With respect to service-level outcomes, the consistency of evidence regarding the use of acute health care services (A&E or inpatient stays) indicates that, across a range of countries (Canada, US, and Italy) there were significant decreases (5 studies, Beland 2006, ++/+; Counsell 2007, ++/+; Toseland 1996, +/+, 1997; Bernabei 1998, +/+; Landi 1999 +/-) and was not different in one study (Boult 2001, +/+). The consistency of the evidence in the use of community and health care services was mixed (no differences, increases, or decreases). One particular limitation is that the impact on nursing home or care home admission was only measured in three studies, and these found no differences between groups, measured over a 12, 22, and 24 month follow-up period (Bernabei 1998, +/+, N=226; Beland 2006, ++/+, N=1,270; Toseland 1997, +/+, N=160).

Improvements in social care related outcomes include vitality and social function at 24 months (Counsell 2007, ++/+); improvements in depression at 12 months (Bernabei 1998, +/+), at 6, 8, and 12 months (Boult 2001, +/+) and at 24 months (Counsell 2007, ++/+).

Health-related outcomes also improved in two studies (Boult 2001, +/+, at 6, 8, and 12 months; Counsell 2007, ++/+ at 24 months), while in one study it was no different (Toseland 1996, 1997, +/+ at 8 and 24 months). Physical function improved in three studies (Boult 2001, +/+, at 6, 8, and 12 months; Bernabei 1998, +/+, 12 months; Counsell 2007, ++/+, and 24 months) and was no different in one study (Toseland 1996, 1997, +/+, at 8 and 24 months). Mortality was no different in three studies (Boult 2001, +/+, at 6, 8, and 12 months; Bernabei 1998, +/+, 12 months; Counsell 2007, ++/+, or 24 months), while in one study; mortality was reduced early in the study but was no different towards the end (Toseland 1996, 1997, +/+, reductions at 8 months but was no different at 24 months). For a sub-group of patients reporting no pain on the SF-20 subscale, mortality was reduced at 24 months (Toseland 1996, 1997, +/+,). The number of medications in one study was reduced at 12 months (Bernabei 1998, +/+,).

In relation to satisfaction, process, and continuity of services, two studies measuring these outcomes found improvements in the process and continuity of health and social care at 8 months (Toseland 1996, 1997, +/+,) and at 24 months (Counsell 2007, ++/+,). In the same studies, one had greater satisfaction with services at 8 months (Toseland 1996, 1997, +/+,) while the other found no differences in satisfaction at 24 months (Counsell 2007, ++/+,).

In terms of carer outcomes, there is limited evidence from one good quality Non-UK RCT (+,+) (Boult 2001) that carer satisfaction and burden improved compared to the control group. It is not explicitly clear what mechanism or intervention led to improvements in carer outcomes, but it could be inferred that these changes occurred as a result of the social worker addressing the patient’s psychosocial and financial needs, and that both social worker and nurse provided health education, self-care management, the creation of advance directives, and also due to improved patient outcomes in the areas of depression, physical health, and physical function.

Personalised approaches to assessment, care planning, and service delivery

Glendinning, C. (2009) (+) is a UK mixed methods study which aimed to identify the impact and outcomes of independent budgets (IBs within the IBSEN study on (hitherto) unpaid relatives and other informal carers. The study focused on the ‘two largest groups of carers likely to be affected by IBs: carers of older people and carers of people with learning disabilities’ (12) so it is not clear what proportion of these are likely to be older people with multiple long-term conditions.

Validity is limited by failure to recruit, and delay in implementing the intervention. In relation to quality of life measures, ‘Carers of IB users scored higher than carers of people using standard social care services; the difference between the two groups of carers was statistically significant in relation to carers’ quality of life’ (p89). It appeared that expenditure on services that could provide respite for carers was higher in the IB group than in the comparison group. The study showed that some IB sites struggled to integrate the interests of carers but they did improve. The sites varied in their consideration of carer needs. Carers sometimes felt that the focus was too much on the service users and not enough on carers needs. Team leaders agreed that the pressure of implementation meant that carers' needs were excluded.

IB group carers were significantly more likely to have planned support together with the service user than comparison group carers. None of the carers taking part in the semi-structured interviews had had a separate assessment of their own needs. Nevertheless they reported that in the service user's IB assessment, their own needs and circumstances were more likely to be recognised and taken into account.' (p71) However, 'For many carers, the IB had created more paperwork and management responsibilities' (p71). These problems related to a 'lack of clarity over how the IB could be used; or to support plans that failed to materialise.' (p71).

Economic evidence relating to use of individual budgets

The evidence on individual budgets (Glendinning et al 2008, +/+) has very serious limitations and is only partially applicable to the review question because of problems with delayed implementation. This meant that a very small proportion of the intervention group actually had a care plan in place by the end of the study period (6-months follow-up).Therefore the results of the cost-effectiveness analysis reported at 6 months should not be taken at face value.

The economic analysis took the perspective of the NHS and personal social services and was evaluated over a 6-month follow up period using prices from 2007/2008. Results from the cost-effectiveness analysis indicate that standard care dominates when using the mental wellbeing outcome; but there is no dominance when using the ASCOT, quality of life, or self-perceived health outcomes. Social care service use was similar for both groups (£227/ £228 per week). It was reported that the intervention group had higher health care costs compared to standard care, although precise estimates and statistical significance was not presented.

Link between primary care and social work practitioners

The non-UK Keefe study (++) described above also found that the health practitioners felt that patients presented with ‘social’ problems, which they had neither time nor expertise to address, and many did not have a consistent family or other caregiver to support them. Challis (2010b) (+/-) is a mixed methods study on case management, with separate sections on self-management. The study is not very clearly reported. This study is about case management in primary care by nurses. It is only assessed here for that part which is relevant to case management for older people with multiple long-term conditions (as it concerns all adults with LTCs). Methods included a survey of case managers (with a poor response rate of 56), qualitative ‘case studies’ with practitioners and a ‘focus group consultation’ with users and carers.

The aims of the study are very broad, and the findings – which do not concern impact – are not clearly related to different methodologies. As a scoping study, it has some use in defining the problems of integrated services in case management – itself a poorly defined construct. These are the domination of case management by healthcare practitioners (mostly primary care nurses in community settings); inability of these case managers to access social services except by referral (and then often with very slow response rates); and ineffective case funding where patients were 'allocated on the basis of staff qualification or the predicted intensity of involvement' (p187), so that they ended up in disease specific care – rather than holistic care – services. Service users and carers involved in the focus groups recognised the gaps in care, many of which related to help with housework, finances, and day to day living, i.e. those services that might be addressed through social services involvement.

The authors conclude that: ‘Participants felt the key priorities for a case management service should be to improve the range of services available to care for people at home and to provide more intensive long-term support. Service users clearly placed more import on the meeting of basic needs first, before self-care could be supported.’ (p181)

GP-centred models for service delivery (without case management)

One low quality non-UK study [-, +] (Sommers 2000, N=543) tested the addition of a nurse and social worker to a GP practice to assist in health and social care assessment (through a comprehensive assessment) and care planning plus the provision of other service components (disease self-management, education on self-care, and referring patients to community health and social care services), compared to usual GP care. This study was identified through additional searches of the literature conducted by the NCCSC economist.

The study focused on community-dwelling older adults over aged 65 with at least 2 chronic conditions (stable or unstable) with few restrictions in activities of daily living (bathing and/or dressing only) and at least one restriction in instrumental activities of daily living. Between 42%-55% of the sample lived alone.

The economic evaluation was presented as a cost-consequence analysis (presenting changes in costs alongside changes in outcomes). This economic evaluation is only partially applicable in determining whether the intervention is cost-effective in the UK context due to differences in institutional context, unit costs, and additional issues of relevance as findings are based on older data. Altogether though, the quality of the economic evaluation was moderate due to some issues of unclear reporting in the calculation of net costs but had good reporting quality in changes in all relevant health and social care resource use. Taken together, the findings indicate that the intervention leads to improvements in outcomes alongside reductions in the use of acute care services, small increases in community health care services, and no changes in use of nursing or care home services.

The findings indicate that the intervention can improve some individual-level outcomes at the end of an 18-month follow-up period. Improved outcomes include patient higher social activities count, reduced symptoms, and higher self-rated health. There were no differences in physical health (as measured by the *Health Activities Questionnaire*), emotional state (as assessed by the *Geriatric Depression Scale*), nutritional status, or number of medications.

In relation to service-level outcomes, there is evidence of reduced hospitalisation (p=0.03) at 12 and 18 months follow up; reduced re-admission rates at 12 months follow up; and reduced admissions related to a chronic condition (13% compared to 22% of admissions (no statistical significance figure provided) at 12 and 18 months follow up. However, when looking at the post-intervention period (18-24 months afterwards), these reductions in admissions were not sustained (were not statistically different between groups).

With regards to A&E and admissions to nursing homes, there were not statistically significant differences between groups at 18-months. With respect to the use of community healthcare services, there were significant reductions in specialist visits (p=0.003) but no differences in home care visits or GP visits. It is not possible to present estimates of total costs per person for the intervention and control groups, as there was poor reporting of net cost information. The authors do report that the intervention group produced a savings of $90 per person but estimates of statistical significance were not provided and price year was also not reported.

GP-centred models for service delivery (with case management)

One good quality multi-site [+/+] non-UK study (Battersby, 2007) tested the addition of service coordinators (a social worker, allied health professional, or nurse) to GP-working, in combination with patient-directed goals in the health and social care assessment and care planning process. The intervention was also coupled with changes in funding mechanisms by switching from fee-for-service to a 12-month care plan funded by pooling resources across acute and community health and social care services.

The sample covered community-dwelling older adults over the age of 60, with a range mean age between 61 to 74 years old across the four study sites and varying numbers of chronic conditions. Approximately 58% of the sample was at risk for at least one hospital admission. No information was reported as to the proportion of individuals living alone or with an informal carer.

Findings from the study indicate that the intervention can lead to improved patient health and social care outcomes, including, vitality, mental health, and physical health on the SF-36 subscale and on the work and social adjustment scale (WSAS) for the subscales of home, social, private, and total WSAS scores over an average intervention period of 16 to 20 months. In terms of service-level outcomes, measured over a 24-month follow-up period, there were mixed impacts on acute care service use, in some areas, there were no differences in acute care services, while in others there were reductions in inpatient stay but increases in A&E visits, and some sites had increased elective inpatient admissions. From the view of community social care services; the authors report that the intervention was associated with higher use of home care services.

Admission to nursing or care homes was not measured. However the authors note several limitations that may underestimate potential benefits of the intervention. The authors believe that the time horizon was not long enough to capture improvements in patient's health that may lead to longer-term reductions in hospital use (Battersby, 2007, +/+ p.60). The authors also believe that the intervention was not fully implemented in the early stages of the study period, for example, GPs needed to be reminded to order services as prescribed in the care plan (p.62). Furthermore, the authors believe that the intervention might have better results by targeting patients most likely to benefit – for example, focusing on individuals needing care coordination the most and those with higher risk of hospitalisation (Battersby, 2005, +/+, p.664).

Taken together, the results indicate improvements in outcomes and increases in costs from the perspective of health and social care services, however, the applicability of findings (Battersby, 2007, +/+) has potentially serious limitations due to some issues in the comprehensiveness in the collection of resource use (due to issues with administrative databases). Furthermore, there are issues due to differences in institutional contexts, unit costs, and issues of relevance as findings are based on older data.

Economic evidence on good care models in care homes

This review found no research evidence to address the question of barriers and facilitators to good care models in care homes.

Evidence statements

ES4	**Models of interdisciplinary working** There is moderate quality evidence (Trivedi, 2013, +/-, Goodman, 2012, +/+) that inter-professional working (IPW) may be cost-effective but does not show clearly that any particular model (e.g. care management, collaborative working or integrated teams) delivers better outcomes. User and carers consistently value aspects of integrated service delivery which foster confidence in the reliability of services, continuity of paid carers, user and carer involvement in planning and reviewing care, services to support carers and the ability of services to respond effectively at times of crisis. There is also qualitative evidence that inter-professional working can reduce carer burden.
ES13	**Primary care practitioners' perceptions of the impact of complex health needs on older people's social care needs** One study of good quality (Keefe, 2009, ++) reported from the perspective of primary care practitioners (albeit from the US) that older patients with complex healthcare needs are adversely affected by loneliness and have emotional and practical needs which could not be addressed by primary care physicians and nurses, and might be addressed by having a social worker in the practice.
ES14	**User and practitioner perspectives on community-based case management** One study of moderate quality (Challis 2010b, +/-) suggested – largely on the basis of healthcare practitioner views, supplemented by those of users and carers - that case management in the community is undertaken mostly by nurses, who have difficulty in assessing for or referring into social services, and that consequently, as flagged up by user and carer comments, the basic and personal care needs of people with LTCs (not particularly older people) are not assessed or provided for.
ES15	**Older people's perceptions of the Community Matron service** Two studies of moderate quality (Sargent 2007, +) and Brown 2008, +) suggested that older people with complex long term conditions and their carers highly valued the Community Matron service. They reported enhanced confidence, improved quality of life, and improved ability to manage their conditions and medication with less support from other health services. They valued direct access to advice and clinical care in their own homes. They also reported that the Matron was 'a friend' and a social and psychological support to themselves and their carers. However, the stated impact of the Matron on social isolation may indicate that the role is less effective in directing patients to other possible social or community sources of support.

ES16	**Potential benefits of multi-disciplinary working, and potential barriers to implementation** There is generalisable evidence of moderate quality (Johansson, 2010, ++/+) that multidisciplinary team working may involve the processes of caring for older people with complex needs in the community, and that this may reduce hospital admissions. The development of teams relied on individual and the management or organisation, and had the potential to increase capacity. However, the development of 'teams' is not a simple process. Involving clients and discussing individual needs may provide the hub around which 'teams' can develop. Multidisciplinary geriatric assessments, combined with appropriate interventions could improve on clinical outcomes such as hospital admissions, and reduced length of stay
ES17	**Outpatient geriatric multidisciplinary evaluation and management plus case management** This evidence statement is based on the findings of two studies of excellent quality controlled trials from Canada (++/+) (Beland 2006) and the US (++/ +) (Counsell 2007), three good quality controlled trials (+,/+) two of which were from the US (Boult 2001; Toseland 1997) and one from Italy (Bernabei 1998), and one low quality before and after study (-/+) from Italy (Landi 1999). Taken together, there is moderate evidence from six international studies of mixed quality that the coordination of health and social care services through the use of case management plus outpatient multidisciplinary health and social care geriatric teams can improve a range of service user health and social care outcomes while reducing or having no changes on the use of acute care services with mixed impacts on health and social care resource use. It is important to note that not all of the same outcomes were measured, and where there were overlaps, in some cases, findings were equivocal (improvements or no differences) but none of the findings indicated worse outcomes.
ES18	**Personalised approaches to assessment, care planning and service delivery** There is moderate quality evidence from the (Glendinning 2008, +/-; and 2009, +/+) studies, published by Individual Budgets Evaluation Network (Ibsen) that the introduction of individual budgets for older people (at the time of the study) did not benefit older people as there were poorer outcomes for mental wellbeing outcomes using the GHQ-12 measurement tool. There were no differences in quality of life, self-rated health, or social care related outcomes as measured by the ASCOT tool. Qualitative interviews conducted on 40 older people (Glendinning, 2008, p.46) indicated that "Most notably for older people, three types of experience emerged: those who did not want anything different; those who were anxious but could see some potential benefits; and those embracing the potential for choice and control over their own support." (p.72). There is evidence that for a sub-group of individuals in the intervention group experienced better mental health outcomes when comparing the proportion of individuals scoring 4+ on the GHQ-12 (higher scores indicate better outcomes) but there is some uncertainty with this estimate as these improvements were no longer significant when caregiver proxy outcomes were excluded.

ES19	**Economic evidence relating to use of individual budgets** The applicability of the economic evidence in relation to individual budgets is very limited due to delayed implementation of the intervention, meaning that only a very small proportion of individuals had a care plan in place at the time of the economic evaluation. Therefore, results of the economic evaluation, measured over a 6-months period, should not be taken at face value. The economic analysis is comprehensive in including both health and social care service use and prices reflect 2007/08 year. Results from the cost-effectiveness analysis indicate that, standard care dominates when using the mental wellbeing outcome; but there is no dominance when using the ASCOT, quality of life, or self-perceived health outcomes. Social care service use was similar for both groups (£227/ £228 per week) but it was reported that the intervention group had higher health care costs compared to standard care, although precise estimates and statistical significance was not presented.
ES20	**Link between primary care and social work practitioners** There is some good quality evidence (Keefe, 2009, ++) that primary care staff realise their inability to address the social care needs of older people with complex needs living in the community, and hypothesise that having a social worker in the practice would improve outcomes for users and carers in need of practical, financial and social support. There is moderate quality evidence (Challis, 2010b, +/-) that clinical case managers (the majority of whom are community nurses) find it difficult to refer people to social services, and do not have a good grasp of people's holistic needs. There is evidence of moderate quality (Davey, 2005 +/-) that it is feasible to co-locate a social work team in a primary care setting, but that co-location, whether or not it fostered closer integrated working, showed no particular advantages that could be traced to patient outcomes.
ES21	**GP-centred models for service delivery (without case management)** One low quality US study [-/+] (Sommers 2000, N=543) tested the addition of a nurse and social worker to a GP practice to assist in comprehensive health and social care assessment, care planning and service provision (self-management, education on self-care and referral) compared to usual GP care. The sample included community-dwelling older adults over aged 65 with at least 2 chronic conditions, few restrictions in activities of daily living, and at least one restriction in instrumental activities of daily living. Findings indicate that the intervention leads to improvements in outcomes alongside reductions in the use of acute care services, small increases in community health care services, and no changes in use of nursing or care home services The economic evaluation was presented as a cost-consequence analysis (presenting changes in costs alongside changes in outcomes). This economic evaluation is only partially applicable in determining whether the intervention is cost-effective in the UK context due to differences in institutional context, unit costs, and additional issues of relevance as findings are based on older data. Altogether though, the quality of the economic evaluation was moderate due to some issues of unclear reporting in the calculation of net costs but had good reporting quality in changes in all relevant health and social care resource use.

ES22	**GP-centred models for service delivery (with case management)** One good quality multi-site [+/+] non-UK RCT (Battersby, 2007) tested the addition of service coordinators (a social worker, allied health professional, or nurse) to GP-working, in combination with patient-directed goals in the health and social care assessment and care planning process. The intervention was also coupled with changes in funding mechanisms by switching from fee-for-service to a 12-month care plan funded by pooling resources across acute and community health and social care services. The sample covered community-dwelling older adults over the age of 60, with a range mean age between 61 to 74 years old across the four study sites and varying numbers of chronic conditions. The results show that the intervention is associated with improvements in outcomes and increases in costs from the perspective of health and social care services. However the applicability of findings is limited by potentially serious limitations due to some issues in the comprehensiveness in the collection of resource use (due to issues with administrative databases). Furthermore, there are issues due to differences in institutional contexts, unit costs, and issues of relevance as findings are based on older data.
ES23	**Economic evidence on good care models in care homes** This review found no research evidence to address the question of barriers and facilitators to good care models in care homes

Included studies for these review questions

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Glendinning, C. (2009) The Individual Budgets Pilot Projects: Impact and Outcomes for Carers. Social Policy Research Unit, University of York, York.

Goodman, C. (2012) A study of the effectiveness of inter-professional working for community-dwelling older people - Final Report . NIHR. UK

Johansson, G. (2010) Multidisciplinary team, working with elderly persons living in the community: a systematic literature review. Scandinavian Journal of Occupational Therapy. 17(20. 101-16.

Keefe (2009) Integrating social workers into primary care: Physician and nurse perceptions of roles, benefits, and challenges. Social Work in Health Care. 48 (6) 579-96.

Landi F, Gambassi G, Pola R, et al. (1999). Impact of integrated home care services on hospital use. J Am Geriatr Soc; 47:1430–1434.

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3.3 Self-management support

Introduction to the review questions

The purpose of the review questions on self-management was to seek evidence which would guide recommendations about different ways services for older people with multiple long-term conditions can be supported in managing aspects of their care. The reviews sought evidence from effectiveness studies and views and experiences of service users and their families and/ or carers as well as views and experiences of service practitioners.

Review questions

Q 2.1.5. How effective are different types of support for older people to enable them to self-manage (aspects of) their own conditions?

Q.1.1.1. What are the views and experiences of older people with multiple long-term conditions and their carers, of the social care services they receive?

Q.1.1.2. Do service users and carers consider that their care is (a) personalised; (b) integrated or coordinated with healthcare?

Q.1.1.2. What do they think works well and what needs to change?

Q.1.2.1. What are the views and experiences of practitioners, managers and commissioners in health and social care who procure, manage or deliver care to older people with multiple long-term conditions, in community and care home settings?

Q.1.2.2. What do they think works well, and what needs to change?

Summary of review protocol

The protocol sought to identify studies which would:

- To identify the effectiveness of the different ways in which self-management is facilitated within care packages.

Population: Older people, aged 65 years and older, with multiple long-term conditions who use social care services, and their families, partners and carers. Self-funders and people who organise their own care are included.

Interventions: Assessment and care planning as it facilitates self-management; may also include direct and indirect factors that support self-management such as housing adaptations or Telecare, personal budgets and direct payments, peer support, and access to transport in so much as they relate to a package of care for long-term conditions.

Setting: Service users' home, including sheltered housing accommodation; care (residential and nursing) homes (not hospital settings).

Comparator: Comparative studies could compare alternative ways to help older people with multiple long-term conditions to self-manage.

Outcomes: These should relate primarily to social care outcomes, such as choice, control and dignity, and to service use and costs (rather than clinical outcomes). Emergency hospital admissions and inappropriate entry into residential care may also be considered outcomes of poor support to self-manage.

The study designs relevant to these questions were expected to include:

- Systematic reviews of qualitative and quantitative evaluations on this topic;
- Qualitative studies of service user and carer views;
- Standardised scales measuring satisfaction and wellbeing
- Randomised controlled trials (RCTs) and cluster RCTs of support to self-manage;
- Other comparative/controlled evaluations;
- Observational & descriptive studies of implementation and process.

Full protocols can be found in Appendix A.

How the literature was searched

The evidence reviews used to develop the guideline recommendations were underpinned by systematic literature searches. The aim of the systematic searches was to comprehensively identify the published evidence to answer the review questions developed by the Guideline Committee and NICE Collaborating Centre for Social Care.

The search strategies for the review questions (based on the scope) were developed by the NICE Collaborating Centre for Social Care in order to identify empirical research. The search strategies are listed at the end of this appendix.

Searches were based upon retrieving items for the population groups: ‘older people’, ‘carers’, ‘long-term conditions’, ‘workforce/social care organisation’ in the settings of ‘residential care’, ‘nursing/care homes’, ‘intermediate care’ or ‘community care . Searches were developed using subject heading and free text terms, aiming to balance sensitivity and precision, and the strategy was run across a number of databases. The searches limited results to studies published from 2004 onwards. The database searches were not restricted to specific geographical areas; however, in selecting the websites to search, research on people's views was focused on the UK. The sources searched are listed below. Forward and backwards citation searches using Google Scholar was undertaken in January 2015 for all of the included studies.

The Guideline Committee members were also asked to alert the NICE Collaborating Centre for Social Care to any additional evidence, published, unpublished or in press, that met the inclusion criteria.

Full details of the search can be found in Appendix A.

How studies were selected

Search outputs (title and abstract only) were stored in EPPI Reviewer 4 - a software programme developed for systematic review of large search outputs - and screened against an exclusion tool informed by the parameters of the

scope. Formal exclusion criteria were developed and applied to each item in the search output, as follows:

- Language (must be in English),
- Population (must be older people with multiple long-term conditions, with a social care need)
- Intervention (must be identification/assessment of social care needs; personalised care planning; support to self-manage; integrate social & health care; training of staff to recognise/manage common LTCs; support for carers to care; interventions to support involvement & participation, including information for users and carers
- Setting (must be in the person's home or care home.)
- Workforce. (must involve people who work in social care, are integrated with social care or act as gatekeepers to social care)
- Country (must be UK, European Union, Denmark, Norway, Sweden, Canada, USA, Australia and New Zealand)
- Date (not published before 2004)
- Type of evidence (must be research)
- Relevance to (one or more) review questions.

Title and abstract of all research outputs were screened against these exclusion criteria. Those included at this stage were marked for relevance to particular review questions and retrieved as full texts.

Full texts were again reviewed for relevance and research design. If still included, critical appraisal (against NICE tools) and data extraction (against a coding set developed to reflect the review questions) was carried out. The coding was all conducted within EPPI Reviewer 4, and formed the basis of the analysis and evidence tables. All processes were quality assured by double coding of queries, and of a random sample of 10%.

There were 39 studies which appeared relevant (by title and abstract), we ordered full texts of those which appeared to concern either evaluations of self-management support, reporting impacts for service users, or UK studies which reported older people's and/or their carers' views on self-management support. On receiving and reviewing the full texts, we identified 11 which fulfilled these criteria. These were numbered alphabetically in the discussion below. We divided them according to whether they primarily reported views of users and carers, or primarily concerned effectiveness and outcomes. Where applicable, the evidence statements reflect the findings from both views and impact studies.

All of the studies included in this paper concern UK data, except for Brody 2006, which is from USA.

The included studies were critically appraised using NICE tools for appraising different study types, and the results tabulated. Further information on critical appraisal is given in the introduction at the beginning of Section 3. Study findings were extracted into findings tables. For full critical appraisal and findings tables, see Appendix B.

Narrative summary

Expert Patients Programme

Abraham (2009, +) is a small UK qualitative study of 5 males and 27 females, aged 33–79 years, mean age 56.9 years) who had completed a 6 week Expert Patient Programme (EPP) in Tower Hamlets, London. The EPP course comprised six weekly structured self-management training sessions, delivered to groups of 8–16 patients with heterogeneous health conditions, led by trained volunteer lay tutors with chronic health conditions. Patients also received a self-help manual (entitled ‘living a healthy life with chronic conditions’). The programme provided information and employed a variety of cognitive and behavioural modification techniques addressing topics such as action planning, problem solving, dealing with depression, nutrition and exercise.

Although the sample was ethnically diverse, it was not confined to the age range and health profiles of interest to our topic, and the study is too small to adequately separate out views and experiences of our target population. Respondents reported challenges of coping with chronic conditions: there was a strong sense of frustration over inability to function, and loss of social confidence leading to social isolation. However, although there was not consensus across the group, most respondents benefitted from the increased social contact, and the goal setting aspect of the course, and reported improvements in self-efficacy. When the course ended, most participants felt the loss of a social activity, and this aspect appeared more dominant than the educative aspect of EPP.

Implementation and content of the Expert Patients' Programme

Rogers (2008) is a mixed methods study (evidence rating +/+) evaluating the pilot of the Expert Patient Programme (EPP) in England. It reports on the survey of 299 PCTs, and case study analysis of implementation issues. This paper also includes the RCT of 629 patients randomised to the EPP (which is discussed more fully in Kennedy 2007, +/+). The paper illustrates the difficulties experienced by NHS staff in supporting the Programme. These include organisational problems in implementing a service which aims to provide generic, rather than specialist, support to people with different LTCs (an issue also picked up by the participating patients), and the lack of NHS experience of engaging with patients and the public, and lack of familiarity with the concept of 'Expert Patients'.

The data was collected between 2003 and 2006, and there may have been significant progress in these areas since then. Personal comments from Programme participants were varied in their opinions, although most people appeared to value the social aspect of the group work. The generic nature of the programme was criticised by some service users, who felt disease-specific groups would be more worthwhile, and the inflexibility of the content was criticised, with some participants suggesting that they would have preferred more coverage of generic issues such as welfare benefit entitlements.

As reported more fully in Kennedy (2007, +/+), which is a randomised controlled trial of the effects of the pilot phase of the Expert Patient Programme in England. 629 patients with at least one LTC were randomised (1:1) to the EPP or to the waiting list control (who were to be offered the programme 6 months later. Although the characteristics of the 629 sample population are not entirely clear – mean age 55, with only the main LTC reported, and unclear social care need – the programme did demonstrate some self-reported improvements in the primary outcomes. Patients receiving immediate course access reported considerably greater self-efficacy and energy at 6-month follow-up, but reported no statistically significant reductions in routine health services utilisation over the same time period. The cost-effectiveness analysis showed that patients receiving immediate course access reported considerably greater health related quality of life, and a small reduction in costs. If a quality adjusted life year was valued at £20,000, there was a 70% probability that the intervention was cost effective.

There was no change in health services utilisation (sum of GP consultations, practice nurse appointments, A&E attendances and outpatient visits), although overnight hospital stays and use of day case facilities were reduced in the EPP group.

Medication adherence

Banning (2008) is a literature review of international qualitative research (evidence rating +/+), which applies some of the methods of systematic review, and includes 30 studies. It considers reasons why older people (65+) do not adhere to their prescribed medication. Some ‘intentional’ non-adherence concerns dislike of side effects or future affects, dislike of ‘unnatural’ medication, fear of addiction to analgesics, lack of faith in the prescriber and inadequate explanation of what the medication does and why it is important. Non-intentional reasons include forgetfulness, change in routine, lifestyle change, change in prescribed dosage, unclear instructions, feeling asymptomatic, and the cognitive effects of medication.

Mobility and transport

Challis (2010b) is a mixed methods report (Evidence rating +/-) which aims to assess the interaction between UK self-care initiatives and case management services. Mobility and transport was also found to be an issue for older people using services in the community. Older people were also often frail and struggled with tasks associated with daily living. This limited their ability to access self-care resources and also the appropriateness of self-care for this group, given the complexity and severity of their conditions. Instructions would help older people to manage their medication more effectively.

Signposting to services

Challis (2010b, +/-) as described above found that it was difficult to find research which focused on self-care for older people. This UK study does not measure outcomes, but focuses on problems and variations in practice, and as such is limited in its applicability to this topic. However, the paper does highlight some issues which might affect the implementation and efficacy of self-management, including the importance of information being made available to the service user and (all) carers about a person’s conditions, and information about locally available services that would facilitate self-care/self-management. Some people commented that information was not readily available making a proactive approach difficult. Other said that the internet is a good source of information but not everyone has access.

Urinary incontinence

Horrocks (2004) is a qualitative study (evidence rating +) reporting interviews with 20 older people in the UK who had reported urinary incontinence (UI) in a wider survey. It establishes, on the basis of experience of the interviewees, that primary care professionals do not raise UI with elderly people, even though the problem is common, and may often co-exist with other chronic conditions. It then considers reasons why older people do not ask for support with UI. Findings are that older people have reduced health expectations, and may see UI as a 'natural' consequence of ageing. They were often embarrassed to seek help, and were likely to try to contain the problem, but at some social and psychological cost: restricting fluid intake, wearing certain clothing, avoiding social situations. Some did use pads (and one described an embarrassing and public disclosure when she went to pick them up). Management of urinary incontinence is an aspect of self-management which social care staff could support, while also prompting referral to a GP or community nurse.

Understanding and using Telecare

May (2011, ++) is a UK qualitative study which aims to understand the general dynamics of service implementation and integration across a range of settings, and in particular understand the factors inhibiting the implementation and integration of Telecare systems for chronic disease management. Authors noted a range of factors that affect or inhibit the implementation of Telecare which mean that ‘uncertainty is continuously cycled’ (May 2011, Figure 1). These include, for example: the difficulty of negotiating its use with people who use services; Telecare systems being inflexible, inadequate or incoherent across organisational boundaries; and, insufficient or inappropriate evidence underpinning its use.

Service user experience: Service users reported not being informed on how Telecare may impact on other technologies in the home - there was little opportunity to individualise the system, and the workings of the machine forced the user to adapting to the workings of the machine. There was a sense of a lack of purpose in collecting the kind of information demanded by the systems

For some service users Telecare was "stepping up" from what they were already doing and provided an extra feeling of security. From service users’ perspective, the system provided a fast-track route to access to professional care as and when required.

Education for self-care

Berzins (2009) is a good quality systematic review with a high degree of relevancy to the topic and takes a UK perspective on self-management. The study looks at characteristics of self-care support initiatives in the UK, aimed at older people with long-term conditions. 18 studies were included, and the average age of participants was 60, so was clearly not confined to older people. The review looks at a range of health and social care outcomes including physical functioning, self-efficacy, quality of life, admissions and adherence to treatment. The studies showed a particular emphasis on patient education to enhance self-efficacy in self-managing particular long-term conditions, and included only one paper on the generic Expert Patients Programme.

The studies focused on the following long-term conditions: arthritis, congestive obstructive pulmonary disease and one on stroke. The review observed that each study linked self-management interventions to the needs of the group concerned, so, pain management was important for arthritis sufferers and dietary advice was a central part of intervention for diabetes patients. A tailored approach for different conditions was clearly adopted.

Of studies included in the review, none showed large effects on outcomes following the intervention. Some of the studies showed positive effects: the best effects were found in relation to physical functioning. Exercise was part of 16 of the pilots but not reported as an outcome in most, of the three that did two found positive effects. Interventions which targeted pain as an outcome had little success in securing improvements with one study of 13 showing a small effect. The study authors suggest that the lack of significant outcomes could be due to short follow up periods in some of the studies.

Self-management support in primary care

Kennedy (2013) is a methodologically rigorous, UK cluster randomised control trial (evidence rating +/+).   The intervention trialled involved training primary care staff in practices to develop a 'whole system' approach to self-management support. The intervention included: tools to assess the needs of patients regarding self-care, guides on self-care and access on an online resource with links to self-management resources. The study attempted to embed self-management support into practice. The study took place in 44 practices in North West England, and study aimed to measure outcomes such as shared decision making, self-efficacy and generic health related quality of life.

Outcome measures aimed to determine the effects of self-management support on primary care patients with chronic conditions in the UK. The findings are disappointing, as, although follow ups were carried out at 6 and twelve months, no significant effects were observed in the intervention group.

The authors conclude that the intervention to enhance self-management support in routine primary care did not add noticeable value to existing care for long-term conditions. The active components required for effective self-management support need to be better understood, both within primary care and in patients' everyday lives. The authors also suggest that there was variation between practices in the way that self-management support was embedded into treatment, and that some professionals were not given adequate training.

Managing insomnia

Morgan (2011, +/+) is a UK randomised controlled trial of a self-help cognitive behavioural therapy (CBT) programme which offers a practical first line response to older people (55+) being treated with hypnotic drugs for insomnia symptoms associated with chronic disease in primary care settings. The intervention is delivered through 6 booklets on aspects of sleep hygiene and management, and a telephone helpline staffed by trained ‘expert patients’ was made available at restricted times of the day to provide support in using the CBT materials.

193 patients (aged 55-87) were randomly allocated to the intervention (n = 98) or treatment as usual (n = 95) groups. Patients in the self-help arm showed: significantly improved sleep quality, and significantly reduced insomnia symptom severity at post-treatment, 3 and 6 month follow-ups (all $p < 0.001$); and significantly reduced sleep medication use at the post treatment follow-up ($p < 0.05$). Effect sizes were moderate (range of adjusted Cohen d = 0.51–0.75), and treatment had no effect on levels of daytime fatigue, which the authors suggest may be a result of symptoms of long-term chronic conditions. Most treated patients (73%) said they would recommend the self-help programme to others. Management of insomnia is a problem which social care staff might support.

Evidence statements

ES24	**Expert Patient's Programme** There is moderately good evidence (from Abraham 2009, +) that group activities such as the Expert Patients Programme are valued by participants (age unclear) as an opportunity for social contact; and that the goal-setting aspect of the Programme increased self-efficacy. There is additional evidence of moderate quality (Kennedy 2007, +/+, see below) that the Expert Patients Programme may achieve some statistically significant increases in self-efficacy and energy in people of all ages who undertake the programme.
ES25	**Medication adherence** There is moderate evidence (Banning 2008, +) that older people who do not adhere to their prescribed medication may have both intentional and non-intentional reasons for not doing so. The evidence suggests that shared decision-making between clinicians and patients on what to prescribe, aided by better explanations of effects and clearer instruction, could increase older people's ability and willingness to take their prescribed medication.
ES26	**Signposting** There is evidence of moderate quality (Challis, 2010b, +/-) that older people might be enabled to play a more effective role in managing their conditions if they had better information about their conditions, and were signposted to local services that might support them.
ES27	**Transport availability** There is evidence of moderate quality (Challis, 2010b, +/-) that frailty of older people may reduce their ability to self-manage their health conditions, as well as their personal and household care tasks. Availability of transport may be of particular importance in maintaining independence in the community.
ES28	**Urinary incontinence** There is moderate to good evidence (Horrocks 2004, +) that older people often do not seek help with urinary incontinence, out of embarrassment or belief that it is a natural outcome of ageing, and that primary care staff do not routinely enquire about this. Consequently, people with urinary incontinence lead more restricted lives than they otherwise might, avoiding unfamiliar social situations and restricting fluid intake.
ES29	**Information about telecare** There is good evidence (May 2011, ++) that potential and actual users of telecare services are not well-informed about their purposes, and how they do or might support person-centred care within an individual care plan.
ES30	**Implementation of the Expert Patient's Programme** There is evidence of moderate quality (Rogers 2008, +/+) that, at least in 2006, NHS PCTs struggled to implement the Expert Patients Programme due to lack of expertise in public and patient engagement, and the separation of specialist services from generic approaches.

ES31	**Content of the Expert Patient’s Programme** There is evidence of moderate quality (Rogers 2008, +/+) that participants in the Expert Patients’ Programme would also favour a less generic and more disease-specific formula, but would welcome the ability to influence the programme content to reflect generic concerns, such as access to welfare benefits.
ES32	**Education for self-management** There is good evidence (Berzins 2009, ++/++) that self-management educative programmes to support self-care in people with specific long term conditions of average age of 60 may not secure measurable improvements. Some positive effects of exercise on physical functioning were apparent, but it is uncertain whether they made significant improvements within participants’ lives.
ES33	**Economic evidence for self-management programmes** While there is moderate quality evidence on the effectiveness of self-management programs from the Expert Patients Programme (Kennedy 2007, +/+, moderate quality), which also reported on cost-effectiveness, the sample population is insufficiently applicable to draw conclusions about cost-effectiveness for older people with multiple long-term conditions and social care needs.
ES34	**Self-management support in primary care** There is some evidence of moderate quality (Kennedy 2013, +/+) that embedding self-management support in primary care practice is difficult, and may not yield any measurable improvements for patients.
ES35	**CBT for insomnia** There is some moderate evidence (Morgan, 2011, +/+) to support the use of a CBT programme administered in primary care settings in helping older people (55+) with chronic disease to manage insomnia.

Included studies for these review questions

Abraham, 2009: What psychological and behaviour changes are initiated by 'expert patient' training and what training techniques are most helpful? Psychology and Health. 24(10). 1153-65

Banning, 2008: Older people and adherence with medication: A review of the (qualitative) literature. International Journal of Nursing Studies. 45(10).1150-61

Berzins, 2009: UK self-care support initiatives for older patients with long-term conditions: A review. Chronic Illness. 5(1). 56-72

Brody, 2006: Age-related macular degeneration: self-management and reduction of depressive symptoms in a randomized, controlled study. Journal of the American Geriatrics Society. 54(10). 1557-62

Challis, 2010b: Self-care and Case Management in Long-term Conditions: The Effective Management of Critical Interfaces. NIHR. UK

Horrocks, 2004: What prevents older people from seeking treatment for urinary incontinence? A qualitative exploration of barriers to the use of community continence services. Family Practice. 21(6). 689-96.

Kennedy 2007: The effectiveness and cost effectiveness of a national lay-led self care support programme for patients with long-term conditions: a pragmatic randomised controlled trial. Journal of Epidemiology and Community Health. 61(3). 254-61.

Kennedy 2013: Implementation of self-management support for long-term conditions in routine primary care settings: Cluster randomised controlled trial. BMJ. 346, (f2882), 1-11.

Mason, A. Weatherly, H. Spilsbury, K. Arksey, H. Golder, S. Adamson, J. Drummond, M. Glendinning, C. (2007). “A systematic review of the effectiveness and cost-effectiveness of different models of community-based respite care for frail older people and their carers.” Health technology assessment. 11 (15).

May 2011: Integrating telecare for chronic disease management in the community: what needs to be done? BMC Health Services Research. 11:131

Morgan 2011: Self-help treatment for insomnia symptoms associated with chronic conditions in older adults: a randomised controlled trial. Journal of the American Geriatrics Society. 60(10). 1803-10.

Rogers (2008): The United Kingdom Expert Patients Programme: results and implications from a national evaluation. The Medical Journal of Australia. 190 (10suppl). S21-4

3.4 Social isolation

Introduction to the review questions

The purpose of the review questions on social isolation was identify evidence that would guide recommendations about different ways to recognize and respond to social isolation experienced by older people with multiple long-term conditions. The review sought evidence from effectiveness studies and views and experiences of service users and their families and/ or carers as well as views and experiences of service practitioners.

Review questions

Q.2.1.6. How can older people with multiple long-term conditions living in the community or in care home settings be supported to participate in community, family and social activities

Q.1.1.1. What are the views and experiences of older people with multiple long-term conditions and their carers, of the social care services they receive?

Q.1.1.2. Do service users and carers consider that their care is (a) personalised; (b) integrated or coordinated with healthcare?

Q.1.1.2. What do they think works well and what needs to change?

Q.1.2.1. What are the views and experiences of practitioners, managers and commissioners in health and social care who procure, manage or deliver care to older people with multiple long-term conditions, in community and care home settings?

Q.1.2.2. What do they think works well, and what needs to change?

Summary of review protocols

The protocols sought to identify studies which would:

- To review material identified to address 2.1.1, to consider how social participation is reflected in care assessment and planning; and how people access information about participation-related activities

- To consider how social participation can be improved in each of the relevant care settings as part of a coordinated package of care

Population: Older people, aged 65 years and older, with multiple long-term conditions that use social care services, and their families, partners and carers. Self-funders and people who organise their own care are included.

Intervention: Interventions and approaches targeted at reducing isolation, including: befriending schemes, group activities, volunteer schemes; strengths-based approaches.

Setting: Service users' home, including sheltered housing accommodation; care (residential and nursing) homes (not hospital settings).

Comparator: comparisons could be made between usual care and different ways of alleviating social isolation.

Outcomes: Measures of wellbeing and quality of life, participation in community, family and social activities, measures of social support and effects on social isolation and loneliness.

The study designs relevant to these questions were expected to include:

- Systematic reviews of qualitative and quantitative studies on interventions on this topic;
- Qualitative studies of service user views;
- Standardised scales measuring satisfaction and wellbeing;
- Randomised controlled trials (RCTs) and cluster RCTs;
- Other studies with controlled comparisons;
- Analyses of care planning materials.

Full protocols can be found in Appendix A.

How the literature was searched

The evidence reviews used to develop the guideline recommendations were underpinned by systematic literature searches. The aim of the systematic searches was to comprehensively identify the published evidence to answer the review questions developed by the Guideline Committee and NICE Collaborating Centre for Social Care.

The search strategies for the review questions (based on the scope) were developed by the NICE Collaborating Centre for Social Care in order to identify empirical research. The search strategies are listed at the end of this appendix.

Searches were based upon retrieving items for the population groups: ‘older people’, ‘carers’, ‘long-term conditions’, ‘workforce/social care organisation’ in the settings of ‘residential care’, ‘nursing/care homes’, ‘intermediate care’ or ‘community care . Searches were developed using subject heading and free text terms, aiming to balance sensitivity and precision, and the strategy was run across a number of databases. The searches limited results to studies published from 2004 onwards. The database searches were not restricted to specific geographical areas; however, in selecting the websites to search, research on people's views was focused on the UK. The sources searched are listed below. Forward and backwards citation searches using Google Scholar was undertaken in January 2015 for all of the included studies.

The Guideline Committee members were also asked to alert the NICE Collaborating Centre for Social Care to any additional evidence, published, unpublished or in press, that met the inclusion criteria.

Full details of the search can be found in Appendix A.

How studies were selected

Search outputs (title and abstract only) were stored in EPPI Reviewer 4 - a software programme developed for systematic review of large search outputs - and screened against an exclusion tool informed by the parameters of the

scope. Formal exclusion criteria were developed and applied to each item in the search output, as follows:

- Language (must be in English),
- Population (must be older people with multiple long-term conditions, with a social care need)
- Intervention (must be identification/assessment of social care needs; personalised care planning; support to self-manage; integrate social & health care; training of staff to recognise/manage common LTCs; support for carers to care; interventions to support involvement & participation, including information for users and carers
- Setting (must be in the person's home or care home.)
- Workforce. (must involve people who work in social care, are integrated with social care or act as gatekeepers to social care)
- Country (must be UK, European Union, Denmark, Norway, Sweden, Canada, USA, Australia and New Zealand)
- Date (not published before 2004)
- Type of evidence (must be research)
- Relevance to (one or more) review questions.

Title and abstract of all research outputs were screened against these exclusion criteria. Those included at this stage were marked for relevance to particular review questions and retrieved as full texts.

Full texts were again reviewed for relevance and research design. If still included, critical appraisal (against NICE tools) and data extraction (against a coding set developed to reflect the review questions) was carried out. The coding was all conducted within EPPI Reviewer 4, and formed the basis of the analysis and evidence tables. All processes were quality assured by double coding of queries, and of a random sample of 10%.

We screened the papers (titles and abstracts) identified in the search outputs and retrieved full texts for those that appeared relevant. We then screened the papers using the full study to assess quality and relevance. The focus of this search was to find high quality studies which contained the views and experiences of service users, carers and practitioners.

Qualitative studies and papers with a mixed methodology were assessed for quality and relevance for older people with long-term conditions. Our focus for this question was on identifying high quality and contextually relevant evidence, as a result so we looked only at UK studies. The following two studies met the criteria.

The included studies were critically appraised using NICE tools for appraising different study types, and the results tabulated. Further information on critical appraisal is given in the introduction at the beginning of Section 3. Study findings were extracted into findings tables. For full critical appraisal and findings tables, see Appendix B.

Narrative summary

The two papers identified are both of moderate to good quality (+) in relation to their qualitative methods. Both of their samples were relatively small and taken in localised areas. The sample demographics for either study were not representative in terms of gender or ethnic origin .The Granville study (2010, +) set out to gather views and experiences of older people on a variety of topics and so may be relevant to other questions to be addressed during the guidance development process. The Blickem study (2013, +) has data which specifically relates to social isolation but its findings around community interventions are inconclusive. There appears to be a particular lack of evidence which focuses on the views and experiences of practitioners and carers in relation to social isolation.

Due to the specificity of our target group there remains a paucity of evidence which reports older people’s views and experiences around social isolation.

Factors that can contribute to social isolation

Isolation and loneliness were revealed to relate to getting older, the loss of a partner or spouse, retirement, poor finances and peers dying or going into care homes. Social Isolation is also shown to be related to poor health and mobility problems which made getting about difficult or impossible. Problems accessing transport was shown to be a key barrier to participation in community activities. 'Deprived Communities' (Blickem, 2013 p 56) might also lack the resources to hold community groups. The socially isolated may also lack the connections within their communities to find out about resources in their area.

Extent of social isolation in communal living environments compared to when living alone

Both papers found that social isolation and loneliness were a 'significant issue for older people with high support needs - both for those living in care homes and those living at home' (Granville, 2010 p69). Blickem reports an assumption that being with other older people in a care home means that a person is not lonely, and participants in this study refute this. Older people in care home who were able to maintain links with friends and family reported that they maintained a sense of identity and meaning in their live, (Granville 2010, +. Participants in the Granville study ask that care staff raise their expectations of what older people want from their social lives and provide more assistance to realise these ambitions.

Older people’s perceptions of social isolation and opportunities to meet others

Participants in Granville’s study reported that loneliness and isolation was 'the most difficult part of getting older or coping with poor health' (p16). Blickem reports that older people feel isolated not only from family and friends but also their local communities as a whole, particularly those living in care homes.

Older people also wanted to diversify their interactions beyond people of their own age groups; 'Having friends of diverse ages and with varying levels of need for support themselves might help people maintain fuller social lives’

(Granville, 2010 p31) Day centres were also not necessarily seen as a providing an adequate mix of ages or opportunities to be involved in "normal life". (Granville, 2010 p31)

Facilitators of, and structures to support participation and involvement

Involvement in community activities of various types expanded older people’s social networks, sometimes helping them to remain in their own homes for longer (Blickem 2013). Older people who were able to keep visiting familiar social places retained a sense of participation in normal life. (Granville 2010), Community groups they visited provided a 'rare opportunity for social contact' (Blickem, 2013 p52). Community groups were an environment which normalized chronic illness and could function as a 'forum for exchange of emotional and practical support' (Blickem, 2013 p52) for users. Blickem also found that community groups provided additional services for the socially isolated like transport services and advice on welfare benefits.

Evidence statements

ES36	**Factors that can contribute to social isolation** Two qualitative papers of good quality (Blickem, 2013, +; Granville, 2010, +) found that social isolation was a significant problem for older people with high support needs – whether they lived in the community at home, or in care homes. Isolation and loneliness were exacerbated by the loss of a partner or spouse, retirement, peers dying or going into residential care, poor finances and poor mobility and lack of transport.
ES37	**Extent of social isolation in communal living environments compared to when living alone** A good quality paper (Blickem, 2013, +) reports that older people who live in communal environments are as likely to feel isolated and lonely as those remaining in their own homes. Granville (2020,+) also confirms that people in care homes who maintained a network of friends and family retained 'more of their own sense of identity and have more meaning in their lives' (p69).
ES38	**Older people's perceptions of social isolation** Two good quality studies (Blickem, 2013,+, Granville, 2010,+) found that older people felt cut off from the wider 'community', not just from family and friends. Some had left their home and could no longer access local facilities and community activities. This led to a sense of disconnection, and a loss of activity and interaction that was part of 'normal life'. People therefore want to take part in activities that are situated in the community. Community participation was felt to be a motivating factor to be positive about themselves, their lives and their health.
ES39	**Older people's perceptions of opportunities for meeting other people** There is good evidence from a good quality study (Blickem, 2013,+), that people valued the opportunity to meet with people who shared similar frustrations and needs because of their health: support from other older people with LTCs could be a 'forum for exchange of emotional and practical support' (52). The groups also provided additional services for the socially isolated in that they could help access transport services, advice on welfare benefits 'Linkage to these resources through the groups was described as a lifeline to help which otherwise participants struggled to know how access.' (52). There is evidence from one good study (Granville, 2010,+) that older people also want diverse opportunities for social participation with people of different ages and interests as in 'normal life', so day centres (for example) were not necessarily an adequate response. Some people said they wanted more support to carry out activities such as shopping and going to the pub as opportunities to participate in 'normal' life.
ES40	**Facilitators of, and structures to support participation and involvement** Two good quality studies (Blickem, 2013,+; Granville, 2010,+) conclude that older people living in the community or care homes need more opportunities for social participation in the community, and that transport is a vital service needed to support this. Granville (2010 +) emphasises the importance of visibility and retaining/strengthening personal and social networks as people age (80), and recommends further development of approaches such as: 'circles of support, time-banking, home-share, and other forms of mutual support' (p80).

ES41	**Economic evidence on interventions to address social isolation** There was no economic evidence to draw conclusions about the cost-effectiveness of different interventions to address social isolation.

Included studies for these review questions

Blickem C, Kennedy A, Vassilev I, Morris R, Brooks H, Jariwala P, Blakeman T, Rogers A. (2013) Linking people with long-term health conditions to healthy community activities: development of Patient-Led Assessment for Network Support (PLANS) Health Expect. 16(3):e48-59

Granville G, Runnicles D, Barker S, Lee M, Wilkins A, Bowers H, 2010 Increasing the Voice, Choice and Control of Older People with High Support Needs: A Research Findings Paper from the South East Regional Initiative (SERI). Centre for Policy on Aging. 1-122.

Expert witnesses

In response to gaps in the evidence two expert witnesses were called to give additional evidence on social isolation. A summary of the testimony provided by each expert witness is provided below. For full testimonies see Appendix D.

Section A: NCCSC to complete	
Name:	Melissa March
Job title:	Director – Learning for the Fourth Age
Rationale for, and aims of expert witness testimony:	There is no good research evidence about the ability of interventions to reduce social isolation, and provide stimulating and social activity for older people with multiple long term conditions, whether they are living in community dwellings or in care homes. The aims of such activity might be to reduce loneliness, increase social contact with people of all ages, continue to sustain and develop interests, activities and identities of older people, and enable older people with multiple long-term conditions to participate meaningfully in their local communities. These are all outcomes which research tells us are valued by older people. This group of people are likely to have health and mobility problems which act as barriers to social participation and other activity. They may also be living with dementia, have sensory impairment, and may not speak English as a first language.
Expert testimony Learning for the Fourth Age (L4A) provides learning opportunities for older people receiving care. We focus on better quality of life, mental stimulus and delaying the onset of dementia by learning through activities, pastimes and roles, which bring pleasure and meaning. Learning Mentors encourage existing interests or developing new ones, with resources meeting support needs. L4A is a social enterprise providing learning opportunities to older people receiving care across in Leicester and Leicestershire. A not-for-profit organisation, we work with over 150 older people each week and have 80 volunteers at any one time. During 2013/14, L4A volunteers provided over 14,500 hours of volunteering time to fourth agers living across Leicester and Leicestershire. Any surplus created is reinvested in to our work with some of the oldest people across the city and county. L4A is strongly established in Leicester, with a track record of providing high quality, personalised learning opportunities to older people receiving care. Our work makes a real difference to the quality of older people's lives and provides mental stimulus, for example using new technologies, and getting engaged with absorbing practical activities, such as gardening, art and music.	

From “Exploring Learning in Later Life: External Evaluation of Learning for the Fourth Age (L4A)” by independent evaluators: Dr Trish Hafford-Letchfield (University of Middlesex) and Dr Peter Lavender (NIACE) in December 2013:

Learning for the Fourth Age (L4A) provides learning opportunities for older people receiving care. We focus on better quality of life, mental stimulus and delaying the onset of dementia by learning through activities, pastimes and roles, which bring pleasure and meaning. Learning Mentors encourage existing interests or developing new ones, with resources meeting support needs.

Independent evaluators, Dr Trish Hafford-Letchfield and Dr Peter Lavender, found:

“There are significant benefits. L4A’s creates successful learning partnerships with traditionally neglected groups of older people in poor health and with limiting disabilities.”

L4A has developed methods that engage older people in one-to-one learning, in couples and groups, with some taking up lead roles e.g. facilitating music appreciation, art and computing.”

We saw rich examples of learning experiences.... “Within care homes, older people had made significant progress, found new skills and knowledge and had become more confident by:

- learning new things (e.g. painting)
- keeping the body active (e.g. knitting): learning for health (e.g. armchair exercise)
- learning what’s going on in the world (e.g. discussion of news) learning more capability
- keeping the mind active (e.g. discussing topics, books)
- stimulating the process of learning (e.g. through arts-based learning)
- reflecting on a life well spent (through reminiscence using films, biography, storytelling).
- helping maintain independence (e.g. better social contact, developing new relationships)
- developing skills and knowledge for survival (e.g. online shopping, emailing relatives)
- learning to understand and build relationships with other people in relation to age and ethnicity, and particularly being in contact with younger people
- learning about oneself in later life and how to connect, contribute, feel productive and promoting resilience where there are adverse health conditions.

These make a significant difference to individuals’ wellbeing, bringing new ideas, improving understanding and maintaining a positive outlook. L4A is creative and ground-breaking in non-formal learning”.

Section A: NCCSC to complete	
Name:	Rachel Mortimer
Job title:	Founder - Engage and Create
Subject of expert testimony:	Research Question 2.1.6: Social isolation: How can older people with multiple long-term conditions living in the community or in residential care be supported to participate in community, family and social activities?
Rationale for, and aims of expert witness testimony:	There limited good research evidence base concerning the ability of interventions to reduce social isolation, and provide stimulating and social activity for older people with multiple long-term conditions, whether they are living in community dwellings or in care homes. The aims of such activity might be to reduce loneliness, increase social contact with people of all ages, continue to sustain and develop interests, activities and identities of older people, and enable older people with multiple long-term conditions to participate meaningfully in their local communities. These are all outcomes which research tells us are valued by older people. This group of people are likely to have health and mobility problems which act as barriers to social participation and other activity. They may also be living with dementia, have sensory impairment, and may not speak English as a first language. Philippa Thompson (GDG member) suggested that Rachel Mortimer provides the kind of community/continuity activities that we were talking about in care home and could give evidence/case studies.

Rachel Mortimer is a social entrepreneur and professional artist. Her background is an eclectic mix of media organisation (ITV, Saatchi's), teaching and caring. Having gained a Montessori Diploma with distinction she is currently completing a BSc Psychology. Rachel started Engage & Create after visiting a dementia care home and realising the lack of opportunities for residents to participate in meaningful activity that provided cognitive stimulation. She developed the Ignite Sessions to provide a cultural and stimulating way of getting people engaging with each other. They will be available to access via a licence later this year with training in the technique used to facilitate these sessions with people at all stages of dementia.

Rachel has been awarded a Fellowship from The School of Social Entrepreneurs, been a winner of the SE Assist programme (Legal & General), Juice FM's chosen social enterprise 2014/15

Research Question 2.1.6: Social isolation: How can older people with multiple long-term conditions living in the community or in residential care be supported to participate in community, family and social activities?

What we know

- Social identities are built from group membership. Feeling a sense of belonging affects our self-esteem
- Passive activities (watching tv/listening to radio) for both women and men increase risk of death
- Social activities are very important for not only wellbeing but longer life

Solution 1: Future planning, build to encourage community inclusion and social opportunities

- Humanitas NL - Apartments for life - sick and healthy people live together, old and young, poor and rich, migrant and Dutch. There is a deliberate mixing of residents, in terms of health status and socio-economic status. Their inclusion is seen as an important element in avoiding an ‘institutional’ feel.
- Hogeway Dementia Village – themed houses of 6/7 people. The restaurant & theatre are open to the public, help towards the running costs and bring local community into the setting breaking down barriers.

Solution 2: Making the most of what we have, bring the outside in

- Engage & Create’s Ignite Sessions for people with dementia – Use culture as an opportunity to bring people together, Ignite Sessions introduce art appreciation as a social experience in care homes/day centres/art galleries
- Festival in a Box, Bloomsbury – connect festivals to care homes and bring parts of them into the home or create ‘dementia friendly’ performances
- Community Visitor Scheme, Essex - dedicated community volunteers befriending those in care homes. Encouraged participation in activities.
- Gloucestershire Care Homes Part of Our Community (POPPs) – unlocked potential and skills of current care home workforce. Used quality training to help activities coordinators.

Solution 3: Sharing spaces, the outdoors

- Kastaniehaven, Denmark - Kindergarten and care homes use the same spaces, older people can watch the children playing.
- Dementia Adventure (Essex) - provide easy walks on wheelchair friendly paths in local parks

Solution 4: Sharing spaces, residential care and learning

- Lasell Village, Boston, USA - Combines retirement community with the cultural, social, and recreational opportunities of lifelong learning
- Hillcrest Mable Rose, Omaha, USA - Students from the Montessori School visit every Friday to study alongside the centre’s residents
- Peder Lykke Centre, Copenhagen - Day High School offers opportunity to have an active life, challenging and developing individuals

Solution 5: Sharing spaces, virtually

- CNA Language Exchange, Brazil – retirement home residents and language students share conversation over Skype to help improve children's English language skills. They also become pen pals.

Solution 5: Sharing spaces, creatively

- Alive! Activities Paint Pals project – intergenerational project twinning junior schools with care homes to send painted postcards to one another.

Solution 7: Creating communities within the care home

- The Gentlemen's Club, Truro - While decreasing well-being tends to be the norm in long-term residential care, building new social group memberships in the form of gender clubs can counteract this decline, particularly among men.

3.5 Workforce competencies

Introduction to the review questions

The purpose of the review questions on workforce was to seek evidence which would guide recommendations about the induction, training, supervision and support given to social care staff providing care to older people in their own homes or in the community, in recognizing and referring on commonly occurring, but often neglected conditions. Examples of common conditions raised by stakeholders included urinary incontinence, dehydration, malnutrition as well as others.

Review questions

RQ 3.1 How can social care practitioners delivering services to people with multiple long-term conditions be assisted to recognise, refer on and/or manage common health conditions and symptoms?

Q.1.1.1. What are the views and experiences of older people with multiple long-term conditions and their carers, of the social care services they receive?

Q.1.1.2. Do service users and carers consider that their care is (a) personalised; (b) integrated or coordinated with healthcare?

Q.1.1.2. What do they think works well and what needs to change?

Q.1.2.1. What are the views and experiences of practitioners, managers and commissioners in health and social care who procure, manage or deliver care to older people with multiple long-term conditions, in community and care home settings?

Q.1.2.2. What do they think works well, and what needs to change?

Summary of review protocols

The protocol sought to identify studies which would:

- To identify the effectiveness of approaches to existing induction, training and continuing personal development delivered to social care staff and (unregulated) personal assistants working with older people with multiple LTCs

- To identify barriers and facilitators to the implementation of approaches which enable social care staff to identify and manage common health conditions and symptoms
- To consider whether and how increased integration could foster shared learning and improved communication between care staff in relation to the identification and management of these common conditions

Population: Social care practitioners (providers, workers, managers, social workers), and social care commissioners involved in delivering social care to people with long-term conditions in the community or care homes; personal assistants engaged by people with LTCs and their families.

Nurses in residential care settings, primary and community healthcare staff, community matrons (who have a role in supporting care homes to access healthcare).

Intervention: Organisational skills support and continuing personal development; models of integration and cross-agency work and training; personalised services which identify and respond to the physical and mental existing and evolving care needs of the individual. Staff support, supervision, training and assessment. Development of and use of protocols.

Setting: Service users' home, including sheltered housing accommodation; care (residential and nursing) homes (not hospital settings).

Comparator: Comparative studies could compare different approaches to training in before and after studies in individuals, or comparing training outcomes in different organisations

Outcomes: Effectiveness studies of 'training' with follow up; outcomes relating to safeguarding and safety, such as (e.g. falls prevention; prevention of back injury in carer); reduction in emergency hospital admissions: implementation of CQC regulations and contract monitoring; initiation of treatments, e.g. for depression; measures of staff confidence.

The study designs relevant to these questions were expected to include:

- Systematic reviews of qualitative and quantitative studies on interventions designed to improve staff competencies
- Qualitative studies of service user and carer views of training and competencies of staff and themselves (drawing on 1.1.1);
- Standardised scales measuring satisfaction and wellbeing;
- Randomised controlled trials (RCTs) and cluster RCTs on training;
- Other comparative studies;
- Observational & descriptive studies of implementation and process.
- Full protocols can be found in Appendix A.

How the literature was searched

The evidence reviews used to develop the guideline recommendations were underpinned by systematic literature searches. The aim of the systematic searches was to comprehensively identify the published evidence to answer the review questions developed by the Guideline Committee and NICE Collaborating Centre for Social Care.

The search strategies for the review questions (based on the scope) were developed by the NICE Collaborating Centre for Social Care in order to identify empirical research. The search strategies are listed at the end of this appendix.

Searches were based upon retrieving items for the population groups: ‘older people’, ‘carers’, ‘long-term conditions’, ‘workforce/social care organisation’ in the settings of ‘residential care’, ‘nursing/care homes’, ‘intermediate care’ or ‘community care . Searches were developed using subject heading and free text terms, aiming to balance sensitivity and precision, and the strategy was run across a number of databases. The searches limited results to studies published from 2004 onwards. The database searches were not restricted to specific geographical areas; however, in selecting the websites to search, research on people's views was focused on the UK. The sources searched are listed below. Forward and backwards citation searches using Google Scholar was undertaken in January 2015 for all of the included studies.

The Guideline Committee members were also asked to alert the NICE Collaborating Centre for Social Care to any additional evidence, published, unpublished or in press, that met the inclusion criteria.

Full details of the search can be found in Appendix A.

How studies were selected

Search outputs (title and abstract only) were stored in EPPI Reviewer 4 - a software programme developed for systematic review of large search outputs - and screened against an exclusion tool informed by the parameters of the scope. Formal exclusion criteria were developed and applied to each item in the search output, as follows:

- Language (must be in English),
- Population (must be older people with multiple long-term conditions, with a social care need)
- Intervention (must be identification/assessment of social care needs; personalised care planning; support to self-manage; integrate social & health care; training of staff to recognise/manage common LTCs; support for carers to care; interventions to support involvement & participation, including information for users and carers
- Setting (must be in the person’s home or care home.)
- Workforce. (must involve people who work in social care, are integrated with social care or act as gatekeepers to social care)
- Country (must be UK, European Union, Denmark, Norway, Sweden, Canada, USA, Australia and New Zealand)
- Date (not published before 2004)
- Type of evidence (must be research)
- Relevance to (one or more) review questions.

Title and abstract of all research outputs were screened against these exclusion criteria. Those included at this stage were marked for relevance to particular review questions and retrieved as full texts.

Full texts were again reviewed for relevance and research design. If still included, critical appraisal (against NICE tools) and data extraction (against a coding set developed to reflect the review questions) was carried out. The coding was all conducted within EPPI Reviewer 4, and formed the basis of the analysis and evidence tables. All processes were quality assured by double coding of queries, and of a random sample of 10%.

In our initial screen (on title and abstract), we found 72 studies which appeared relevant to one or more of the review questions. However, on screening further on title and abstract we did not find any material which directly responded to this question, because there were no experimental studies, for training social care workforce in recognizing common conditions in older people with multiple long-term conditions, either in their own home or in a care home.

Although no evidence was identified recommendations were made on workforce training based on the consensus of the Guideline Committee.

3.6 Carer support

Introduction to the review questions

The purpose of the review questions on carer support were to identify evidence that would guide recommendations about different ways services can support informal and family carers for older people with multiple long-term conditions. The review sought evidence from effectiveness studies and views and experiences of service users and their families and/ or carers as well as views and experiences of service practitioners.

Review questions

Q.3.3.2. How should services work with and support carers of older people with multiple long-term conditions (who may have long-term conditions themselves)?

Q.1.1.1. What are the views and experiences of older people with multiple long-term conditions and their carers, of the social care services they receive?

Q.1.1.2. Do service users and carers consider that their care is (a) personalised; (b) integrated or coordinated with healthcare?

Q.1.1.2. What do they think works well and what needs to change?

Q.1.2.1. What are the views and experiences of practitioners, managers and commissioners in health and social care who procure, manage or deliver care to older people with multiple long-term conditions, in community and care home settings?

Q.1.2.2. What do they think works well, and what needs to change?

Summary of review protocols

The protocol sought to identify studies which would:

- identify approaches in care planning and delivery which enable carers, partners and families to participate in care planning and delivery, both in community and care home contexts

- identify and evaluate interventions and approaches (including information, education) which support carers in the tasks of caring
- consider how providers of social care and health care should work in partnership and support carers of older people with multiple long-term conditions, including identification of remediable difficulties (such as need for training and introduction of lifting equipment; need for support for social interaction and participation).

Population: Carers of older people with multiple long-term conditions, aged 65 years and older with multiple long-term conditions. Carers and family members of self-funders and people who organise their own care are included.

Intervention: Support to care' (involvement in planning and delivery, specific support such as needs assessment and respite, training in skills such as lifting; support to enable social participation and reduce isolation of carers).

Setting: Service users' homes, including sheltered housing accommodation; family carers' role in supporting older people in care home settings.

Comparator: Comparative studies could compare different models and interventions that support carers.

Outcomes: User and carer satisfaction with services; perception of quality and continuity of care; perception of carer burden; choice and control for users and carers; involvement in decision-making; dignity and independence; quality of life; health status of user and carer; safety and safeguarding within both settings. Unplanned hospital admissions and entry into residential care.

The study designs relevant to these questions were expected to include:

- Systematic reviews of qualitative studies on this topic;
- Systematic reviews utilising measures of carer burden and satisfaction;
- Randomised controlled trials (RCTs) and cluster randomised trials of interventions to support carers to care (e.g. education).

Full protocols can be found in Appendix A.

How the literature was searched

The evidence reviews used to develop the guideline recommendations were underpinned by systematic literature searches. The aim of the systematic searches was to comprehensively identify the published evidence to answer the review questions developed by the Guideline Committee and NICE Collaborating Centre for Social Care.

The search strategies for the review questions (based on the scope) were developed by the NICE Collaborating Centre for Social Care in order to identify empirical research. The search strategies are listed at the end of this appendix.

Searches were based upon retrieving items for the population groups: ‘older people’, ‘carers’, ‘long-term conditions’, ‘workforce/social care organisation’ in the settings of ‘residential care’, ‘nursing/care homes’, ‘intermediate care’ or ‘community care . Searches were developed using subject heading and free text terms, aiming to balance sensitivity and precision, and the strategy was run across a number of databases. The searches limited results to studies published from 2004 onwards. The database searches were not restricted to specific geographical areas; however, in selecting the websites to search, research on people's views was focused on the UK. The sources searched are listed below. Forward and backwards citation searches using Google Scholar was undertaken in January 2015 for all of the included studies.

The Guideline Committee members were also asked to alert the NICE Collaborating Centre for Social Care to any additional evidence, published, unpublished or in press, that met the inclusion criteria.

Full details of the search can be found in Appendix A.

How studies were selected

Search outputs (title and abstract only) were stored in EPPI Reviewer 4 - a software programme developed for systematic review of large search outputs - and screened against an exclusion tool informed by the parameters of the

scope. Formal exclusion criteria were developed and applied to each item in the search output, as follows:

- Language (must be in English),
- Population (must be older people with multiple long-term conditions, with a social care need)
- Intervention (must be identification/assessment of social care needs; personalised care planning; support to self-manage; integrate social & health care; training of staff to recognise/manage common LTCs; support for carers to care; interventions to support involvement & participation, including information for users and carers
- Setting (must be in the person's home or care home.)
- Workforce. (must involve people who work in social care, are integrated with social care or act as gatekeepers to social care)
- Country (must be UK, European Union, Denmark, Norway, Sweden, Canada, USA, Australia and New Zealand)
- Date (not published before 2004)
- Type of evidence (must be research)
- Relevance to (one or more) review questions.

Title and abstract of all research outputs were screened against these exclusion criteria. Those included at this stage were marked for relevance to particular review questions and retrieved as full texts.

Full texts were again reviewed for relevance and research design. If still included, critical appraisal (against NICE tools) and data extraction (against a coding set developed to reflect the review questions) was carried out. The coding was all conducted within EPPI Reviewer 4, and formed the basis of the analysis and evidence tables. All processes were quality assured by double coding of queries, and of a random sample of 10%.

From 44 studies which appeared relevant (by title and abstract), we ordered full texts of those which appeared to concern either UK views and experiences of service users and their carers or impact studies of were of acceptable methodological quality On receiving and reviewing the full texts, we found one UK qualitative study of moderate quality looking at inter-professional working in social care planning and delivery published by the National Institute for Health Research (NIHR) . We also found a single systematic review published by the Health Technology Assessment (HTA) NHS R&D HTA Programme, on respite interventions.

The included studies were critically appraised using NICE tools for appraising different study types, and the results tabulated. Further information on critical appraisal is given in the introduction at the beginning of Section 3. Study findings were extracted into findings tables. For full critical appraisal and findings tables, see Appendix B.

Narrative summary

One systematic review (Mason 2007, +/+), was found relevant to this topic. This review of international research included 42 studies of which 20 were other systematic reviews, 22 were effectiveness studies (10 RCTs, 7 controlled and 5 uncontrolled), and 5 economic evaluations. Most of the included studies came from USA, with a few from UK and Australia.

Types of community-based respite for carers identified in the review included:

- Adult day care (rehabilitative; day-care providing case management range of services, including healthcare; special purpose day-care);
- host family, providing a 5-7 day break for both carer and service user;
- in-home respite (in some cases from volunteers, such as Marie Curie/hospice care, serving cancer patients;
- institutional respite (a single study on temporary admissions to nursing home);
- video respite (video respite tape, to be used by carer to combat Attention Deficit (unclear if the tape content was personalised - "Favourite Things").

Topics important to carers also drew on material identified as views of carers in relation to questions on approaches to care planning and delivery (2.1.1) & service delivery (2.1.2).

Impact of carer breaks on outcomes

No reliable evidence was found that respite either benefits or adversely affects care recipients, or that it delays entry to residential care. In-home respite (short stay 56%, overnight 48%) was more popular than either day care (28%) or overnight institutional respite (24%), and there were concerns that loved ones placed outside their familiar surroundings might experience deterioration and/or distress.

Cost-effectiveness of carer breaks

The authors conclude that the literature is unable to inform UK policy due to limitations in the evidence base: firstly, the one UK economic evaluation was not a randomised control trial, and secondly, the other non-UK studies – whether randomised or quasi-experimental – were limited in terms of their documentation of service use and inadequate reporting. Furthermore, none of the studies measured health-related quality of life.

Aspects of the care and support process that are important to older people and carers

Goodman et al (2011) was a study of moderate quality (+/+) using a multi-method approach. The focus was on inter-professional working (IPW) at all stages of care planning and delivery. The study concluded that older people and their carers define effectiveness of IPW by the processes of care as well as the outcomes. Timeliness, completion of actions as promised and perceived expertise, as well as the quality of relationships was considered important.

Evidence statements

ES43	**Impact of carer breaks on outcomes** There is good quality evidence from a systematic review (Mason et al, 2007 +/+) which relies on studies published before 2004 that carer breaks (referred to in the literature as carer respite) for carers of frail elderly people may have a small positive effect upon carers in terms of burden and mental or physical health. No reliable evidence was found that respite either benefits or adversely affects care recipients, or that it delays entry to residential care. In-home respite (short stay 56%, overnight 48%) was more popular than either day care (28%) or overnight institutional respite (24%), and there were concerns that loved ones placed outside their familiar surroundings might experience deterioration and/or distress
ES45	**Cost-effectiveness of carer breaks** There is one good quality systematic review (Mason et al, 2007 +/+) that identified four non-UK economic evaluations and one UK economic evaluation comparing day care with usual care in providing carers with respite (carer breaks). The authors conclude that the literature is unable to inform UK policy due to limitations in the evidence base: firstly, the one UK economic evaluation was not a randomised control trial, and secondly, the other non-UK studies – whether randomised or quasi-experimental – were limited in terms of their documentation of service use and inadequate reporting. Furthermore, none of the studies measured health-related quality of life.
ES44	**Aspects of the care and support process that are important to older people and carers** There is good evidence from two studies (Goodman et al, 2012, +/+; Granville et al, 2010, +) that, for older people and their carers, the process of care is as important as the outcomes. Older people want continuity of care in order to develop relationships with paid carers, a named key person to coordinate care, co-production of care with users and carers, and good links with the wider system of health and social care, allowing effective response at times of crisis.

Included studies for these review questions

Goodman C, Drennan V, Manthorpe J, et al (2012) A study of the effectiveness of interprofessional working for community-dwelling older people - Final Report. National Institute for Health Research (NIHR).

Mason A, Weatherly H, Spilsbury K (2007): A systematic review of the effectiveness and cost-effectiveness of different models of community-based respite care for frail older people and their carers.

3.7 *Evidence to recommendations*

This section of the guideline details the links between the guideline recommendations, the evidence reviews, expert witness testimony and the Guideline Committee discussions. The information is presented in a series of linking evidence to recommendations (LETR tables).

Linking Evidence to Recommendations (LETR) tables

Topic/section heading	**Identifying and assessing social care needs**
Recommendations	**Older people with multiple long-term conditions** 1.1.1 Health and social care 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 social need care and support. **(Guideline Committee Consensus)** 1.1.2 Consider referral for a one-time assessment by a geriatrician or old-age psychiatrist to guide social care planning for older people with multiple long-term conditions: - whose social care needs are likely to increase to the point where they are assessed as ‘substantial’ or ‘critical’ - who may need to go into a nursing or care home. **(ES12)** **All older people, including those with multiple long-term conditions** 1.1.3 When planning and undertaking assessments, health and social care practitioners should: - always involve the person and their carer (if appropriate) - take into account the person's strengths, needs and preferences - involve all relevant practitioners, to address all of the person's needs (including emotional, psychological, social, personal, sensory, communication and environmental care needs, as well as health 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 via an advocate - give people information about the options for services available to them, the cost of services and how they can be paid for. **(ES6, Guideline Committee consensus)** 1.1.4 If the person’s carer has specific social care needs of their own, refer them to the local authority for a needs assessment in their own right. **(Guideline Committee consensus)** 1.1.5 Ask the person if they have caring responsibilities and, if so, ensure they are offered a carer's assessment. **(Guideline Committee consensus)**

Research recommendations	3.2 Which models of service delivery are effective and cost-effective for older people with multiple long-term conditions?
Review questions	**Main review question** Q 2.1.1 What are the effects (benefits and harms) of different types of assessment and planning of personalised care on outcomes for older people with multiple long-term conditions and their carers? Other relevant review questions Q.1.1.1. What are the views and experiences of older people with multiple long-term conditions and their carers, of the social care services they receive? Q.1.1.2. Do service users and carers consider that their care is (a) personalised; (b) integrated or coordinated with healthcare? Q.1.1.2. What do they think works well and what needs to change? Q.1.2.1. What are the views and experiences of practitioners, managers and commissioners in health and social care who procure, manage or deliver care to older people with multiple long-term conditions, in community and care home settings? Q.1.2.2. What do they think works well, and what needs to change?
Quality of evidence	Most of the evidence for this topic of assessment and care planning was of moderate quality, and was largely based on the views and experiences of service users, their carers and practitioners. There was one high quality systematic review but the majority of the included studies in the review were largely outside of the date inclusion criteria and may be out of date in terms of current practice. None of the studies compared the effectiveness of different models of assessment and care planning and there was a lack of evidence of social care contribution to personalised care in assessment and care planning. The quality of research evidence in respect of users' and carers' views of services is of moderate to good quality. There was consistency across studies in relation to the issues of communication between professionals, service users and their carers care and barriers to a shared approach to assessment and care planning.
Relative value of different outcomes	The absence of effectiveness studies relevant to this question meant that it was not possible to ascertain and compare the relative value of outcomes associated with different models of assessment.
Trade-off between benefits and harms	These recommendations were informed predominantly by data on views and the Guideline Committee's experiences. Views data and the Guideline Committee's experience indicated that assessment which does not take into account 'the whole person' may result in a care plan which does not meet their needs.
Economic considerations	The economic evidence in relation to cost-effective models of service delivery are based on three non-UK studies: Australia (ES22), US, (ES17), and Canada (ES17). The economist conducted additional bibliographic searches that identified an additional 7 economic evaluations but these studies are older it is

	unclear whether they are relevant for informing current practice and recommendations. Of the studies identified from the additional searches, there was only 1 UK study (ES12) and remaining studies came from the USA or Italy (ES17). The internal validity of most studies was of moderate quality or higher quality (+ or ++) and only one study was rated as having low quality (-). Please refer to the evidence statements regarding the applicability of the economic evaluations' in informing recommendations for UK practice. The studies are grouped into four main model types and even then interventions are not completely identical. Further economic analysis, as agreed in the Economic Plan, was carried on one particular model of assessment, care planning, and service delivery (from Counsell 2007, ++/+, USA). A cost-utility and cost-consequence analysis was performed, along with sensitivity analyses, to test the likelihood of the intervention being cost-effective in the English context. This model was an outpatient, multidisciplinary geriatric team (composed of a geriatrician, pharmacist, physical therapist, mental health social worker, community-based services liaison, practice manager and administrative assistant) plus case management (performed jointly by an advanced practice nurse and social worker). While social care economic evaluation does not have an established outcome measure nor a threshold on which to determine whether interventions are cost-effective, the GDG concluded that the intervention is likely to be cost-effective at the £20,000 to £30,000 per QALY threshold based on the results of the sensitivity analysis and using evidence of improved outcomes identified in the cost-consequence analysis based on findings from additional studies. These studies found improvements or no differences in mental health, general health, activities of daily living, physical function, cognitive function, mortality, and carer outcomes. More specifically, whether or not the intervention is cost-effective depends to a large extent on the length of period considered, and in particular on whether the intervention would lead to improvements in quality of life beyond the period of the intervention. Whether or not this is realistic will depend on whether some residual gain could be expected post-intervention due to improvements in the design of the care package associated with the improved care management arrangements.
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	**ES6 What older people want from care and support** There is good evidence from one qualitative study (Granville et al, 2010,+) that older people value the importance of living a 'normal' life, maintaining social contact with people of all generations, having money and knowing their rights, and the ability to choose meaningful activities. **(RECs 1.1.2 and 1.1.5)** **ES11 Health and social care inputs into social care assessment and planning** This evidence statement is based on one good quality UK study measured over a 6-month period (Challis 2004) [+/++]. Findings from this study indicate that from the perspective of the NHS, personal social services, and individuals' private costs, the

	intervention is cost-effective, from the perspective of NHS, social services and individuals, for community-dwelling older people who may have ‘substantial’ or ‘critical’ social care needs or be at risk of nursing or care home placement.. The intervention is a one-time healthcare assessment by a geriatrician or old age psychiatrist to guide the social care manager in social care planning. **(REC 1.1.2)**
Other considerations	The detailed recommendation on how the assessment process (1.1.2) should be delivered aimed to emphasise and build on Care Act guidance specifically by aiming it at all practitioners involved in the assessment process, and by emphasising explicitly: - the importance of a multidisciplinary approach to assessment (an aspect which was strengthened by the economic analysis) to ensure health, social care and wider needs are a considered by the most appropriate professionals from the outset. - the importance of seeing the person as a whole, within the context of the life they want to lead and designing support accordingly (rather than seeing them as a collection of symptoms or conditions to be ‘treated’). - that the person and their carer or advocate should be central to, and involved in the whole assessment process. Committee members gave a range of examples that illustrated how people can be excluded or marginalised during assessment, and the negative impact this can have on their experience of care and the package of support available to them. In considering, based on their experiences, people’s variable experience of assessment and planning, they also agreed to emphasise, as distinct recommendations (1.1.5 and 1.1.6): - the rights of carers to an independent assessment (noting particularly that older people’s carers are frequently other older people with complex needs of their own that may not have been addressed). - - people’s legal right to a copy of the planning and assessment documentation. Members gave examples illustrating that this does not always happen.

Topic/section heading	Identifying and assessing social care needs Telecare to support older people with multiple long-term conditions
Recommendations	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 manage their conditions, potential benefits, risks and costs. **(ES 29)** 1.1.7 The leading practitioner should consider, in discussion with the person, whether a demonstration of telecare equipment would help them to make an informed decision about it. **(ES29, Guideline Committee consensus)**
Research recommendations	The Guideline Committee did not identify this as a priority area to make research recommendations on.
Review questions	**Main review question** Q 2.1.1 What are the effects (benefits and harms) of different types of assessment and planning of personalised care on outcomes for older people with multiple long-term conditions and their carers? Other relevant review questions Q.1.1.1. What are the views and experiences of older people with multiple long-term conditions and their carers, of the social care services they receive? Q.1.1.2. Do service users and carers consider that their care is (a) personalised; (b) integrated or coordinated with healthcare? Q.1.1.2. What do they think works well and what needs to change? Q.1.2.1. What are the views and experiences of practitioners, managers and commissioners in health and social care who procure, manage or deliver care to older people with multiple long-term conditions, in community and care home settings? Q.1.2.2. What do they think works well, and what needs to change?
Quality of evidence	Most of the evidence for this topic of assessment and care planning was of moderate quality, and was largely based on the views and experiences of service users, their carers and practitioners. There was one high quality systematic review but the majority of the included studies in the review were largely outside of the date inclusion criteria and may be out of date in terms of current practice. None of the studies compared the effectiveness of different models of assessment and care planning and there was a lack of evidence of social care contribution to personalised care in assessment and care planning. The quality of research evidence in respect of users' and carers' views of services is of moderate to good quality. There was consistency across studies in relation to the issues of communication between professionals, service users and their carers care and barriers to a shared approach to assessment and care planning.

Relative value of different outcomes	The absence of effectiveness studies relevant to this question meant that it was not possible to ascertain and compare the relative value of outcomes associated with different models of assessment.
Trade-off between benefits and harms	In discussing telecare based on their experience, the Guideline Committee highlighted some of the complexities related to defining outcomes. For example, they noted the potential benefits of telecare in terms of promoting people's independence but also that reduced contact (e.g. if telecare is used as a substitution for face-to-face time) may be disadvantageous for the person. They also noted that many older people may have to fund their own telecare.
Economic considerations	No directly applicable economic evidence was identified. The guideline committee were, however, mindful of potential costs and resource use when making the recommendations.
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	**ES29 Information about telecare** There is good evidence (May 2011, ++) that potential and actual users of telecare services are not well-informed about their purposes, and how they do or might support person-centred care within an individual care plan. **(RECs 1.1.6 and 1.1.7)**
Other considerations	Based on their experience, the Guideline Committee thought that the assessment stage would be the right time to discuss telecare with people to ensure they are informed about what is available and how it might help them achieve the outcomes identified in their support plan. They discussed the rapid pace of technological change and the fact that many older people may be very unfamiliar with different telecare devices, or anxious about using them. They agreed that offering people the option to test equipment before committing to it may therefore be useful.

2789

Topic/section heading	**Care planning**
Recommendations	**Older people with multiple long-term conditions** 1.2.1 Ensure that older people with multiple long-term conditions have a single, named care coordinator who acts as their first point of contact. The named care coordinator should: - be involved in the assessment process - liaise and work with all health and social care services, including those provided by the voluntary and community sector. **(ES4, ES5)** 1.2.2 Ensure care plans are tailored to the individual and focused on ensuring the person has choice and control. Offer the person the opportunity to: - have a range of needs addressed (including emotional, psychological, social, personal, sensory, communication and environmental care needs, as well as health needs) - be supported to minimise the impact of health problems, including continence needs, -if appropriate identify how they can be helped to manage their own care and support, which may include information and support to manage their condition/s, taking part in their preferred activities, hobbies and interests - ensure that care plans cover leisure and social activities outside and inside the home, mobility and transport needs, adaptations to the home and any support needed to use them. **(ES6, ES7, ES10, ES39 and Guideline Committee consensus)** 1.2.3 Discuss medicines management as part of care planning. **(GC consensus)** 1.2.4 Write any medicines management requirements into the care plan including: - The purpose of, and information on medicines - The importance of timing and implications of non-adherence **(ES25 and Guideline Committee consensus)** 1.2.5 Develop care plans in collaboration with GPs and representatives from other agencies that will be providing support to the person in the care planning process. **(ES17, ES22)** 1.2.6 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 multiple long-term conditions. **(ES4, ES17, ES22 and Guideline consensus)**

	1.2.7 Ensure older people with 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 the different mechanisms they can use to manage the budget available to them, including information about any impact different funding mechanisms may have on carers - 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 those whose care is publicly funded - ensuring that carers' needs are taken fully into account. **(Guideline Committee consensus)**
Research recommendations	The Guideline Committee did not identify this as a priority area to make research recommendations on.
Review questions	Main review question Q 2.1.1 What are the effects (benefits and harms) of different types of assessment and planning of personalised care on outcomes for older people with multiple long-term conditions and their carers? Other relevant review questions Q.1.1.1. What are the views and experiences of older people with multiple long-term conditions and their carers, of the social care services they receive? Q.1.1.2. Do service users and carers consider that their care is (a) personalised; (b) integrated or coordinated with healthcare? Q.1.1.2. What do they think works well and what needs to change? Q.1.2.1. What are the views and experiences of practitioners, managers and commissioners in health and social care who procure, manage or deliver care to older people with multiple long-term conditions, in community and care home settings? Q.1.2.2. What do they think works well, and what needs to change?
Quality of evidence	Most of the evidence for this topic of assessment and care planning was of moderate quality, and was largely based on the views and experiences of service users, their carers and practitioners. There was one high quality systematic review but the majority of the included studies in the review were largely outside of the date inclusion criteria and may be out of date in terms of current practice. None of the studies compared the effectiveness of different models of assessment and care planning and there was a lack of evidence of social care contribution to personalised care in assessment and care planning.

	The quality of research evidence in respect of users' and carers' views of services is of moderate to good quality. There was consistency across studies in relation to the issues of communication between professionals, service users and their carers and barriers to a shared approach to assessment and care planning.
Relative value of different outcomes	The absence of effectiveness studies relevant to this question meant that it was not possible to ascertain and compare the relative value of outcomes associated with different models of care planning.
Trade-off between benefits and harms	These recommendations were informed predominantly by data on views and the Guideline Committee's experiences. Views data and the Guideline Committee's experience indicated that assessment which does not take into account 'the whole person' may result in a care plan which does not meet their needs.
Economic considerations	The economic evidence (ES18, ES24) and the analysis conducted by the NCCSC economist (Appendix C) supported the need for an integrated approach to care, involving a community-based health or social care practitioner with a coordinating role who also ensures multidisciplinary assessment links to care planning. Further economic analysis, as agreed in the Economic Plan, was carried on one particular model of assessment, care planning, and service delivery (from Counsell 2007, ++/+, USA). A cost-utility and cost-consequence analysis was performed, along with sensitivity analysis, to test the likelihood of the intervention being cost-effective in the English context. This model was an outpatient, multidisciplinary geriatric team (composed of a geriatrician, pharmacist, physical therapist, mental health social worker, community-based services liaison, practice manager and administrative assistant) plus case management (performed jointly by an advanced practice nurse and social worker). While social care economic evaluation does not have an established outcome measure nor a threshold on which to determine whether interventions are cost-effective, the GDG concluded that the intervention is likely to be cost-effective at the £20,000 to £30,000 per QALY threshold based on the results of the sensitivity analysis and using evidence of improved outcomes identified in the cost-consequence analysis based on findings from additional studies. These studies found improvements or no differences in mental health, general health, activities of daily living, physical function, cognitive function, mortality, and carer outcomes. More specifically, whether or not the intervention is cost-effective depends to a large extent on the length of period considered, and in particular on whether the intervention would lead to improvements in quality of life beyond the period of the intervention. Whether or not this is realistic will depend on whether some residual gain could be expected post-intervention due to improvements in the design of the care package associated with the improved care management arrangements.

Evidence statements – numbered evidence statements from which the recommendation(s) were developed	**ES4: Models of interdisciplinary working** There is moderate quality evidence (Trivedi, 2013, +/-, Goodman, 2012, +/+) that inter-professional working (IPW) may be cost-effective but does not show clearly that any particular model (e.g. care management, collaborative working or integrated teams) delivers better outcomes. User and carers consistently value aspects of integrated service delivery which foster confidence in the reliability of services, continuity of paid carers, user and carer involvement in planning and reviewing care, services to support carers and the ability of services to respond effectively at times of crisis. There is also qualitative evidence that inter-professional working can reduces carer burden.. **(RECS 1.2.1, 1.2.6)** **ES5: Aspects of the care and support process that are important to older people and carers** There is good evidence from two studies (Goodman et al, 2012, +/+; Granville et al, 2010,+) that, for older people and their carers, the process of care is as important as the outcomes. Older people want continuity of care in order to develop relationships with paid carers, a named key person to coordinate care, co-production of care with users and carers, and good links with the wider system of health and social care, allowing effective response at times of crisis**. (REC 1.2.1)** **ES6 What older people want from care and support** There is good evidence from one qualitative study (Granville et al, 2010,+) that older people value the importance of living a 'normal' life, maintaining social contact with people of all generations, having money and knowing their rights, and the ability to choose meaningful activities. **(REC 1.2.2.)** **ES7: Older people's experience of choice and control in care homes** There is good evidence from one qualitative study (Granville et al, 2010,+) that older people living in care homes feel they are required 'to fit in' at the expense of their choice and control, personal identity and preferences, while those in the community felt they lacked choice and control over the amount and content of homecare services they could have, particularly when other stakeholders clearly felt that the residential option was preferable. **(REC 1.2.2)** **ES10: Importance of support that extends beyond personal care** There is moderately good evidence (Challis, 2010b, +/-) that service users, especially those living alone without an unpaid carer, want services, whether organised by care management or not, to deliver different types of essential support, prioritising the basic needs for shopping, laundry, housework and other practical needs over personal care. **(REC 1.2.2)**

	ES17: Outpatient geriatric multidisciplinary evaluation and management plus case management This evidence statement is based on the findings of two studies of excellent quality controlled trials from Canada (++/+) (Beland 2006) and the US (++/ +) (Counsell 2007), three good quality controlled trials (+,/+) two of which were from the US (Boult 2001; Toseland 1997) and one from Italy (Bernabei 1998), and one low quality before and after study (-/+) from Italy (Landi 1999). Taken together, there is moderate evidence from six international studies of mixed quality that the coordination of health and social care services through the use of case management plus outpatient multidisciplinary health and social care geriatric teams can improve a range of service user health and social care outcomes while reducing or having no changes on the use of acute care services with mixed impacts on health and social care resource use. It is important to note that not all of the same outcomes were measured, and where there were overlaps, in some cases, findings were equivocal (improvements or no differences) but none of the findings indicated worse outcomes. **(REC 1.2.5 and 1.2.6)** **ES22 GP-centred models for service delivery (with case management)** One good quality multi-site [+/+] non-UK study (Battersby, 2007) tested the addition of service coordinators (a social worker, allied health professional, or nurse) to GP-working, in combination with patient-directed goals in the health and social care assessment and care planning process. The intervention was also coupled with changes in funding mechanisms by switching from fee-for-service to a 12-month care plan funded by pooling resources across acute and community health and social care services. The sample covered community-dwelling older adults over the age of 60, with a range mean age between 61 to 74 years old across the four study sites and varying numbers of chronic conditions. The results show that the intervention is associated with improvements in outcomes and increases in costs from the perspective of health and social care services. However the applicability of findings is limited by potentially serious limitations due to some issues in the comprehensiveness in the collection of resource use (due to issues with administrative databases). Furthermore, there are issues due to differences in institutional contexts, unit costs, and issues of relevance as findings are based on older data. **(RECs 1.2.5 and 1.2.6).** **ES25 Medication adherence** There is moderate qualitative evidence (Banning 2008, +) that older people who do not adhere to their prescribed medication may have both intentional and non-intentional reasons for not doing so. The evidence suggests that shared decision-making between clinicians and patients on what to prescribe, aided by better explanations of effects and clearer instruction, could increase older people's ability and willingness to take their prescribed medication. **(REC 1.2.4)**

	ES27 Transport availability There is evidence of moderate quality (Challis, 2010b, +/-) that frailty of older people may reduce their ability to self-manage their health conditions, as well as their personal and household care tasks. Availability of transport may be of particular importance in maintaining independence in the community. **(REC 1.2.2)** **ES 39: Older people's perceptions of social isolation** There is good evidence from a good quality study (Blickem, 2013,+), that people valued the opportunity to meet with people who shared similar frustrations and needs because of their health: support from other older people with LTCs could be a 'forum for exchange of emotional and practical support' (52). The groups also provided additional services for the socially isolated in that they could help access transport services, advice on welfare benefits 'Linkage to these resources through the groups was described as a lifeline to help which otherwise participants struggled to know how access.' (52). There is evidence from one good study (Granville, 2010,+) that older people also want diverse opportunities for social participation with people of different ages and interests as in ‘normal life’, so day centres (for example) were not necessarily an adequate response. Some people said they wanted more support to carry out activities such as shopping and going to the pub as opportunities to participate in ‘normal’ life. **(REC 1.2.2)**
Other considerations	The recommendations here drew on views studies of service users and carers, economic evidence and analysis and a small amount of evidence of impact. It was supplemented by expert witness testimony and expertise from the Guideline Committee. The Guideline Committee consensus was that there should be a named coordinator to proactively navigate the various services for health and social care which was likely to be challenging for older people with multiple long terms conditions. This was a theme that was raised in several Guideline Committee meetings (4,5,7 & 9) and was also relevant to issues around enabling self-care (including medicines management) and undertaking assessments for care planning. The economic evidence supported the use of both service integration and involvement of key professionals, including GPs.

Topic/section heading	**Care Planning** **Stakeholder involvement in care planning**
Recommendations	All older people, including those with multiple long-term conditions 1.2.8 Named care coordinators should offer the older 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, to recognise that people want to do different things with their lives at different times. (see also section 1.5) **(ES22 and Guideline Committee consensus)** 1.2.9 Ensure that care plans enable people 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 **(ES17, ES21, ES22 and Guideline Committee consensus)** 1.2.10Ensure that care plans include ordinary activities outside the home (whether that is a care home or the person's own home) that reduce isolation, for example, shopping or visiting public gardens and build confidence by being involved in their wider community, as well as with family and friends (see also section 1.6). **(Guideline Committee consensus)** 1.2.11 Named care coordinators should ensure the person, their carers or advocate and the care practitioners jointly own the care plan and sign it to indicate they agree with it. **(ES4, ES5 and Guideline Committee Consensus)** 1.2.12 Named care coordinators should review and update care plans regularly to reflect changing needs, and at least annually (in line with the Care Act). Record the results of the review in the care plan, along with any changes made. **(Guideline Committee consensus)**
Research recommendations	The Guideline Committee did not identify this as a priority area to make research recommendations on.

Review questions	**Main review question** Q 2.1.1 What are the effects (benefits and harms) of different types of assessment and planning of personalised care on outcomes for older people with multiple long-term conditions and their carers? **Other relevant review questions** Q.1.1.1. What are the views and experiences of older people with multiple long-term conditions and their carers, of the social care services they receive? Q.1.1.2. Do service users and carers consider that their care is (a) personalised; (b) integrated or coordinated with healthcare? Q.1.1.2. What do they think works well and what needs to change? Q.1.2.1. What are the views and experiences of practitioners, managers and commissioners in health and social care who procure, manage or deliver care to older people with multiple long-term conditions, in community and care home settings? Q.1.2.2. What do they think works well, and what needs to change?
Quality of evidence	Most of the evidence for this topic of assessment and care planning was of moderate quality, and was largely based on the views and experiences of service users, their carers and practitioners. There was one high quality systematic review but the majority of the included studies in the review were largely outside of the date inclusion criteria and may be out of date in terms of current practice. None of the studies compared the effectiveness of different models of assessment and care planning and there was a lack of evidence of social care contribution to personalised care in assessment and care planning. The quality of research evidence in respect of users' and carers' views of services is of moderate to good quality. There was consistency across studies in relation to the issues of communication between professionals, service users and their carers and barriers to a shared approach to assessment and care planning.
Relative value of different outcomes	The absence of effectiveness studies relevant to this question meant that it was not possible to ascertain and compare the relative value of outcomes associated with different models of care planning.
Trade-off between benefits and harms	These recommendations were informed predominantly by data on views and the Guideline Committee’s experiences. Views data and the Guideline Committee’s experience indicated that assessment which does not take into account ‘the whole person’ may result in a care plan which does not meet their needs.
Economic considerations	The economic evidence and analysis supported the need for an integrated approach to care, involving a community-based health or social care practitioner with a coordinating role who also ensures multidisciplinary assessment links to care planning. This is supported by economic evidence (ES18, ES22, ES24). This is also supported by the analysis conducted by the NCCSC

	economist (Appendix C). Further economic analysis, as agreed in the Economic Plan, was carried on one particular model of assessment, care planning, and service delivery (from Counsell 2007, ++/+, USA). A cost-utility and cost-consequence analysis was performed, along with sensitivity analysis, to test the likelihood of the intervention being cost-effective in the English context. This model was an outpatient, multidisciplinary geriatric team (composed of a geriatrician, pharmacist, physical therapist, mental health social worker, community-based services liaison, practice manager and administrative assistant) plus case management (performed jointly by an advanced practice nurse and social worker). While social care economic evaluation does not have an established outcome measure nor a threshold on which to determine whether interventions are cost-effective, the GDG concluded that the intervention is likely to be cost-effective at the £20,000 to £30,000 per QALY threshold based on the results of the sensitivity analysis and using evidence of improved outcomes identified in the cost-consequence analysis based on findings from additional studies. These studies found improvements or no differences in mental health, general health, activities of daily living, physical function, cognitive function, mortality, and carer outcomes. More specifically, whether or not the intervention is cost-effective depends to a large extent on the length of period considered, and in particular on whether the intervention would lead to improvements in quality of life beyond the period of the intervention. Whether or not this is realistic will depend on whether some residual gain could be expected post-intervention due to improvements in the design of the care package associated with the improved care management arrangements.
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	**ES4: Models of interdisciplinary working** There is moderate quality evidence (Trivedi, 2013, +/-, Goodman, 2012, +/+) that inter-professional working (IPW) may be cost-effective but does not show clearly that any particular model (e.g. care management, collaborative working or integrated teams) delivers better outcomes. User and carers consistently value aspects of integrated service delivery which foster confidence in the reliability of services, continuity of paid carers, user and carer involvement in planning and reviewing care, services to support carers and the ability of services to respond effectively at times of crisis. There is also qualitative evidence that inter-professional working can reduces carer burden. **(REC 1.2.11)** **ES5 Aspects of the care and support process that are important to older people and carers** There is good evidence from two studies (Goodman et al, 2012, +/+; Granville et al, 2010,+) that, for older people and their carers, the process of care is as important as the outcomes. Older people want continuity of care in order to develop relationships with paid carers, a named key person to coordinate care, co-production of care with users and carers, and good links with the wider system of health and social care, allowing effective response at times of crisis. **(REC 1.2.11)**

ES17 Outpatient geriatric multidisciplinary evaluation and management plus case management

This evidence statement is based on the findings of two studies of excellent quality controlled trials from Canada (++/+) (Beland 2006) and the US (++/ +) (Counsell 2007), three good quality controlled trials (+,/+) two of which were from the US (Boult 2001; Toseland 1997) and one from Italy (Bernabei 1998), and one low quality before and after study (-/+) from Italy (Landi 1999). Taken together, there is moderate evidence from six international studies of mixed quality that the coordination of health and social care services through the use of case management plus outpatient multidisciplinary health and social care geriatric teams can improve a range of service user health and social care outcomes while reducing or having no changes on the use of acute care services with mixed impacts on health and social care resource use. It is important to note that not all of the same outcomes were measured, and where there were overlaps, in some cases, findings were equivocal (improvements or no differences) but none of the findings indicated worse outcomes. **(REC 1.2.9)**

ES21: GP-centred models for service delivery (without case management)

One low quality US study [-/+] (Sommers 2000, N=543) tested the addition of a nurse and social worker to a GP practice to assist in comprehensive health and social care assessment, care planning and service provision (self-management, education on self-care and referral) compared to usual GP care. The sample included community-dwelling older adults over aged 65 with at least 2 chronic conditions, few restrictions in activities of daily living, and at least one restriction in instrumental activities of daily living. Findings indicate that the intervention leads to improvements in outcomes alongside reductions in the use of acute care services, small increases in community health care services, and no changes in use of nursing or care home services The economic evaluation was presented as a cost-consequence analysis (presenting changes in costs alongside changes in outcomes). This economic evaluation is only partially applicable in determining whether the intervention is cost-effective in the UK context due to differences in institutional context, unit costs, and additional issues of relevance as findings are based on older data. Altogether though, the quality of the economic evaluation was moderate due to some issues of unclear reporting in the calculation of net costs but had good reporting quality in changes in all relevant health and social care resource use. **(REC 1.2.9)**

ES22: GP-centred models for service delivery (with case management)

One good quality multi-site [+/+] non-UK RCT (Battersby, 2007) tested the addition of service coordinators (a social worker, allied health professional, or nurse) to GP-working, in combination with patient-directed goals in the health and social care assessment and care planning process. The intervention was also coupled with changes in funding mechanisms by switching from fee-for-service

	to a 12-month care plan funded by pooling resources across acute and community health and social care services. The sample covered community-dwelling older adults over the age of 60, with a range mean age between 61 to 74 years old across the four study sites and varying numbers of chronic conditions. The results show that the intervention is associated with improvements in outcomes and increases in costs from the perspective of health and social care services. However the applicability of findings is limited by potentially serious limitations due to some issues in the comprehensiveness in the collection of resource use (due to issues with administrative databases). Furthermore, there are issues due to differences in institutional contexts, unit costs, and issues of relevance as findings are based on older data. **(RECs 1.2.8, 1.2.9)**
Other considerations	These recommendations drew on views studies of service users and carers and was supplemented by economic evidence, expert witness testimony and expertise from the Guideline Committee. The Guideline Committee consensus that there should be a named coordinator to proactively navigate the various services for health and social care which was likely to be challenging for older people with multiple long terms conditions. This was a theme that was raised in several Guideline Committee meetings (4,5,7 & 9) and was also relevant to issues around enabling self-care and undertaking assessments for care planning.

Topic/section heading	**Supporting carers**
Recommendations	All older people, including those with multiple long-term conditions 1.3.1 In line with the Care Act local authorities must offer carers an individual assessment of their needs. Ensure this assessment: - takes into account carers' views about services that could help them maintain their caring role and live the life they choose - involves cross-checking any assumptions the person has made about the support their carer will provide **(Guideline Committee consensus)** 1.3.1 Check what impact the carer's assessment is likely to have on the person’s care plan. **(Guideline Committee consensus)** 1.3.2 Support carers to explore the possible benefits of personal budgets and direct payments, and how they might be used for themselves and for the person they care for. Help them to administer their budget, so that their ability to support the person's care is not undermined by anxiety about managing the process. **(Guideline Committee consensus)**

	1.3.3 Consider helping carers access support services and interventions, such as carer breaks. **(ES44 and Guideline Committee consensus)**
Research recommendations	The Guideline Committee did not identify this as a priority area to make research recommendations on
Review questions	3.2 Carer support: How should services work with and support carers of older people with multiple long-term conditions (who may have long-term conditions themselves)?
Quality of evidence	The search identified only one systematic review. The rating of the study was affected because it was outside the remit dates for this guideline. All the studies included in the review were published before 2003. Because the search did not identify any UK focused or high quality studies in relation to this question. The review included 42 studies, mainly from the USA with some from the UK and Australia. The criteria for inclusion on age matched the one for this guideline and the focus was on ‘frail’ older people, which was assumed would include those with multiple long term conditions. All the included studies were effectiveness studies and had strong methodologies.
Relative value of different outcomes	Given that only one paper was reviewed for this question it is not possible to compare outcomes of different approaches to carer support. The study focuses on community based respite for carers including, adult day care, host families, in-home respite, institutional and video respite. The study is critical of the ways that many of the studies measured outcomes and none of the studies were powered on the basis of carer outcomes. In general the review reports that many of the trials it reviewed only found modest outcomes for carers and not everyone benefitted. Some of the studies provided qualitative evidence about carers experiences of respite care. Some expressed satisfaction with the services and also talked about what options for respite they preferred.
Trade-off between benefits and harms	The Guideline Committee discussed the potential trade-offs between the benefits of respite for carers and the harms for older people who may find respite a negative experience. Guideline Committee members also said that respite could sometimes be stressful for the carer and so might not be as beneficial as other options.
Economic considerations	See evidence statement below.
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	**ES44: Cost-effectiveness of carer breaks** There is one good quality systematic review (Mason et al, 2007 +/+) that identified four non-UK economic evaluations and one UK economic evaluation comparing day care with usual care in providing carers with respite (carer breaks). The authors conclude that the literature is unable to inform UK policy due to limitations in the evidence base: firstly, the one UK economic evaluation was not a randomised control trial, and secondly, the other non-UK studies – whether randomised or quasi-

	experimental – were limited in terms of their documentation of service use and inadequate reporting. Furthermore, none of the studies measured health-related quality of life.
Other considerations	The Guideline Committee discussed evidence on carer assessment at length and agreed that, in spite of gaps in, and limitations of the evidence, this was an important area on which to make recommendations. They agreed how to build on the mandatory requirements of the Care Act by specifying how carers assessments could be delivered, and also agreed a high-level recommendation about the need to consider possible options in terms of support for carers, to emphasise the importance of this issue. They also extrapolated from other views evidence related to the importance of information and signposting - particularly to enable people to manage their finances and know their entitlements - to develop a recommendation related to funding mechanisms.

Topic/section heading	**Integrating health and social care planning**
Recommendations	**Older people with multiple long-term conditions** 1.4.1Commissioners should build into service specifications and contracts the need: - to direct older people with multiple long-term conditions to different services - for seamless referrals between practitioners. **(ES3, ES8 and Guideline Committee consensus)** 1.4.2 Make provision for community-based multidisciplinary support for older people with multiple long-term conditions. The health and social care practitioners involved in the team might include, for example, a community pharmacist, physical or occupational therapist, a mental health social worker or psychiatrist, and a community-based services liaison. (ES17) 1.4.3 Health and social care practitioners should inform the named care coordinator if the person has needs that they cannot meet. **(ES3 and Guideline Committee consensus)** 1.4.4 Named care coordinators should record any needs the person has that health and social care practitioners cannot meet. Discuss and agree a plan of action to address these needs with the person and their carer. **(ES3 and Guideline Committee consensus)**
Research recommendations	The Guideline Committee did not identify this as a priority area to make research recommendations on.

Review questions	**Main review question** Q 2.1.1 What are the effects (benefits and harms) of different types of assessment and planning of personalised care on outcomes for older people with multiple long-term conditions and their carers? **Other relevant review questions** Q.1.1.1. What are the views and experiences of older people with multiple long-term conditions and their carers, of the social care services they receive? Q.1.1.2. Do service users and carers consider that their care is (a) personalised; (b) integrated or coordinated with healthcare? Q.1.1.2. What do they think works well and what needs to change? Q.1.2.1. What are the views and experiences of practitioners, managers and commissioners in health and social care who procure, manage or deliver care to older people with multiple long-term conditions, in community and care home settings? Q.1.2.2. What do they think works well, and what needs to change?
Quality of evidence	Most of the evidence for this topic of assessment and care planning was of moderate quality, and was largely based on the views and experiences of service users, their carers and practitioners. There was one high quality systematic review but the majority of the included studies in the review were largely outside of the date inclusion criteria and may be out of date in terms of current practice. None of the studies compared the effectiveness of different models of assessment and care planning and there was a lack of evidence of social care contribution to personalised care in assessment and care planning. The quality of research evidence in respect of users' and carers' views of services is of moderate to good quality. There was consistency across studies in relation to the issues of communication between professionals, service users and their carers care and barriers to a shared approach to assessment and care planning.
Relative value of different outcomes	The absence of effectiveness studies relevant to this question meant that it was not possible to ascertain and compare the relative value of outcomes associated with different models of assessment.
Trade-off between benefits and harms	It was not possible to ascertain trade-offs between benefits and harms of different models, however, views data and the committee's experience indicated that assessment which does not take into account 'the whole person' may result in a care plan which does not meet their needs.
Economic considerations	The economic evidence and analysis supported the need for an integrated approach to care, involving a community-based health or social care practitioner with a coordinating role who also ensures multidisciplinary assessment links to care planning. This is supported by economic evidence (ES18). This is also supported by the analysis conducted by the NCCSC

	economist (Appendix C). Further economic analysis, as agreed in the Economic Plan, was carried on one particular model of assessment, care planning, and service delivery (from Counsell 2007, ++/+, USA). A cost-effectiveness analysis was performed, along with sensitivity analysis, to test the likelihood of the intervention being cost-effective at the £20,000 to £30,000 threshold. This model was an outpatient, multidisciplinary geriatric team (composed of a geriatrician, pharmacist, physical therapist, mental health social worker, community-based services liaison, practice manager and administrative assistant) plus case management (performed jointly by an advanced practice nurse and social worker). The analysis by the NCCSC economists indicates that the intervention is likely to be cost-effective the £20,000 to £30,000 threshold. Whether or not the intervention is cost-effective depends to a large extent on the length of period considered, and in particular on whether the intervention would lead to improvements in quality of life over the third year. Under the two-year time horizon, the intervention is not cost-effective at the £20,000 threshold. Under the three-year time horizon the intervention is cost-effective at the £20,000 cost-effectiveness threshold in most scenarios. However, these results depend on the assumption of improved QALYs in the intervention group in the third year. Whether or not this is realistic will depend on whether some residual gain could be expected post-intervention due to improvements in the design of the care package associated with the improved care management arrangements.
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	**ES3 Assessment functions within case management** There is good evidence (King (2012, ++) and Challis (2010b, +/), and evidence of uncertain quality (Reilly et al, 2010, uncertain selection of studies) that assessment functions within case management might involve little continuity with care delivery and review of care plans; that nurses are overwhelmingly likely to be case managers, with little support from social workers; and that nurses without community training were likely to under-estimate the impact of social and environmental factors in improving the health of patients, and be constrained by the shortage of services to support social care needs. Assessment records were unlikely to detail the contribution and responsibilities of different practitioners. Nurse case managers were likely to act as brokers, but found it difficult to refer people onto social care services. **(RECs 1.4.1, 1.4.3, 1.4.4)** **ES8 Areas of support that older people and carers think need improving** There is good evidence (Goodman, 2012, +/+) that service users and carers want improvement in, areas of care assessment and delivery that concern the integration of health and social care practitioners, including discharge planning, GP involvement in the care delivery team, and the inability and/or unwillingness of health and social care assessors and providers to access or refer into these complementary care agencies. **(REC 1.4.1,)**

	ES17: Outpatient geriatric multidisciplinary evaluation and management plus case management This evidence statement is based on the findings of two studies of excellent quality controlled trials from Canada (++/+) (Beland 2006) and the US (++/ +) (Counsell 2007), three good quality controlled trials (+,/+) two of which were from the US (Boult 2001; Toseland 1997) and one from Italy (Bernabei 1998), and one low quality before and after study (-/+) from Italy (Landi 1999). Taken together, there is moderate evidence from six international studies of mixed quality that the coordination of health and social care services through the use of case management plus outpatient multidisciplinary health and social care geriatric teams can improve a range of service user health and social care outcomes while reducing or having no changes on the use of acute care services with mixed impacts on health and social care resource use. It is important to note that not all of the same outcomes were measured, and where there were overlaps, in some cases, findings were equivocal (improvements or no differences) but none of the findings indicated worse outcomes. **(REC1.4.2)**
Other considerations	The recommendations here drew on views studies of service users and carers, economic literature and supplementary analysis and Guideline Committee expertise. The recommendations seek to address the areas of practice where views evidence indicates people are experiencing a poor quality of care, most notably: people 'falling through the gap' when they have been referred to a service which can then not meet their needs disjoint care (or lack of ownership of care) at the point of hospital discharge the need for joined up working at both strategic and operational levels, which requires both commissioner and practitioner input.

Topic/section heading	**Delivering care in care homes** **Choice and control**
Recommendations	These recommendations for care home providers are about ensuring that care and support addresses the specific needs of older people with multiple long term conditions. 1.5.1 Identify ways to address particular nutritional and hydration requirements and ensure people have a choice of things to eat and drink and varied snacks throughout the day (including outside regular meal times). **(ES7, expert witness and Guideline Committee consensus)** 1.5.2 Identify how the care home environment and layout can encourage social interaction, activity and peer support. **(Expert witness and Guideline Committee consensus)** 1.5.3 Ensure people are physically comfortable, for example, by allowing them control over the heating in their rooms. **(ES7 and Guideline Committee consensus)**
Research recommendations	3.5. What is the most effective and cost-effective way of supporting older people with multiple long-term conditions in care homes to live as independently as possible? 3.6 What is the effectiveness and acceptability of different strategies to enable positive risk-taking in care homes?
Review questions	Q 2.1.4 What are the barriers and facilitators to the delivery of effective, personalised, integrated care for people with multiple long-term conditions in care home settings?
Quality of evidence	There were no experimental evaluations or views studies found that directly addressed questions on how to best support delivery of care in care homes. Data were extracted from evidence emerging in response to other review questions.
Relative value of different outcomes	The absence of effectiveness studies relevant to this question meant that it was not possible to ascertain and compare the relative value of outcomes associated personalised, integrated care in care homes.
Trade-off between benefits and harms	The absence of effectiveness studies relevant to this question meant that it was not possible to ascertain and compare the benefits and harms associated with different models delivery of care in care homes.
Economic considerations	There was no economic evidence to draw conclusions about the cost-effectiveness of personalised and integrated care for older people with multiple long term conditions in care homes. The guideline committee were, however, mindful of potential costs and resource use when making the recommendations.

Evidence statements – numbered evidence statements from which the recommendation(s) were developed	**ES7 Older people's experience of choice and control in care homes** There is good evidence from one qualitative study (Granville et al, 2010,+) that older people living in care homes feel they are required 'to fit in' at the expense of their choice and control, personal identity and preferences, while those in the community felt they lacked choice and control over the amount and content of homecare services they could have, particularly when other stakeholders clearly felt that the residential option was preferable. **(RECs 1.5.1, 1.5.3)**
Other considerations	The Guideline Committee supported and strengthened the finding summarised in ES7, emphasising, based on their experience and the expert witness testimony, particular aspects of choice and control they deemed important. These include: food and drink - when they discussed the very significant effect this can have on people's health and wellbeing - and their physical environment.

2801

Topic/section heading	**Delivering care in care homes** **Information**
Recommendations	Care home providers should ensure that care and support addresses the specific needs of older people with multiple long term conditions by: 1.5.4 Encourage social contact and provide opportunities for education and entertainment by: - making it easier for people to communicate and interact with others, for example reducing background noise, providing face-to-face contact with other people, using accessible signage and lighting - using a range of technologies such as IT platforms and wifi, hearing loops and TV listeners - involving the wider community in the life of the care home through befriending schemes and intergenerational projects. **(ES36, ES37, expert witness and Guideline Committee consensus)** When providing care for older people with long-term conditions, care home providers should: 1.5.5 Make publicly available information about: - tariffs for self-funded and publicly-funded care - what residents are entitled to and whether this could change if their funding status or ability to pay changes. **(Guideline Committee consensus)** 1.5.6 Make available a statement for each person using their services about what their funding pays for. **(Guideline Committee consensus)** 1.5.7 Build links with local communities, and encourage

	interaction between residents and local people of all ages and backgrounds. **(ES36, ES37, ES38, expert witness and Guideline Committee consensus)** 1.5.8 Inform people about, and direct them to, advocacy services. **(Guideline Committee consensus)** 1.5.9 Health and social care practitioners should offer older people with multiple long-term conditions: - opportunities to interact with older people with similar conditions - help to access one-to-one or group support, social media and other activities, such as dementia cafes, walking groups and specialist support groups, exercise and dance. **(ES37, ES39, ES40, expert witness and Guideline Committee consensus)**
Research recommendations	3.5 What is the most effective and cost-effective way of supporting older people with multiple long-term conditions in care homes to live as independently as possible? 3.6 What is the effectiveness and acceptability of different strategies to enable positive risk-taking in care homes?
Review questions	**Main review questions** Q 2.1.4 What are the barriers and facilitators to the delivery of effective, personalised, integrated care for people with multiple long-term conditions in care home settings? Q 2.1.6 How can older people with multiple long-term conditions living in the community or in care home settings be supported to participate in community, family and social activities? **Other relevant review questions** Q.1.1.1. What are the views and experiences of older people with multiple long-term conditions and their carers, of the social care services they receive? Q.1.1.2. Do service users and carers consider that their care is (a) personalised; (b) integrated or coordinated with healthcare? Q.1.1.2. What do they think works well and what needs to change? Q.1.2.1. What are the views and experiences of practitioners, managers and commissioners in health and social care who procure, manage or deliver care to older people with multiple long-term conditions, in community and care home settings? Q.1.2.2. What do they think works well, and what needs to change?
Quality of evidence	There were no experimental evaluations or views studies found that directly addressed questions on how to best support delivery of care in care homes.

Relative value of different outcomes	The absence of effectiveness studies relevant to this question meant that it was not possible to ascertain and compare the relative value of outcomes associated personalised, integrated care in care homes.
Trade-off between benefits and harms	The absence of effectiveness studies relevant to this question meant that it was not possible to ascertain and compare the trade-off between benefits and harms associated with personalised, integrated care in care homes. The Guideline Committee did discuss extensively however the potential negative experience older people can have if they are in a care home that does not provide opportunities for them to take part in the activities they would like, or to spend time with others in their local community.
Economic considerations	There was no economic evidence to draw conclusions about the cost-effectiveness of personalised and integrated care for older people with multiple long term conditions in care homes. The guideline committee were, however, mindful of potential costs and resource use when making the recommendations.
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	**ES36 Factors that can contribute to social isolation** Two qualitative papers of good quality (Blickem, 2013, +; Granville, 2010, +) found that social isolation was a significant problem for older people with high support needs – whether they lived in the community at home, or in care homes. Isolation and loneliness were exacerbated by the loss of a partner or spouse, retirement, peers dying or going into residential care, poor finances and poor mobility and lack of transport. **(RECs 1.5.4, 1.5.7)** **ES37 Extent of social isolation living in communal environments compared to when living alone** A good quality paper (Blickem, 2013, +) reports that older people who live in communal environments are as likely to feel isolated and lonely as those remaining in their own homes. Granville (2020,+) also confirms that people in care homes who maintained a network of friends and family retained ‘more of their own sense of identity and have more meaning in their lives’ (p69) **(RECs 1.5.4, 1.5.7, 1.5.9)** **ES38 Older people's perceptions of social isolation** Two good quality studies (Blickem, 2013,+, Granville, 2010,+) found that older people felt cut off from the wider ‘community’, not just from family and friends. Some had left their home and could no longer access local facilities and community activities. This led to a sense of disconnection, and a loss of activity and interaction that was part of ‘normal life’. People therefore want to take part in activities that are situated in the community. Community participation was felt to be a motivating factor to be positive about themselves, their lives and their health. **(REC 1.5.7)**

	ES39 Older people's perceptions of opportunities for meeting other people There is good evidence from a good quality study (Blickem, 2013,+), that people valued the opportunity to meet with people who shared similar frustrations and needs because of their health: support from other older people with LTCs could be a 'forum for exchange of emotional and practical support' (52). The groups also provided additional services for the socially isolated in that they could help access transport services, advice on welfare benefits 'Linkage to these resources through the groups was described as a lifeline to help which otherwise participants struggled to know how access.' (52). There is evidence from one good study (Granville, 2010,+) that older people also want diverse opportunities for social participation with people of different ages and interests as in 'normal life', so day centres (for example) were not necessarily an adequate response. Some people said they wanted more support to carry out activities such as shopping and going to the pub as opportunities to participate in 'normal' life. **(REC 1.5.9)** **ES40 Facilitators of, and structures to support participation and involvement** Two good quality studies (Blickem, 2013,+; Granville, 2010,+) conclude that older people living in the community or care homes need more opportunities for social participation in the community, and that transport is a vital service needed to support this. Granville (2010) emphasises the importance of visibility and retaining/strengthening personal and social networks as people age (80), and recommends further development of approaches such as: 'circles of support, time-banking, home-share, and other forms of mutual support' (p80). **(REC 1.5.9)**
Other considerations	The recommendations here drew on and expert witness testimony as well as Guideline Committee consensus. The Guideline Committee discussed the lack of good research evidence concerning the availability, effectiveness and cost-effectiveness of different interventions to reduce social isolation, and facilitate social contact for people in care homes. The expert witness testimony provided a range of examples of how this has been delivered successfully elsewhere which the Guideline Committee felt strongly should inform recommendations. They agreed that care homes should promote a culture which reflects the interest and need of their clients, allowing them to live the life they choose, so far as possible. They also noted that this should involve everyone being able to access information about the cost of care home services so they can make informed decisions about their support. Guideline Committee members also gave examples, from their own experience, of how care homes can improve residents' experience and facilitate social contact both in and outside the home.

Topic/section heading	Delivering care Provision of information
Recommendations	1.5.15 Give people information about how your service can help them manage their lives. This should be given: - at the first point of contact and when new problems or issues arise - in different formats which should be accessible (including through interpreters). **(ES26, ES39 and Guideline Committee consensus)** 1.5.17 Named care coordinators should review information needs regularly, recognising that people may not take in information when they receive a new diagnosis. **(Guideline committee consensus)** 1.5.18 Consider continuing to offer information and support to people and their family members or carers even if they have declined it previously. **(Guideline Committee consensus)**
Research recommendations	3.2 What is the lived experience of older people with multiple long-term conditions? 3.4 What is the impact of reablement interventions on outcomes for older people with multiple long-term conditions?
Review questions	**Main review question** 2.1.5 Self-management support: How effective are different types of support for older people to enable them to self-manage (aspects of) their own conditions? Other relevant review questions Q.1.1.1. What are the views and experiences of older people with multiple long-term conditions and their carers, of the social care services they receive? Q.1.1.2. Do service users and carers consider that their care is (a) personalised; (b) integrated or coordinated with healthcare? Q.1.1.2. What do they think works well and what needs to change? Q.1.2.1. What are the views and experiences of practitioners, managers and commissioners in health and social care who procure, manage or deliver care to older people with multiple long-term conditions, in community and care home settings? Q.1.2.2. What do they think works well, and what needs to change?
Quality of evidence	The evidence related to service user and carer views and self-management was of moderate, and moderate to good quality. Three studies using qualitative or mixed methods provided experiences of self-management interventions like expert patent programmes. Another three studies looked more generally at patient's ability to manage their symptoms, adhere to

	medications and the challenges of implementing measure like telecare. Some of the studies had very small sample sizes, and the samples included individuals outside our age range and the studies were too small to adequately separate out the views and experiences of our population, it was also sometimes unclear whether the sample suffered from multiple long term conditions. Another issue affecting the quality of the evidence was that several of the studies did not discuss social care adequately
Relative value of different outcomes	It was not possible from the evidence to ascertain the relative value of different outcomes in respect of different levels, or types of information provision.
Trade-off between benefits and harms	It was not possible from the evidence to ascertain and compare the trade-offs between benefits and harms in respect of different levels, or types of information provision.
Economic considerations	There were no applicable economic evaluations to support recommendations for information and signposting. While there is moderate quality evidence on the effectiveness of self-management programs from the Expert Patients Progam (Kennedy 2007, +/+, moderate quality), which also reported on cost-effectiveness, the sample population is insufficiently applicable to draw conclusions about cost-effectiveness for older people with multiple long-term conditions and social care needs (ES35).
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	**ES26 Signposting** There is evidence of moderate quality (Challis, 2010b, +/-) that older people might be enabled to play a more effective role in managing their conditions if they had better information about their conditions, and were signposted to local services that might support them. **(REC 1.5.15)** **ES39 Older people's perceptions of opportunities for meeting other people** There is good evidence from a good quality study (Blickem, 2013,+), that people valued the opportunity to meet with people who shared similar frustrations and needs because of their health: support from other older people with LTCs could be a 'forum for exchange of emotional and practical support' (52). The groups also provided additional services for the socially isolated in that they could help access transport services, advice on welfare benefits 'Linkage to these resources through the groups was described as a lifeline to help which otherwise participants struggled to know how access.' (52). There is evidence from one good study (Granville, 2010,+) that older people also want diverse opportunities for social participation with people of different ages and interests as in 'normal life', so day centres (for example) were not necessarily an adequate response. Some people said they wanted more support to carry out activities such as shopping and going to the pub as opportunities to participate in 'normal' life. **(REC 1.5.15)**.
Other considerations	Building on the evidence statements about the importance of understanding what services and support is available, the Guideline Committee agreed that recommendations should

	explicitly recognise: - the impact of the extremely stressful situations that people with long-term conditions can encounter, on their ability to take in information - that as is the case with general needs and preferences, people's information needs and preferences are not static. They should therefore be given the option to ask for more or different information as time goes on. - - the concerns people may have about alternative funding mechanisms and the potential benefit there may be in offering people a chance to trial them, with support, before fully committing.

Topic/section heading	**Delivering care** **Self-management and support**
Recommendations	1.5.10 Health and social care practitioners should review recorded information about medicines and therapies regularly and follow up any issues related to medicine management. This includes making sure information on changes to medicines is made available to relevant agencies. **(ES25 and Guideline Committee consensus)** 1.5.11 Social care practitioners should contact the person's healthcare practitioners with any concerns about prescribed medicines. **(Guideline Committee consensus)** 1.5.12 Social care practitioners should tell the named care coordinator if any prescribed medicines are affecting the person's wellbeing. This could include known side effects or reluctance to take medicines. **(Guideline Committee consensus)** 1.5.13 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. **(ES28 and Guideline Committee consensus)** 1.5.14 Health and social care providers should give information and advice about continence to older people. Make a range of continence products available, paying full attention to people's dignity and respect. **(ES328 and Guideline Committee consensus)** 1.5.16 Health and social care providers should ensure that care is person-centred and that the person is supported in a way that is respectful and promotes dignity and trust. **(ES5 and Guideline Committee consensus)**
Research recommendations	3.1 What is the lived experience of older people with multiple long-term conditions?

	3.3 What is the impact of reablement interventions on outcomes for older people with multiple long-term conditions? 3.6 What is the impact of different early intervention-focused approaches to self-management on outcomes for older people?
Review questions	**Main review questions** 2.1.5 Self-management support: How effective are different types of support for older people to enable them to self-manage (aspects of) their own conditions? Other relevant review questions Q.1.1.1. What are the views and experiences of older people with multiple long-term conditions and their carers, of the social care services they receive? Q.1.1.2. Do service users and carers consider that their care is (a) personalised; (b) integrated or coordinated with healthcare? Q.1.1.2. What do they think works well and what needs to change? Q.1.2.1. What are the views and experiences of practitioners, managers and commissioners in health and social care who procure, manage or deliver care to older people with multiple long-term conditions, in community and care home settings? Q.1.2.2. What do they think works well, and what needs to change?
Quality of evidence	The evidence related to service user and carer views and self-management was of moderate, and moderate to good quality. 3 studies using qualitative or mixed methods provided experiences of self-management interventions like expert patent programmes. Another three studies looked more generally at people's ability to manage their symptoms, adhere to medications and the challenges of implementing specific self-management interventions, such as telecare. There were some considerable methodological limitations such as small sample size, poorly reported participant characteristics, bias or concerns about relevance. Results were therefore interpreted with caution and the Guideline Committee relied on their experience of self-management interventions for wider context.
Relative value of different outcomes	There is moderately good evidence that the 'Expert Patients' programme was valued as an opportunity for social contact and that some evidence that it increased self-efficacy (over five months) however the Guideline Committee noted that this was no longer delivered by the NHS and also was not specific to older people with multiple long-term conditions. Self-management education programmes had some positive effects in terms of the effects of exercise on physical functioning but the effect on quality of life was uncertain.
Trade-off between benefits and harms	The effect of a number of interventions included were often slight and was extremely limited information about their long term effects or their effects on quality of life. The Guideline Committee were therefore hesitant to base recommendations on the evidence. The Guideline Committee also noted the lack of

	evidence on the impact of timing of self-management interventions on outcomes, noting that when people first receive a diagnosis they may not be ready to immediately start managing their own support.
Economic considerations	There were no economic evaluations to support recommendations in relation to medication and continence management. The guideline committee were, however, mindful of potential costs and resource use when making the recommendations.
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	**ES5: Aspects of the care and support process that are important to older people and carers** There is good evidence from two studies (Goodman et al, 2012, +/+; Granville et al, 2010,+) that, for older people and their carers, the process of care is as important as the outcomes. Older people want continuity of care in order to develop relationships with paid carers, a named key person to coordinate care, co-production of care with users and carers, and good links with the wider system of health and social care, allowing effective response at times of crisis. **ES25 Medicines adherence** There is moderate evidence (Banning 2008, +) that older people who do not adhere to their prescribed medication may have both intentional and non-intentional reasons for not doing so. The evidence suggests that shared decision-making between clinicians and patients on what to prescribe, aided by better explanations of effects and clearer instruction, could increase older people's ability and willingness to take their prescribed medication. **(RECs 1.5.10 and 1.5.12)** **ES28 Urinary incontinence** There is moderate to good evidence (Horrocks 2004, +) that older people often do not seek help with urinary incontinence, out of embarrassment or belief that it is a natural outcome of ageing, and that primary care staff do not routinely enquire about this. Consequently, people with urinary incontinence lead more restricted lives than they otherwise might, avoiding unfamiliar social situations and restricting fluid intake. **(RECS 1.5.13 and 1.5.15)**
Other considerations	The Guideline Committee saw the management of medicine and urinary continence as issues of particular importance. They spent considerable time discussing the specific recommendations to make, building on the evidence reviewed on these two topics and informed by their own extensive experience. They also noted that this guideline should cross-reference existing NICE guidance on these topics. The Guideline Committee also emphasised the importance of ensuring that people are supported to manage their lives and their conditions in the way that they choose, so far as possible.

Topic/section heading	**Delivering care** **Provision of information**
Recommendations	1.5.19 Named care coordinators should take responsibility for: - giving older people and their carers information about what to do and who to contact in times of crisis, at any time of day and 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 older people and their carers have information about their particular condition, and how to manage it - knowing where to access specialist knowledge and support, about particular health conditions - involving carers and advocates. **(ES5, ES9 and Guideline Committee consensus)**
Research recommendations	The Guideline Committee did not identify this as a priority area to make research recommendations on.
Review questions	Q 2.1.3 What are the barriers and facilitators to the delivery of effective, personalised, integrated care for people with multiple long-term conditions in community settings?
Quality of evidence	There were no experimental evaluations or views studies found that directly addressed questions on how to best support delivery of care in care homes. Data were extracted from evidence emerging in response to other review questions.
Relative value of different outcomes	The absence of effectiveness studies relevant to this question meant that it was not possible to ascertain and compare the benefits and harms associated with different approaches to keeping records up to date
Trade-off between benefits and harms	The absence of effectiveness studies relevant to this question meant that it was not possible to ascertain and compare the relative value of outcomes associated with different approaches to keeping records up to date
Economic considerations	There was no applicable economic evidence relevant to these recommendations. The guideline committee were, however, mindful of potential costs and resource use when making the recommendations.
Evidence statements – numbered evidence statements from which the recommendations were developed	**ES5: Aspects of the care and support process that are important to older people and carers** There is good evidence from two studies (Goodman et al, 2012, +/+; Granville et al, 2010,+) that, for older people and their carers, the process of care is as important as the outcomes. Older people want continuity of care in order to develop relationships with paid carers, a named key person to coordinate care, co-production of care with users and carers, and good links with the wider system of health and social care, allowing effective response at times of crisis. **(RECs 1.5.171.6.1,1.5.20 1.6.2 and 1.6.3)**

	ES9 Importance of continuity of care to older people and carers There is good evidence (Goodman, 2012, +/+) that service users and carers want more continuity of staff, as they are otherwise liable to experience care of a lower quality, plus embarrassment and loss of dignity in receiving personal care. They also want a designated person with a remit across all care services who is accessible in a crisis. **(RECs 1.5.2 and 1.6.3)**
Other considerations	The Guideline Committee strongly supported, and built on the findings summarised in ES5 and ES9 providing examples of the poor experiences or outcomes that can result from not having continuity of care or effective crisis response. They also described the importance of having a coordinated team of workers who have generalist and specialist knowledge, as appropriate, recognising that it is not always possible (or appropriate) for a single worker to be competent in all aspects of care or support needed.

Topic/section heading	**Preventing social isolation**
Recommendations	All older people, including those with multiple long-term conditions 1.6.1 Health and social care practitioners should support older people with multiple long-term conditions to maintain links with their friends, family and community, and identify if people are lonely or isolated. **(ES36, ES 37, ES38, ES39 and ES40)** 1.6.2 Named care coordinators and advocates should 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. **(ES37 and Guideline Committee consensus)** 1.6.3 Health and social care practitioners should give advice and information about social activities and opportunities that can help people have more diverse social contacts. **(ES38 and Guideline Committee consensus)** 1.6.4 Commissioners should consider funding and collaborating with community enterprises and services to help people to remain active in the home and engaged in the community, including when people are in care homes. **(ES39, ES40 and Guideline Committee consensus)** 1.6.5 Voluntary and community sector providers should consider collaborating with local authorities to develop new ways to help people to remain active and engaged in their communities, including when people are in care homes. **(ES40 and Guideline Committee consensus)**
Research recommendations	3.1 What is the lived experience of older people with multiple long-term conditions?
Review questions	**Main review question** Q 2.1.6 How can older people with multiple long-term conditions living in the community or in care home settings be supported to participate in community, family and social activities? **Other relevant review questions** Q.1.1.1. What are the views and experiences of older people with multiple long-term conditions and their carers, of the social care services they receive? Q.1.1.2. Do service users and carers consider that their care is (a) personalised; (b) integrated or coordinated with healthcare? Q.1.1.2. What do they think works well and what needs to change? Q.1.2.1. What are the views and experiences of practitioners, managers and commissioners in health and social care who procure, manage or deliver care to older people with multiple long-term conditions, in community and care home settings? Q.1.2.2. What do they think works well, and what needs to change?

Quality of evidence	The search identified three papers relevant to this question. There were both of good quality, one with qualitative methods and the other a case control trial. Both papers had a UK focus. Blickham et al (2013) provides valuable information on the experiences of older people with regard to social isolation. The paper has limitations in that none of the participants were very old and it is not clear what services were provided locally and no the views seem somewhat out of context. Dickens (2011) had samples of a reasonable size and robust methods for data collection and analysis. The limitations related to the compatibility of the intervention and the control groups were adequately discussed in the paper.
Relative value of different outcomes	The search only identified only one effectiveness study relevant to this question. As a result the outcomes related to different approaches to tackling social isolation cannot be compared.
Trade-off between benefits and harms	The search only identified only one effectiveness study relevant to this question. As a result the trade-offs between benefits and harms in terms of addressing social isolation cannot be identified.
Economic considerations	No economic evaluations were identified to support recommendations related to social isolation. The guideline committee were, however, mindful of potential costs and resource use when making the recommendations.
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	**ES36 Factors that can contribute to social isolation** Two qualitative papers of good quality (Blickem, 2013, +; Granville, 2010, +) found that social isolation was a significant problem for older people with high support needs – whether they lived in the community at home, or in care homes. Isolation and loneliness were exacerbated by the loss of a partner or spouse, retirement, peers dying or going into residential care, poor finances and poor mobility and lack of transport. **(RECs 1.6.1 and 1.6.2)** **ES37 Extent of social isolation in communal living environments compared to when living alone** A good quality paper (Blickem, 2013, +) reports that older people who live in communal environments are as likely to feel isolated and lonely as those remaining in their own homes. Granville (2020,+) also confirms that people in care homes who maintained a network of friends and family retained 'more of their own sense of identity and have more meaning in their lives' (p69). **(REC 1.6.2)** **ES38 Older people's perceptions of social isolation** Two good quality studies (Blickem, 2013,+, Granville, 2010,+) found that older people felt cut off from the wider 'community', not just from family and friends. Some had left their home and could no longer access local facilities and community activities. This led to a sense of disconnection, and a loss of activity and interaction that was part of 'normal life'. People therefore want to take part in activities that are situated in the community. Community participation was felt to be a motivating factor to be positive about themselves, their lives and their health. **(REC 1.6.3)**

	ES39 Older people's perceptions of opportunities for meeting other people There is good evidence from a good quality study (Blickem, 2013,+), that people valued the opportunity to meet with people who shared similar frustrations and needs because of their health: support from other older people with LTCs could be a 'forum for exchange of emotional and practical support' (52). The groups also provided additional services for the socially isolated in that they could help access transport services, advice on welfare benefits 'Linkage to these resources through the groups was described as a lifeline to help which otherwise participants struggled to know how access.' (52). There is evidence from one good study (Granville, 2010,+) that older people also want diverse opportunities for social participation with people of different ages and interests as in 'normal life', so day centres (for example) were not necessarily an adequate response. Some people said they wanted more support to carry out activities such as shopping and going to the pub as opportunities to participate in 'normal' life. **(RECS 1.6.4) and 1.6.3)** **ES40 Facilitators of, and structures to support participation and involvement** Two good quality studies (Blickem, 2013,+; Granville, 2010,+) conclude that older people living in the community or care homes need more opportunities for social participation in the community, and that transport is a vital service needed to support this. Granville (2010) emphasises the importance of visibility and retaining/strengthening personal and social networks as people age (80), and recommends further development of approaches such as: 'circles of support, time-banking, home-share, and other forms of mutual support' (p80). **(RECs 1.6.4 and 1.6.5)**
Other considerations	The Guideline Committee discussed that older people need to be supported to continue their lives and hobbies despite their conditions, and even if they are in residential care. Expert witness evidence responded to some of the gaps in effectiveness data and the Guideline Committee also described a range of initiatives that can facilitate social contact based on their experience. They agreed the recommendations should focus on the need for commissioners and providers to work together to address this problem - particularly given the limited resource available and the need to use the capacity and expertise of voluntary and community sector organisations. The recommendations are therefore aimed at building local capacity to address social isolation, and ensuring that helping people to stay in touch with the people they want to - is built into both assessment and care planning.

Topic/section heading	**Training and supporting health and social care practitioners**
Recommendations	**Older people with multiple long-term conditions** 1.7.1 Commissioners and providers should ensure health and social care practitioners caring for people with multiple long-term conditions have the necessary training and are assessed as competent in medicines management. **(Guideline Committee Consensus)** 1.7.2 Ensure health and social care practitioners are able to recognise: - common conditions, such as dementia and sensory loss, and - common care needs, such as nutrition, hydration and skin integrity, and - common support needs, such as dealing with bereavement and end-of-life, and deterioration in someone's health or circumstances. **(Recommendations adapted from draft NICE guideline on Home Care)**
Research recommendations	The Guideline Committee did not identify this as a priority area to make research recommendations on and were mindful of a potential future NICE guideline on management of medication in the home.
Review questions	Q. 3.1 How can social care practitioners delivering services to people with multiple long-term conditions be assisted to recognise, refer on and/or manage common health conditions and symptoms? Q.1.1.1. What are the views and experiences of older people with multiple long-term conditions and their carers, of the social care services they receive? Q.1.1.2. Do service users and carers consider that their care is (a) personalised; (b) integrated or coordinated with healthcare? Q.1.1.2. What do they think works well and what needs to change? Q.1.2.1. What are the views and experiences of practitioners, managers and commissioners in health and social care who procure, manage or deliver care to older people with multiple long-term conditions, in community and care home settings? Q.1.2.2. What do they think works well, and what needs to change?
Quality of evidence	No studies were identified which directly answered this question.
Relative value of different outcomes	No studies were identified which directly answered this question.
Trade-off between benefits and harms	No studies were identified which directly answered this question.
Economic considerations	No economic evaluations were identified to support recommendations on workforce training. The guideline committee were, however, mindful of potential costs and resource use when making the recommendations.

Evidence statements – numbered evidence statements from which the recommendation(s) were developed	
Other considerations	The Guideline Committee thought this an important topic on which to make recommendations and, in the absence of literature, drew on their own experience. The Guideline Committee members discussed the competencies and skills that would most likely be required of social care practitioners in recognising, refer on and/or manage common health conditions and symptoms. They also discussed workforce competence more broadly, particularly in relation to the recommendations that relate to a 'named care coordinator' for which some additional mapping work was undertaken. They agreed that frontline social care practitioners should have the skills and competence to: - recognise common conditions - know when to raise concerns, signpost or refer on - understand when and how to keep the care coordinator informed about a person's condition or support needs - understand how technology can/is used to support the person. The Guideline Committee also discussed the wide range of relevant NICE guidance already in existence or development (including for example, Urinary Incontinence in Women, Faecal Incontinence, and Managing Medicines in Care Homes). They agreed that, given the existing guidance, the remit of this guideline and the absence of evidence, they should develop general, rather than condition-specific, recommendations in respect of this issue. The NCCSC research team highlighted to the Guideline Committee that recognition of common conditions by frontline workers had been discussed extensively as part of the Home care guideline development. On reviewing the draft recommendation used in the Home care guideline, and discussing the nature and needs of the people using Home care services, the Long-term conditions Guideline Committee agreed to adopt the wording for inclusion in this guideline. The Guideline Committee also raised an implementation issue in these discussions, about the difficulty of ensuring new information reaches the frontline practitioner workforce. This was recorded to inform the NCCSC's work on dissemination and adoption.

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5 Related NICE guidance

Details of related guidance are correct at the time of consultation on the guideline (June 2015).

Published

- Osteoarthritis NICE guideline CG177 (February 2014).
- Hypertension NICE guideline CG127 (August 2011).
- Chronic heart failure NICE guideline CG108 (August 2010).
- Depression in adults with a chronic physical problem NICE guideline CG91 (October 2009).
- Rheumatoid arthritis NICE guideline CG79 (2009).
- Occupational therapy and physical activity interventions to promote the mental wellbeing of older people in primary care and residential care NICE guideline PH16 (2008).
- Type 2 diabetes NICE guideline CG66 (partially updated by CG87) (2008).
- Dementia NICE guideline CG42 (2006).
- Parkinson's disease NICE guideline CG35 (2006).

In development

NICE is developing the following guidance:

- Home care. NICE guideline. Publication expected September 2015.
- Transition between inpatient hospital settings and community or care home settings for adults with social care needs. NICE guideline. Publication expected November 2015.
- Multi-morbidities: system integration to meet population needs. NICE guideline. (Publication date to be confirmed).

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Declarations of interests

The following members of the Guideline Committee made declarations of interest. All other members of the Group stated that they had no interests to declare.

Committee member	Interest declared	Type of interest	Decision taken
Ann McFarlane	Works for Care Quality Commission on work commissioned by Age UK, Trustee at SCIE, ad-hoc assignments with NHS (Department of Health), works at local level in Kingston upon Thames, Patron of Kingston Centre for Independent Living: ex officio on Board, member of Healthwatch, Kingston at Home: RBK Older Peoples' Reference Group member, Interim	Non-personal pecuniary interest	None

	Chair for People at Risk Group (service user group that reports to Kingston's Adult Safeguarding Partnership Board), Better Services Better Value: Member for South West Commissioning Group.		
Belinda Black	Received a grant from the European Research Council to undertake a 3 year project that commenced in February 2015 looking at how technology can be used to support people with cognitive problems and dementia.	Personal non-pecuniary interest	None
Bernard Walker	Occasional consultancy work for local authorities and other bodies in the social care field, Associate Research in Practice for Adults, provides advice to HSA Global (Health Care Consultancy) on integration of Local Government with NHS.	Personal pecuniary interest	None
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	Foundation Trust and are both shareholders in Rubrum, a company developing eHealth solutions for long-term conditions.		
Beth Britton	Freelance consultant on learning disability/Dementia and Ageing with MacIntyre, involved in work with UK Gov G8 Dementia Summit, NHS IQ (Commitment for Carers), National Council for Palliative Care (Dementia and End of Life, Guideposts Trust (Dementia Awareness), Age UK Brent (Dementia and Ageing), Crossroads Care, Sensory Plus, Gracewell Healthcare, Swan Advocacy (Dementia and Advocacy), NHS/BMA 'Timely Diagnosis of Dementia', GB Care Shows, Care Show Bournemouth, GE Healthcare, NHS Expo, CQC and Royal College of Psychiatry Memory Services National Accreditation Programme (Memory Service Peer Review),	Personal pecuniary interest	None

	Local Gov Digital Dept, Bucks New University, Royal College of Nursing, Royal College of General Practitioners, Age UK and Carewatch, member on Standing Commission on Carers.		
Beth Britton	Member of Dementia Post Diagnosis Support Working Group (Dept of Health); Dementia Friends - Dementia Friends Champion; CQC - Member Adult Social Care Co-Production Group; Dementia Action Alliance- Member of the DAA and support the Carers' Call to Action; BRACE - Ambassador; Alzheimer's Society – Volunteer, Public Health England; National Mental Health Intelligence Network; Dementia Expert Reference Group.	Personal non-pecuniary interest	None
Diana Robinson	Has a small shareholding in Reckitt Benckiser and indivior (yields less than £1,000 pa), Patient and Public Involvement work - the following may pay expenses and/or honoraria for meetings, workshops or	Personal pecuniary interest	None

	conference attendance; and for reviewing research proposals, National Institute for Health Research, Programme Grants for Applied Research funding panel; occasional lay peer reviews; National Cancer Research Institute; National Cancer Intelligence Network; NICE UK Database of Uncertainties of Effects Treatments Steering Group; Health Research Authority; University of Leeds (IMPACCT study and Leeds Clinical Research Facility Executive); Care Quality Commission;, NHS England; Health Quality Improvement Partnership - Service User Network; National Institute for Cardiovascular Outcomes Research; involvement coach for Cancer Research UK;), Royal College of Radiologists; Academic Committee and Lay Network; Royal College of Physicians; Care of the Dying Adult and Lower Back Pain Guidance Development		

	Groups; British Heart Foundation		
Diana Robinson	Sister-in-law works for University College London as Credit Control Manager	Personal family interest	None
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Jeremiah Kelleher	Undertaking paid work with Healthwatch Norfolk which involves visiting a care home as part of a project to examine service for older people with dementia. It is strictly local and project will report in 2014.	Personal non-pecuniary interest	None
Karin Tancock	Works part time for the College of Occupational Therapists as the Professional Affairs Officer for Older People.	Personal pecuniary interest	None
Maggie Winchombe	Contracted to Southwark to deliver Trusted Assessor training programmes to staff.	Personal non-pecuniary interest	None
Philippa Thompson	Works at Independent Lives and Kate Mercer Training (KMT) has been contracted to write the assessment, support planning, personal budget and direct	Non-personal pecuniary interest	None

	payment parts of the new training materials for advocacy under the Care Act 2014. KMT is providing this service for the Department of Health, which is funding the development of the materials.		
Philippa Thompson	Member of the English steering committee of the Campaign for a Fair Society.	Personal non-pecuniary interest	None

3146 7 Glossary and abbreviations

3147 *Abbreviations*

Abbreviation	**Term**
ADL	Activities of daily living
ASCOT	Adult Social Care Outcomes Toolkit
C	Comparison Group
DP	Direct payment
EQ-5D	EuroQol: a standard health measure that allows the calculation of quality-adjusted life years (QALYs)
GHQ	General Health Questionnaire
GP	General practitioner
IADL	Instrumental activities of daily living
IB	Individual budget
ICER	Incremental cost effectiveness ratio as a ratio of change in costs to change in benefits
I	Intervention group
N	Number of participants
p	p-value: a measure that indicates whether the change in outcome was due to chance; a p-value of less than 0.05 suggests that the change was not due to chance (statistically significant)
RCT	Randomised controlled trial
SCRQOL	Social care-related quality of life
SD	Standard deviation
SE	Standard error

wk	Week
WTP	Willingness-to-pay value: a threshold set by NICE that the government is prepared to pay for a year in perfect health; the threshold is set between £20,000 and £30,000

Please see the NICE glossary for an explanation of terms not described above.

About this guideline

What does this guideline cover?

The Department of Health (DH) asked the National Institute for Health and Care Excellence (NICE) to produce this guideline on social care of older people with multiple long-term conditions (see the scope).

The recommendations are based on the best available evidence. They were developed by the Guideline Committee (GC) – for membership see section 6.

For information on how NICE guidelines are developed, see Developing NICE Guidelines: The Manual.

Other information

For consultation document: We will develop a pathway and information for the public and tools to help organisations put this guideline into practice. Details will be available on our website after the guideline has been issued.

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