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NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

DRAFT GUIDELINE

Home care: delivering personal care and practical support to older people living in their own homes

Draft for consultation, March 2015

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Introduction

3 Home care is one of several services that can be offered to people assessed
4 as needing social care support. It can be funded by health or social care
5 commissioners or the person using services. Although the range and type of
6 services that can be classed as home care varies, it usually encompasses:

7 • personal care, for example help to wash
8 • support with the activities of daily living, which might also include telecare
9   (for example providing personal alarms)
10 • essential domestic tasks.

11 A number of recent reports have identified significant concerns about the
12 quality, reliability and consistency of home care services. A themed inspection
13 of home care by the Care Quality Commission (Not just a number: Review of
14 home care services) also highlighted some specific areas for improvement (for
15 more detail, see: Context).

16 The Department of Health asked the National Institute for Health and Care
17 Excellence (NICE) to develop a guideline to help address these issues (see
18 the scope). The guideline was developed by a guideline development group
19 (GDG) following a detailed review of the evidence on home care.

20 This guideline focuses on older people receiving home care. It does not cover
21 younger adults (although many of the recommendations may also be relevant
22 to younger adults). This is because the largest group of people using home
23 care is older people.

24 This guideline considers how person-centred home care should be planned
25 and delivered. It addresses how those responsible for managing and providing
26 home care should work together to deliver safe, high-quality home care
27 services that promote independence.

1 Context

2 *Legislation, policy and guidance*

3 This guideline has been developed in the context of a complex and rapidly

4 evolving landscape of guidance and legislation, most notably the Care Act

5 2014 which has a significant impact on home care providers and people who

6 use home care services and their carers. The majority of the Care Act takes

7 effect from April 2015, with specific financial provisions coming into force from

8 April 2016. This legislation places a duty on local authorities to promote

9 wellbeing and meet needs (rather than requiring them simply to provide

10 services). It also requires local authorities to assess and offer support to

11 address the needs of carers, independently of the person they care for. This is

12 aligned with a range of other carer-specific policies[1], which emphasise the

13 value of carers, and the importance of enabling them to have 'a life alongside

14 caring'.[2]

15 Under the Act, local authorities have a duty to prevent, delay or reduce the

16 development of people's social care needs, so far as possible, and to work in

17 an integrated, person-centred way, with all other support agencies including

18 those in the third sector. They also have a duty to provide information and

19 advice for the whole population, not just those who are receiving services that

20 they fund. This means that people funding their own home care and support

21 are entitled to guidance from the local authority, including on financial matters.

22 The Care Act 2014 requires local authorities to stimulate and manage their

23 local market to benefit the whole population, again, not just those in receipt of

24 local authority funded support.

25 While the Care Act and other legislation describes what organisations must

26 do, this guideline is focused on 'what works' in terms of how they fulfil those

27 duties, and deliver support to older people using home care and their carers.

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[1] For example: Department of Health (2014) Carers strategy: the second national action plan 2014-2016 London: DH; and, NHS England (2014) NHS England's Commitment to Carers, London: DH.
[2] Department of Health (2014) Carers strategy: the second national action plan 2014-2016 London: DH, p40

1 Home care may include both regulated and unregulated activity. Home care

2 providers (including those providing support attached to housing) must

3 register with the CQC and are subject to fundamental standards, monitoring

4 and inspection. The CQC guidance, though not mandatory, articulates what is

5 expected of providers under the Health and Social Care Act 2008 and the

6 Care Quality Commission (Registration) Regulations 2009. Home care

7 providers are governed by the Domiciliary Care Agencies Regulations 2002.

8 In addition, where work is not classed exclusively as 'domestic services',

9 workers are also subject to the Health and Safety at Work Act 1974.

10 There is no regulation of self-commissioned personal assistants or other

11 home care workers directly employed by people who use services.

12 ***Use of home care***

13 In 2013-14 470,000 people used home care funded by local authorities in

14 England, equating to 186 million hours of contact time.[3] The vast majority

15 (79%) of these were people aged 65 or older. Despite the rising numbers of

16 older people in the population, the number receiving publicly funded care is

17 decreasing.[4] Just over two-fifths (46 per cent) of people receiving home care

18 get intensive support, defined as 'more than 10 hours per week with overnight,

19 live-in or 24-hour services'.[5] Alongside this, eligibility thresholds have risen

20 over recent years and there is evidence that many local authorities now offer

21 home care services only to those who have the highest levels of need.[6] Local

22 authorities will, however, direct people with social care needs of all levels, to

23 other sources of support. The Care Act has enhanced local authorities' role in

24 this respect, by providing more detail about the information and advice they

25 must offer people

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[3] Community Care Statistics: Social Services Activity Health and Social Care, England. 2013-14. Final Release. Health and Social Care Information Centre (2014)

[4] Community Care Statistics: Social Services Activity Health and Social Care, England. 2013-14. Final Release. Health and Social Care Information Centre (2014)

[5] Community Care Statistics: Social Services Activity Health and Social Care, England. 2013-14. Final Release. Health and Social Care Information Centre (2014)

[6] The State of Health Care and Adult Social Care in England, 2010-11 (2011). Page 29. http://www.cqc.org.uk/sites/default/files/media/documents/state_of_care_2010_11.pdf

1 People may use home care to respond to long-term care and support needs,

2 or episodically, for example during recuperation from an operation, or until

3 they take up alternative living arrangements. Some older people using home

4 care may be particularly vulnerable or have specialist needs, for example

5 those with dementia; multiple long term conditions; people who may be

6 approaching the end of life; and, people with mobility or communication

7 difficulties. People who live alone are more likely to be particularly dependent

8 on their home care support. Many people who use home care have carers

9 and this role can be hugely demanding: for example, most people with

10 dementia, living at home, are supported by unpaid carers.[7] Carers may also

11 be in need of support for their own health or social care needs, especially

12 given that approximately 110,000 carers are over 85.[8] The Care Act 2014

13 requires local authorities to assess carers' needs independently of the needs

14 of the people they care for and a number of policy documents have

15 emphasised the importance of involving carers in service design, delivery and

16 review.[9]

17 *Funding and funding mechanisms*

18 Over half (51% or £8.8bn) of personal social services expenditure by councils

19 in 2013–14 was spent on older people. [10] The majority of this (£4.7bn) is

20 spent on residential care, with £1.8bn spent on home care. Direct payments

21 (DPs) made to older people (which may be spent on home care) cost councils

22 £410m in 2013-14.[11] As a proportion of council's overall expenditure, this

23 equates to 8% (compared to 4% in 2008-09). [12]

24 Comparison with expenditure on residential care costs illustrates the potential

25 value of enabling people to stay in the community rather than in residential

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[7] Carers UK (no date) Key facts about carers [online]
[8] NHS England (2014) Commissioning for carers: principles and resources to support effective commissioning for adult and young carers
[9] NHS England (2014) Commissioning for carers: principles and resources to support effective commissioning for adult and young carers
[10] Information Centre for Health and Social Care (2014) Personal Social Services: Expenditure and Unit Costs, England, 2013-14 Final release.
[11] Information Centre for Health and Social Care (2014) Personal Social Services: Expenditure and Unit Costs, England, 2013-14 Final release.
[12] Information Centre for Health and Social Care (2014) Personal Social Services: Expenditure and Unit Costs, England, 2013-14 Final release.

1 settings, although high-intensity home care support can also be costly. In

2 2013-14, the average unit cost of home care (across all adults) was £17.20

3 per hour.[13] The average cost of home care (across all adults) per person per

4 week was £219, compared to £597 per person per week for adults supported

5 in 'residential care, nursing care or intensively in their own home'.[14]

6 An estimated 170,000 people fund their own home care and this figure rises to

7 270,000 when additional activities such as help with housework or shopping

8 are included[15].

9 ## *Provision of home care*

10 The independent sector provided 92% of home care contact hours in 2013-14

11 compared to 81% in 2008-09.[16] In 2011–12, 6830 home care agencies of

12 varying sizes were registered with the Care Quality Commission (CQC).

13 The UK Homecare Association conducted a survey in 2011–12 of councils

14 with social services responsibilities focusing on home care.[17] Responses

15 covered 96% of councils in England. Findings suggest that the rates paid per

16 hour by councils varied from £9.95 to £22.00, with a weighted average of

17 £12.84. Considerable regional variation was reported, with lower rates in the

18 West Midlands and North West of England. Both workers' pay and

19 organisational costs are funded from these amounts.

20 ## *Potential for improvements in home care*

21 The CQC's themed inspection of home care services in England drew on data

22 from 250 home care agencies, 91% of which were owned by the independent

23 sector. The report found that 74% of inspected services met all 5 CQC

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[13] Information Centre for Health and Social Care (2014) Personal Social Services: Expenditure and Unit Costs, England, 2013-14 Final release.
[14] Information Centre for Health and Social Care (2014) Personal Social Services: Expenditure and Unit Costs, England, 2013-14 Final release. p30

[15] Estimates from: http://ipc.brookes.ac.uk/publications/index.php?absid=646 cited in Community Care Statistics: Social Services Activity Health and Social Care, England. 2013-14. Final Release. Health and Social Care Information Centre (2014)
[16] Community Care Statistics: Social Services Activity Health and Social Care, England. 2013-14. Final Release. Health and Social Care Information Centre (2014)
[17] United Kingdom Home care Association (2012) Care is not a commodity. UKHCA Commissioning Survey

1　standards, but identified important areas of improvement in a significant

2　minority of agencies. The 5 core standards and major needs for improvement

3　were:

4　• **Respecting and involving people who use services and their carers** -

5　　The CQC found a lack of continuity in care workers, with evidence that

6　　people were not informed of changes. Some service providers gave only

7　　limited information about choices available to users and carers.

8　• **Care and welfare of people who use services** - Sometimes calls were

9　　missed or late, weekend services were inconsistent, and there was a lack

10　　of staff knowledge and skill, for example, in respect of dementia and other

11　　long term conditions including sensory loss and residual stroke capacity.

12　　The CQC also found inadequate assessment of needs, lack of detailed

13　　care plans and inadequate recording of preferences and complex care

14　　needs. Coordination of visits involving more than one worker was poor, as

15　　was involvement of carers.

16　• **Safeguarding people who use services from abuse** – The CQC

17　　identified out of date procedures, poor staff understanding of safeguarding

18　　and whistle-blowing procedures, and failure to report concerns.

19　• **Providers' support for their staff** – The CQC identified that staff

20　　sometimes felt unsupported by management and were not always able to

21　　deliver care in the right way because of time pressures, lack of travel time

22　　and unscheduled visits added at short notice. Shortcomings in induction,

23　　supervision, training and performance monitoring systems were identified,

24　　with 13 per cent of micro-sized providers not meeting the standard.

25　• **How providers assess and monitor the quality of services they**

26　　**provide** - There were shortcomings in formal documentation of quality and

27　　complaints. People were sometimes not asked for their views, or no action

28　　was taken.

29

30　The CQC also identified factors that pose challenges for providers but are not

31　within their capacity to change, including commissioning arrangements,

32　pressure on budgets, and the rise in numbers of recipients with complex care

33　needs, including dementia.

1 Person-centred care

2 This guideline assumes that the practitioners using it will read it alongside the

3 Care Act 2014. It is also written to reflect the rights and responsibilities that

4 people and practitioners have as set out in the NHS Constitution for England.

5 Care and support should take into account individual needs and preferences.

6 People should have the opportunity to make informed decisions about their

7 care, in partnership with health and social care practitioners. Practitioners

8 should recognise that each person is an individual, with their own needs,

9 wishes and priorities. They should treat everyone they care for with dignity,

10 respect and sensitivity.

11 If someone does not have capacity to make decisions, health and social care

12 practitioners should follow the code of practice that accompanies the Mental

13 Capacity Act and the supplementary code of practice on deprivation of liberty

14 safeguards.

15 If the person using the service agrees, families and carers should have the

16 opportunity to be involved in decisions about care and support. Families and

17 carers should also be given the information and support they need in their

18 own right.

19

1 Recommendation wording

2 The Guideline Development Group makes recommendations based on an
3 evaluation of the evidence, taking into account the quality of the evidence and
4 cost effectiveness.

5 For most recommendations the group was confident that the recommendation
6 will be effective and cost-effective for most people and used verbs such as
7 'offer', 'ensure', 'discuss' and 'record' to reflect this.

8 Two words have special meanings in our guidelines.

9 The group used the word 'consider' to indicate that the practitioner (or other
10 person that the recommendation is aimed at) should spend more time than
11 usual discussing the various options with the person.

12 The group used 'must' or 'must not' when there is a legal duty to apply the
13 recommendation or that the consequences of following it could be extremely
14 serious or potentially life threatening.

15

1 Recommendations

The guideline is based on the best available evidence. Full details of the evidence are provided in section 3 of the guideline and supporting appendices.

The glossary explains terms used in this guideline.

1.1 Ensuring care is person-centred

Recommendations for home care providers and commissioners

1.1.1 Ensure services support the aspirations, goals and priorities of each person, rather than providing 'one size fits all' services.

1.1.2 Ensure support focuses on what people can or would like to do to maintain their independence, not only on what they cannot do. Recognise:

- that people have aspirations and potential throughout their lives and
- that people with cognitive impairment and those living alone might be at higher risk of having unmet social care-related quality of life needs or worse psychological outcomes.

1.1.3 Ensure everyone working with people using home care services and their carers treats them with empathy, courtesy, respect and in a dignified way by:

- agreeing mutual expectations
- always respecting confidentiality and privacy
- providing a reliable service that people and their carers can trust
- regularly seeking feedback (both positive and negative) about the quality and suitability of care from people using the service, including those who do not have a carer or advocate.

1.1.4 Prioritise continuity of care, using a core team of care workers, so that the person becomes familiar with them.

1   1.1.5   Ensure there is a transparent process for 'matching' care workers

2   to people, taking into account:

3   • the person's needs, and

4   • the care workers' skills, and

5   • if possible and appropriate, both parties' interests and

6   preferences.

7 ## *1.2 Providing information*

8 ***Recommendations for local authorities***

9   1.2.1   In line with the requirements of the Care Act, local authorities must

10   establish and maintain a service that gives people: information

11   about how to access care and support, what support is available

12   and who provides it; independent financial advice; and, details of

13   how to raise concerns.

14   Local authorities should give people who use or who are planning

15   to use home care services and their carers details of:

16   • Different funding mechanisms including the options available for

17   people with personal budgets, for example having a managed

18   budget, an individual service fund or direct payment, and ways

19   to influence or manage them.

20   • Where to find information about the range and quality of services

21   available, the activities they offer and how much they cost.

22   • What needs the home care services are expected to address, for

23   example, personal care (help with tasks such as getting in and

24   out of bed, washing and bathing, going to the toilet, dressing or

25   eating and drinking) and help with housework and other services

26   to help people remain safely at home and in their community.

27   • Other options, such as:

28   − saving allocated hours to be used at a later date (sometimes

29   known as 'timebanking')

              − options such as a live-in carer or 'shared lives' (where the person stays in the community by living with another person or a family)

              − employing personal assistants.

1.2.2   Offer people and their carers information about local and national support groups and networks.

Recommendations for home care providers and commissioners

1.2.3   Ensure people using services and their carers have information that supports them to make informed choices about their care, including:

- what to expect from the home care service, and
- their rights, and
- what they should do if they are not happy with the service.

Consider presenting this as part of a 'welcome pack' (or equivalent).

1.2.4   Offer the person a written summary of the information that has been provided to them (or provide this summary in another format that meets the person's needs). Be aware that the circumstances that lead people to need home care can be traumatic and people may find it difficult to take in a lot of information.

1.2.5   Tailor all information for different audiences to ensure it is accessible and understandable. Ensure information is:

- easy to read and in plain English
- available in the person's language if needed
- available in different formats and media (including information packs, telephone hotlines and electronic media)
- made available in different venues, such as community centres or GP surgeries, as well as through face-to-face meetings with a social care practitioner

- provided in formats that suit people with different communication or capacity needs, for example, large-print, braille or audio versions.

1.2.6 Ensure that information is updated regularly. Design information in a way that allows it to be updated easily.

1.3   Planning and reviewing home care and support

Coordinating and planning home care as part of a multidisciplinary team

Recommendations for commissioners

1.3.1 Ensure integrated care and support is delivered to the person through a multidisciplinary team, where required. The team might include:

- healthcare practitioners
- social care practitioners, including home care workers
- people from voluntary and community organisations, befriending and specialist services
- advocates, including those appointed by the Court of Protection.

Recommendations for multidisciplinary teams

1.3.2 Ensure the person using services and their carers are involved in multidisciplinary team discussions about their care.

1.3.3 Consider identifying a lead practitioner from among the people involved in delivering support to lead home care planning and coordinate care for each person.

Recommendations for home care and health service providers

1.3.4 Ensure that support is delivered in cooperation with a multidisciplinary team, recognising the expertise, knowledge and commitment of all practitioners.

1 Planning home care and support

2 *Recommendations for commissioners*

3 1.3.5 Support home care as an important component of a care package
4 for older people living in their own home, given that is likely to have
5 a positive impact on psychological wellbeing at a relatively low cost,
6 and that it can help people to feel more in control over their daily
7 lives.

8 1.3.6 Consider offering home care support to older people with low to
9 moderate needs. This is because it may mean that they need less
10 intensive support later on or may delay the time at which support is
11 needed.

12 1.3.7 Ensure home care packages address social care-related quality of
13 life and the person's wider wellbeing in addition to practical support,
14 (for example home cleanliness and comfort). Recognise that
15 people who use home care services often need support that goes
16 beyond their personal care needs.

17 1.3.8 If a person chooses to take direct payments for home care, give
18 them the support and information they need to manage the
19 payments effectively. This should be regardless of whether they
20 buy care through a regulated provider, directly employ a personal
21 assistant or choose another way to meet the agreed need.

22 1.3.9 Consider asking people with experience of using a direct payment
23 for home care to help provide training, support or advice to others
24 thinking of doing so.

25 1.3.10 Aligned with the recommendations in Ensuring care is person-
26 centred, ensure that lead practitioners and others involved in home
27 care and support planning:

- understand the principles and importance of involving the person using services, and their carers if relevant, as an equal partner in specifying the support and services they receive
- know how to work in a way that maximises choice, control, dignity and respect for the person using services
- have an awareness of common conditions affecting people using home care services, for example, sensory loss, dementia, physical and learning disabilities, and stroke
- know about local organisations that provide specialist support
- know about the funding options available for care and support
- understand different funding mechanisms including the options available for people with personal budgets, for example having a managed budget, an individual service fund or direct payment.

1.3.11 Give lead practitioners relevant information about a person's circumstances before the home care planning process is started.

Recommendations for lead practitioners (or other practitioners planning care)

1.3.12 Before meetings to plan home care and support, give the person using services and their carer information about how the home care plan will be developed, negotiated and reviewed and the options available to them. Ensure people have enough time to understand this information.

1.3.13 Ask people if they want carers or advocates involved in their home care planning and support, and respect their choice.

1.3.14 Consider planning support that enables the person to take more responsibility, including for the financial arrangements, to increase their independence over time.

1.3.15 Ask people about their aspirations, needs and priorities, as well as what gives them peace of mind, and makes them feel safe and unsafe. Ensure the home care plan:

- empowers the person as much as possible, by recognising what they can and want to do
- explicitly addresses safety, wellbeing, independence and any specialist needs
- is informed by the experience, skills and insight of carers, as appropriate
- addresses the range of practical support needed to help the person to live how they choose, as far as possible, rather than addressing only personal care needs (this could include, for example, support to help a person manage their own financial and personal affairs, do their own shopping and cooking, or socialise, or other help, depending on the person's needs and preferences)
- describes how success and outcomes will be measured
- is clear, concise and easy to navigate
- has a summary at the start, with links to more detailed information.

1.3.16 When assessing risk, balance the risk of a particular behaviour or activity with how it is likely to benefit the person's wellbeing and help improve their quality of life. The lead practitioner should:

- complete a risk plan with the person as part of the home care planning process and include this in the home care plan
- ensure the risk plan includes strategies to minimise risk, for example specialist equipment; use of verbal prompts; use of support from others
- ensure the risk plan includes the implications of taking the risk for the person and the care worker
- carry out risk assessments as part of home care planning and at relevant intervals, such as when significant factors change.

1.3.17 Liaise with healthcare practitioners and other professionals to ensure the home care plan promotes wellbeing, particularly for

1   medicines management, pain management and pressure sore and

2   moisture lesion prevention and care.

3   1.3.18   Write any medicines management requirements into the home care

4   plan including:

5   • the purpose of, and information on, medicines

6   • the importance of timing and implications of non-adherence.

7   1.3.19   Always discuss with the person and their carer whether telecare

8   could complement their home care package (and any other

9   services they are using).

10   1.3.20   Discuss the potential benefits of telecare, such as how it can

11   provide reassurance to the person and their carer, while bearing in

12   mind the rights of a person, particularly in relation to privacy, choice

13   and control.

14   1.3.21   Consider addressing the potential negative effect of social isolation

15   on people's health and consider including voluntary sector and

16   community organisations to maintain family and local community

17   links, working with the carer as appropriate.

18   *Recommendations for home care providers*

19   1.3.22   Ask people:

20   • which elements of their home care service are a priority for

21   them, and

22   • whether some home care time may be used flexibly (that is,

23   used for a variety of jobs according to what is needed).

24   1.3.23   Give people and their carers if appropriate, a copy of their home

25   care plan in a format that meets their needs.

26   1.3.24   Ensure all practitioners providing support complete the home care

27   plan, and deliver support in an integrated way according to the

28   plan.

1.3.25 Undertake an initial review of the home care plan after about 6 weeks, then review regularly at least annually. This should involve the person and their carers (if appropriate) in a meaningful way.

1.3.26 Consider working with other agencies to ensure that people who use home care services have a single home care and support plan rather than separate plans from each service or provider.

Planning telecare

Recommendations for lead practitioners (or other practitioners planning home care)

1.3.27 If the person wishes to use telecare, work with them to identify their preferred telecare options that maximise dignity and help them live in the way that they choose.

1.3.28 Ensure telecare does not replace personal contact, unless the person using services wants it to.

1.3.29 Record in the home care plan how the telecare equipment meets the person's needs and will help them achieve their desired outcomes.

1.3.30 Offer people using home care services information about options for telecare that could help them. Include information on potential risks and benefits, so they can make an informed decision.

1.4   Delivering home care

Recommendations for commissioners

1.4.1 Ensure contracts allow home care workers enough time to provide a good quality service, including having enough time to talk to the person and their carer. They should ensure that workers have time to do their job without being rushed or compromising the dignity of the person who uses services.

1.4.2 Home care visits shorter than half an hour should be made only if:

1   • the home care worker is known to the person, and

2   • the visit is part of a wider package of support, and

3   • it allows enough time to complete specific, time limited tasks or

4   to check if someone is safe and well, for example.

5   1.4.3   Consider contracting and monitoring in a way that allows services

6   to be delivered flexibly to ensure the person can identify what is a

7   priority for them. This might include, for example, allowing providers

8   (with the person's agreement or at their request) to use time

9   flexibly.

10   ***Recommendations for home care managers and providers***

11   1.4.4   Ensure home care visits are long enough for home care workers to

12   complete their work without compromising the quality of their work

13   or the dignity of the person, including scheduling sufficient travel

14   time between visits. Take into account that people with cognitive

15   impairments, communication difficulties or sensory loss may need

16   workers to spend more time with them to ensure they have the

17   support they need.

18   1.4.5   Ensure there is a complaints procedure in place. Tell people about

19   how they can make a complaint either in writing or in person.

20   1.4.6   Make the complaints procedure available on your website and in

21   other ways appropriate to people using the service and their carers.

22   Give information about escalating complaints if necessary (to the

23   commissioning body and Ombudsman) or ensure this information is

24   readily available.

25   1.4.7   Prioritise continuity of care (so that the person knows the home

26   care practitioners and they are familiar with how that person likes

27   support to be given) – particularly given that this can ensure any

28   risks or concerns are identified early – by:

29   • introducing people to new care workers, and

30   • building teams of workers around a person and their carer, and

- informing people in advance if staff will be changed and explaining why, and

- working with people to negotiate any changes to their care plan, for examples when visits will be made, and

- recognising that major changes (for example moving from home care to use of personal assistants) can make people feel unsafe.

1.4.8   Ensure home care workers are able to deliver home care in a way that meets the person's cultural and language needs.

1.4.9   Consider the need for independent advocacy if a person lives alone, has difficulty expressing their views and aspirations or routinely lacks capacity.

1.4.10   Closely monitor risks associated with missed or late visits and take prompt remedial action. Recognise that people living alone (without carers or advocates) or those who lack capacity may be particularly vulnerable if visits are missed or late.

Recommendations for home care workers

1.4.11   Ensure the person who uses services (or their carer) is contacted if you will be late or unable to visit, as well as informing your manager, if appropriate.

1.4.12   Make every effort to avoid missed visits because these can cause major concern or have serious implications for people's health or wellbeing.

1.4.13   Ensure the record you complete routinely on each visit is detailed enough to keep people, their carers and practitioners fully informed about what has been provided. Record any incidents or changes. The record could form an additional part of the home care plan or could be a separate 'care diary'.

1 **Delivering telecare**

2 *Recommendations for the lead practitioner*

3 1.4.14   Ensure that the telecare provider gives the person and their carer
4   information about how to use the equipment, and confirm that the
5   person can confidently use it.

6 1.4.15   Regularly review a person's use of telecare to ensure they find it
7   useful. Involve the person in the review and seek feedback from
8   others, such as carers or call centres. During the review, tell the
9   person about any new telecare options available.

10 1.4.16   Provide telecare call centres with all relevant information about a
11   person's circumstances (if the person agrees).

12 1.4.17   If providing alarm-based telecare, ensure response systems are in
13   place. For example, the alarm can be linked to a warden, live-in
14   carer, family member or contact centre.

15 1.4.18   If the alarm is set to alert a carer who does not live near the person,
16   ensure there is a 24-hour, 7-days-a-week contact close by who is
17   able to provide assistance.

18 *1.5*   *Ensuring safety and safeguarding people using home*
19   *care services*

20 *Recommendations for health care practitioners*

21 1.5.1   Consider regularly liaising with home care workers about the
22   person's medication.

23 1.5.2   Write information and guidance for home care workers about
24   medicines in the home care plan.

25 *Recommendations for home care managers*

26 1.5.3   Ensure there is a written process to follow in the event of a
27   safeguarding concern and ensure that the process is aligned with

local authority procedures. The process should include key contacts such as:

- emergency services
- the registered manager of the home care provider
- the local authority vulnerable adults or safeguarding helpline
- other sources of support, for example, the Care Quality Commission, Action on Elder Abuse, the local Healthwatch.

1.5.4 Ensure home care workers are aware of the process.

1.5.5 Build a culture in which reporting of safety and abuse concerns is understood as a marker of good care, not just as a negative outcome of poor care. Build such a culture by, for example:

- stating explicitly, as part of induction training, that safeguarding alerts are part of delivering a responsible home care service and that home care workers play a vital role in helping to safeguard a person using services, and
- providing case studies that demonstrate the far-reaching effects of not acting on safeguarding concerns.

Recommendations for commissioners

1.5.6 Recognise that safeguarding alerts can be a responsible element of providing home care, given that the home care worker may be the first person to spot abuse and should respond proportionately.

Recommendations for home care providers

1.5.7 Put policies in place that ensure home care workers are supported through any safeguarding process.

1.5.8 Home care providers must have a medicines management policy.

Recommendations for home care providers and home care workers

1.5.9 Ensure the person using the service, and their carers (if the person has involved them in their care), can direct the way home care is

1   delivered. This is so that the person's safety, comfort,

2   independence and sense of security are always promoted.

1.6 Recruiting, training and supporting home care workers

Recommendations for home care providers

1.6.1   Have a transparent and fair recruitment and selection process that:

- uses values-based interviews and approaches to identify the personal attributes and attitudes essential for a caring and compassionate workforce, and
- ensures workers have the necessary literacy and numeracy skills to do the job.

1.6.2   Consider involving people who use home care and their carers in recruiting and training home care workers.

1.6.3   Ensure that new home care workers are observed at work more than once during their probationary period.

1.6.4   Ensure home care workers 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.

1.6.5   Make provision for more specialist support to be available to people who need it – for example, in response to complex health conditions – either by training your own home care workers or through partnerships with specialist organisations.

1 1.6.6 Ensure home care workers have the knowledge and skills needed

2 to perform their duties safely by providing, as part of the full

3 induction and ongoing training package, specific training on:

4 • what constitutes 'safe' care

5 • identifying and responding to possible or actual abuse or neglect

6 • identifying and responding to environmental risks

7 • safe care policies and procedures.

8 1.6.7 Use feedback from people using the service and their carers to

9 assess training needs for the workforce.

10 1.6.8 Ensure home care workers have opportunities to refresh and

11 develop their knowledge and skills.

12 *Recommendations for home care managers*

13 1.6.9 Managers should:

14 • respond promptly to workers when they request support to deal

15 with difficult situations

16 • supervise workers in a timely, accessible and flexible way, at

17 least every 3 months and ensure an agreed written record of

18 supervision is given to the worker

19 • observe workers' practice regularly, at least every 3 months and

20 identify their strengths and development needs

21 • appraise workers' performance regularly and at least annually.

22 The annual appraisal should include a review of workers'

23 learning and development needs, and feedback from people

24 who use the service and their carers.

25 *Recommendations for local authorities*

26 1.6.10 Develop workforce plans for the home care sector, in collaboration

27 with providers, identifying current and future workforce needs.

28 Include training and how such needs might be met by prioritising

29 available local authority resources in the plans.

1 Recommendations for healthcare professionals working in primary and

2 secondary care

3 1.6.11   Liaise with home care workers to provide integrated, person-

4   centred support that promotes wellbeing, particularly for medicines

5   management, pain management and tissue viability care.

6 Recommendations for commissioners

7 1.6.12   Consider commissioning training to ensure health and social care

8   practitioners understand how they should collaborate to provide

9   integrated planning and delivery of home care and support.

10 *1.7   Who should take action*

Who should take action	*Recommendation*
Local authorities	1.2.1, 1.2.2. 1.6.10.
Local authority and health commissioners	1.3.1
Commissioners (incl. CCGs, local authority, self-funders)	1.1.1, 1.1.2, 1.1.3, 1.1.4, 1.1.5. 1.2.3, 1.2.4, 1.2.5, 1.2.6. 1.3.1, 1.3.5, 1.3.6, 1.3.7, 1.3.8, 1.3.9, 1.3.10, 1.3.11. 1.4.1, 1.4.2, 1.4.3. 1.5.6. 1.6.12.
Health service providers	1.3.4
Home care providers	1.1.1, 1.1.2, 1.1,3, 1.1.4, 1.1.5. 1.2.3, 1.2.4, 1.2.5, 1.2.6. 1.3.4, 1.3.22, 1.3.23, 1.3.24, 1.3.25, 1.3.26. 1.4.4, 1.4.5, 1.4.6, 1.4.7, 1.4.8, 1.4.9, 1.4.10. 1.5.7, 1.5.8, 1.5.9. 1.6.1, 1.6.2, 1.6.3, 1.6.4, 1.6.5, 1.6.6, 1.6.7, 1.6.8.

Home care workers	1.4.11, 1.4.12, 1.4.13. 1.5.9.
Home care managers	1.4.4, 1.4.5, 1.4.6, 1.4.7, 1.4.8, 1.4.9, 1.4.10. 1.5.3, 1.5.4, 1.5.5. 1.6.9.
Healthcare practitioners (working in primary and secondary care)	1.5.1, 1.5.2. 1.6.11.
Lead practitioners (or other practitioners planning home care)	1.3.12, 1.3.13, 1.3.14, 1.3.15, 1.3.16, 1.3.17, 1.3.18, 1.3.19, 1.3.20, 1.3.21, 1.3.27, 1.3.28, 1.3.29, 1.3.30. 1.4.14, 1.4.15, 1.4.16, 1.4.17, 1.4.18.
Multidisciplinary teams	1.3.2, 1.3.3.

1

2　Research recommendations

The Guideline Development Group has made the following recommendations for research, based on its review of evidence, to enhance care for people in the future and improve NICE guidance.

2.1　Intensity of home care packages

Research question

What is the cost-effectiveness of different intensities of home care packages for older people with a range of care and support needs?

Why this is important

There is a lack of evidence on the cost-effectiveness of different intensities of home care packages applicable to the UK. Additionally, the 2 included studies that consider the cost-effectiveness of home care only consider home care costs rather than wider resource use.

2.2　Telecare

Research question

What types of telecare are most effective and cost-effective, when provided to older people as part of a package of home care?

Why this is important

There is limited evidence on the components of telecare that could be used as part of a home care package for older people, and their impact. Studies should first collect information on different types of telecare in use, because costs and outcomes are likely to depend on the combination of different components.

Studies should then compare different telecare packages and determine effectiveness and cost-effectiveness of individual components of packages and combinations of components. This could include comparisons with home care packages delivered without a telecare component, or with packages that include other assistive technology. Outcomes for service users should be

1 measured in terms of social care-related quality of life and wellbeing in

2 addition to physical health, acceptability and accessibility (particularly for

3 people with complex needs such as dementia). Studies should collect cost

4 information from a societal perspective. They should include health and social

5 care services, the contribution of carers in the form of unpaid care and out-of-

6 pocket expenditure for privately purchased support.

2.3   Training

7

8 **Research question**

9 What are the effects of different approaches to home care training on

10 outcomes for people who use home care services?

11 **Why this is important**

12 Workforce training is perceived to be beneficial in improving the delivery of

13 home care services to both home care practitioners and people using home

14 care services. The evidence reviewed for this guideline found a lack of

15 evidence on the impact of home care-specific training on outcomes for people

16 using home care.

17 Studies of comparative design are needed to evaluate different approaches to

18 home care training, and their impact on home care workers' practices in

19 improving outcomes for service users and their carers, including aspects of

20 safety and safeguarding. A scoping study needs to be considered to identify

21 the range and content of current training and ongoing support for home care

22 workers, including both specialist and generalist training. Outputs of this work

23 could inform the study design for further evaluation. Studies of qualitative

24 design are needed to ascertain the views and perceptions of older people and

25 their informal carers on worker competence. The views of commissioners and

26 providers on their experiences of training should also be sought.

2.4   Specialist dementia support

Research question

What is the most effective and cost-effective way to support people with dementia living at home?

Why this is important

Dementia is one of the most common conditions in older people using home care services. Home care workers are expected to respond to a wide range of needs, providing both general support (for example personal care) as well as specialist needs. Some home care is delivered by dementia-specific services but there is a lack of evidence about the effectiveness of this approach on outcomes compared with non-specialist home care services (which may instead employ specialist workers or train some workers to develop specialist skills, for example). Future research could involve comparative evaluation or case control studies to determine how to structure the delivery of support so that both a person's specialist dementia needs and general support requirements are accommodated in the most effective way.

2.5   Safety and safeguarding

Research question

What safeguarding practices are most effective in improving outcomes for people using services?

Why it is important

The Guideline Development Group identified variation in organisational attitudes to, and perceptions of, risk in both provider and commissioner organisations. This review found a lack of evidence on the impact of different safeguarding practices on organisational culture, service delivery and outcomes. Studies of comparative design are needed to evaluate the effectiveness of different approaches to safeguarding in maintaining safety and wellbeing of service users and their carers. Analysis of routine monitoring data, for example, from service audits, could illustrate how standards are being met by providers. Surveys and qualitative studies are needed to

1   ascertain the views of older people, and their experiences in respect of safety

2   and safeguarding practice.

3

3 Evidence review and recommendations

Introduction

This guideline was developed in accordance with the processes and methods set out in [The social care guidance manual](#) (2013). The included studies were critically appraised using NICE tools for different study types and the results tabulated (see Appendix B for tables). Where non-standard methods were used or there were deviations from the manual, and for more information on how this guideline was developed, see appendix A.

Rating the included studies was possibly more difficult in social care than in clinical guidelines, as the quality of 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. +/+).

In some cases, studies have been rated according to the quality of methodology applied as economic analyses. Such studies are given (in the notation of -, + and ++) an 'economic evidence rating'. 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 may be included in evidence statements, and taken into account in recommendations, because the GDG independently and by consensus supported its conclusions and thought a recommendation was needed. In the evidence tables below, 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.

A further table reports the details (such as aims, samples) and findings. For full critical appraisal and findings tables, arranged alphabetically by author(s), see appendix B.

3.1 Service user and carer views and experiences

Introduction to the review question

The purpose of these review questions was to consider research which systematically collected the views of service users and carers about home care services. The findings were highly consistent across different UK countries and across different types of study methodologies. Older people agreed on what was important to them and identified that changes were needed to improve services when they were delivered in a way that was consistent with their values. The evidence reviews specific to this topic were undertaken early on in the guideline development process in order that the findings could inform, and be tested against, evidence from other review questions.

The evidence summarised below often does not identify whether it was service users or carers who identified a particular issue or problem. This is

because there was a tendency for researchers to conflate the views of different groups, or to not be explicit about which findings related to which population. However, where carers' views were reported, they indicated very similar concerns to those of older people using services, specifically highlighting the importance of reliability, flexibility, continuity of care, the value of 'caring' characteristics and importance of 'being listened to'.

Review question(s)

Q1.1   What are users' and carers' experiences of home care?

Q1.2   What do they think works well and what needs to change?

Summary of review protocol

The protocol sought to identify studies which would:

- describe the views and experiences of users and carers of home care service;
- highlight aspects of home care which work well, as perceived by service users and their families;
- highlight aspects of home care which service users and their families feel should change in order to improve the service; and,
- contextualise and compare findings from effectiveness questions on home care and consider the extent to which evidence of different kinds is mutually supportive to recommendations.

Population: Older people, aged 65 years and older, who use home care services, and their families, partners and carers.

Intervention: Home care – personal care and practical support – provided by social care practitioners, or by directly employed personal assistants.

Setting: Service users' home, including sheltered housing accommodation, extra care housing, Shared Lives Scheme living arrangement.

Outcomes: None specified in advance, but driven by the data, which concerns narrative or survey-based description of service users' and their

families' views and experience of home care. It was anticipated that the likely outcomes (described or measured) would include: service user satisfaction; quality and continuity of home care; choice and control; involvement in decision-making; dignity and independence; quality of life; health status; safety and safeguarding (as per section 4.4 of the Scope).

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

- systematic reviews of qualitative studies on this topic;
- qualitative studies of service user and carer views of home care;
- qualitative components of effectiveness studies;
- observational and cross-sectional survey studies of service user experience (e.g. Health & Social Care Information Centre reports on service user satisfaction; studies showing the distribution of home care hours).
- grey literature which includes views of people who use services and their carers (possibly as part of 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

Electronic databases in the research fields of social care, health and social science were searched using a range of controlled indexing and free-text search terms based on the setting "home care" and the populations: "older people", "carers", "workforce", "social care organisation". The search aimed to capture both journal articles and other publications of empirical research. Additional searches of websites of relevant organisations was also carried out.

The search for material on this topic was carried out within a single broad search strategy used to identify material which addressed all the agreed review questions on home care. The search strategy did not distinguish

1   research of specific study designs, as filters are often unreliable, so these

2   were to be differentiated at the screening stages of the review.

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

4   **How studies were selected**

5   Search outputs (title and abstract only) were stored in EPPI Reviewer 4 - a

6   software programme developed for systematic review of large search outputs

7   - and screened against an exclusion tool informed by the parameters of the

8   scope. Formal exclusion criteria were developed and applied to each item in

9   the search output, as follows:

10   • Language (must be in English),

11   • Population (must be older people receiving home care, however organised,

12   or their carers)

13   • Intervention (home care)

14   • Setting (home care delivered in person's home)

15   • Country (must be UK, European Union, Denmark, Norway, Sweden,

16   Canada, USA, Australia and New Zealand)

17   • Date (not published before 2004)

18   • Type of evidence (must be research)

19   • Relevance to (one or more) review questions.

20

21   Title and abstract of all research outputs were screened against these

22   exclusion criteria. Those included at this stage were marked for relevance to

23   particular review questions and retrieved as full texts.

24   Full texts were again reviewed for relevance and research design. If still

25   included, critical appraisal (against NICE tools) and data extraction (against a

26   coding set developed to reflect the review questions) was carried out. The

27   coding was all conducted within EPPI Reviewer 4, and formed the basis of the

28   analysis and evidence tables. All processes were quality assured by double

29   coding of queries, and of a random sample of 10%.

In our initial screen (on title and abstract), we found 117 studies which appeared relevant to the review questions. We ordered full texts of 32 papers, which appeared to apply to a UK setting and were therefore most relevant, and were of acceptable methodological quality. On receiving and reviewing the full texts, we identified 18 which fulfilled these criteria (see included studies below). Of these, 7 were qualitative research studies, 6 surveys, 3 mixed methods and 2 studies relying on the secondary analysis of existing data. 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

Characteristics of home care workers

Both the Care Quality Commission (CQC, 2013, evidence level +) and Walsh and Shutes (2013, evidence level +) found that service users valued care workers who demonstrated certain personal qualities. The CQC (2013) reported that service users valued workers who show "… kindness, friendliness and gentleness" (p18), whilst Walsh and Shutes (2013) found that being caring, kind and patient took precedence over technical skills.

In terms of competence, experience and training, Sykes and Groom (2011, evidence level +) found that older people valued the skill and professionalism of their care workers. Similarly, the Older People's Commissioner for Wales (OPCW, 2012, evidence level +) found that 77% of service users said that their care workers 'always' or 'often' had the right knowledge and skills. However, respondents to this survey also highlighted instances when they felt poor training had compromised care, an issue often raised in relation to the care of people with dementia. Although Netten et al (2007, evidence level +) found that some older people associated higher levels of service quality with an older and more highly trained workforce (hours of training), the NVQ2 qualification was negatively associated with service quality.

1 Walsh and Shutes (2013) found that 66% of older people felt that poor English

2 was a significant problem associated with care provided by migrant workers.

3 The impact of poor English on the social and conversational components of

4 care, and the potential for misunderstanding, were a particular concern for this

5 group. Similarly, Sykes and Groom (2011) reported that some older people

6 felt uncomfortable when workers spoke amongst themselves in a language

7 other than English.

8 *Principles of 'good' home care*

9 Feeling in control and maintaining independence was important to older

10 people and carers. Quince (2011, evidence level -/+) found that people with

11 dementia valued home care as it enabled them to be independent, active in

12 the community, and remain in their own home. In contrast, a Department of

13 Health, Social Services and Public Safety of Northern Ireland report

14 (DHSSPS, 2010, evidence level +) found that only 29% of service users said

15 that the help they received made them 'a lot more independent' than they had

16 been. However the study also found that 85% of service users said that they

17 could not manage at all without the help that they get from their care

18 worker(s). A report by the Patient Client Council, Northern Ireland (PCC,

19 2012, evidence level +/+) reported that some participants felt that more

20 practical support from their care worker would help them to achieve more

21 independence.

22 People using home care services also said that communication and 'being

23 listened to' was central to good care (Cattan and Giuntoli, 2010, evidence

24 level +), and that being encouraged and supported to express their views was

25 a positive development (CQC, 2013). The OPCW (2012) found that 72% of

26 older people receiving home care felt that they 'always' or 'often' felt listened

27 to.

28 The potential benefit of home care services in terms of reducing isolation and

29 loneliness was important to people using home care services and carers. A

30 report by the DHSSPS (2010) found that 77% of service users said that their

31 care worker(s) made them feel less lonely. However, Sykes and Groom

32 (2011) reported that some older people felt that care workers rushed through

1   their work leaving little time for conversation, even though this type of social

2   interaction was seen as an important aspect of care.

3   Cattan and Giuntoli (2010) and the London Assembly (2010, evidence level

4   +/+) both reported concerns from some service users regarding the

5   importance of culturally sensitive home care. Cattan and Giuntoli (2010) also

6   found that some service users from minority backgrounds had concerns

7   regarding language barriers which could hinder their ability to communicate

8   their needs and preferences to English speaking care staff.

9   Being treated with dignity and respect is important to people using services.

10 Whilst a report by the CQC (2013) found that some service users felt that they

11 had not been treated with respect by their care worker(s), a report by the

12 DHSSPS (2010) found that 89% of service users who responded felt that they

13 had always been treated with dignity and respect. A report by the PCC (2012)

14 found that most carer respondents viewed home care staff positively and felt

15 reassured by their presence. A report by the CQC (2013) found that some

16 relatives and carers were routinely involved in decisions about care and that

17 this was viewed positively.

18 *Home care in practice*

19 Both Clough et al (2007, evidence level +) and the PCC (2012) reported that

20 older people thought home care should incorporate a wide variety of tasks.

21 The PCC (2012) found that some older people thought definitions of care

22 should be more holistic and take into account non-health and social care

23 related tasks, with 30% of respondents stating that there was something they

24 would like their care worker to do for them which they did not currently do.

25 Clough et al (2007) found that older people felt that home care should

26 incorporate household 'odd jobs', management of personal affairs, shopping,

27 and socialising, recreation and leisure. Similarly, Seddon and Harper (2009,

28 evidence level +) found that some older people felt that home care should be

29 more flexible, for example by allowing staff to take older people shopping

30 rather than collecting it for them. Brannelly and Matthews (2010, evidence

31 level -/-) found that 80% of respondents felt that the existence of a

32 handyperson service was an important factor which enabled them to live at

1 home. People were particularly appreciative when carers were willing to be

2 flexible, and helped them with tasks that were outside realm of 'personal care'

3 such as minor cleaning tasks or pet care (Henderson, 2006, evidence level

4 unrated). A report by the Commission for Social Care Inspection (CSCI,

5 2006, evidence level +) found that some older people felt especially

6 dissatisfied if they were contributing towards the cost of their care and their

7 home care worker refused to carry out certain tasks.

8 Although planning and comprehensive documentation of care needs was

9 viewed positively by service users (CQC, 2013), both the CQC (2013) and

10 Sykes and Groom (2011) found that flexibility was also important. Rigid

11 adherence to care plans in the context of changing needs was seen as

12 inappropriate. A report by the CSCI (2006) found that some older people felt

13 that it was necessary to shift the focus away from plans and record-keeping to

14 ensure that home care remained responsive to service users fluctuating

15 needs and aspirations.

16 *Time to care*

17 Although a report by the DHSSPS (2010) found that 72% of older people

18 thought that the amount of care (in hours) they were allocated was

19 satisfactory, a number of studies reported concerns amongst older people and

20 their carers regarding short visiting slots (CSCI, 2006; London Assembly,

21 2010; Netten et al, 2007; PCC, 2012). The PCC (2012) found that 16% of

22 older people who responded to the survey did not feel that their needs had

23 been met and that this was most commonly attributed to a lack of time. The

24 CSCI (2006) found that older people felt that a 15 minute appointment was not

25 enough time to get dressed properly, and that less than 50% of service users

26 felt that their care worker gave them as much time as they needed. A report

27 by the London Assembly (2010) also found that some older people felt that

28 short time slots undermined the concept of person-centred care. Netten et al

29 (2007) reported that older people associated the incorporation of ten or more

30 minutes of travel time between appointments with higher quality care.

31 Similarly, some respondents to the OPCW study (2012) felt that a lack of

1 allocated travel time had inevitably compromised their care as travel time had

2 to be taken from contact time.

3 Although a report by the DHSSPS (2010) found that 74% of respondents had

4 been asked what times would be convenient for them, Quince (2011) reported

5 that visiting times often varied from day to day, whilst Sykes and Groom

6 (2011) found that some evening visits took place very early in the late

7 afternoon or evening, meaning that the older person had to go to bed before

8 they preferred. Similarly, both the CQC (2013) and the CSCI (2006) found that

9 the reliability of care workers was a concern for older people; however a

10 report by the DHSSPS (2010) found that 69% of service users said that their

11 care worker arrived punctually. The CQC (2013) and the OPCW (2012) found

12 that some older people felt distressed if changes to visiting times were not

13 communicated in advance.

14 *Continuity of care*

15 Sykes and Groom (2011) reported that some older people felt that having the

16 same care worker was essential in building good relationships. Ekosgen

17 (2013, evidence level +) reported that self-funders expected greater continuity

18 in care to be one of the advantages of self-funding. The OPCW (2012) found

19 that only 35% of older people said that their care worker(s) were always

20 familiar to them whilst a report by the DHSSPS (2010) found that only 39% of

21 older people said that they always saw the same care worker(s). A report by

22 the CQC (2013) found that service users appreciated being notified in

23 advance of any changes in personnel and Sykes and Groom (2011) reported

24 that some older people had received no warning when their care worker was

25 changed. A report by the London Assembly (2010) found that having to

26 explain care needs to each new member of staff was frustrating and could be

27 particularly challenging for those individuals with communication difficulties.

28 Having to 'train' new staff was also identified as an issue by the CSCI (2006).

29 Ekosgen (2013) found that although people expected that care arranged

30 and/or funded by themselves or their carers would result in higher levels of

31 continuity and flexibility of care, and improved relationships ('personal

32 chemistry'), many self-funders found the employment aspects difficult and

stressful. The researchers note that some participants were clearly paying relatively high fees and/or had in place distinctly inflexible care plans. Lakey and Saunders (2011, evidence level -/+) also reported that direct employment could benefit people with dementia who needed social activity, flexible approaches and support with practical issues, but again, there was a lack of support for people with dementia and their carers to arrange DPs.

Complaints procedures

A London Assembly report (2010) found that older people and their carers often found complaints procedures to be confusing and did not believe that their concerns would be taken seriously. Similarly, a report by the CSCI (2006) found that older people felt that complaints systems were an ineffective means of ascertaining service user satisfaction. Both the London Assembly (2010) and the PCC (2012) reported that some older people feared that lodging a complaint would negatively affect their service provision.

Evidence statements (including economic evidence statements)

1.1	**Value of home care to users in promoting independence**
	There is moderate and good evidence from two UK mixed methods studies (Quince, 2011, -/+; Lakey and Saunders, 2011, -/+), and one Northern Ireland survey (DHSSPS, 2010, +) that home care users, including those with dementia (Quince, 2011, -/+; Lakey and Saunders, 2011, -/+), value home care because it enables them to live at home independently. There is also good evidence from a UK survey (PCC, 2012, +/+) that some people feel that more practical support, such as help with household tasks, would help them achieve greater independence and control over their lives.
1.2	**Users' views of quality of care**
	There is good evidence from one UK qualitative (Sykes and Groom, 2011, +) and two UK survey studies (OPCW, 2012,+; Netten et al, 2007, +) that users recognise and value the competence of home care workers, and some good evidence from the first survey that poor training may compromise the quality of care (OPCW, 2012, +).
1.3	**Users value kind and caring workers and developing relationships**
	There is good evidence from a number of UK studies, for example, a survey (CQC, 2013, +) and a qualitative study (Walsh and Shutes, 2013, +), consistent over most studies, that users and carers acknowledge and value warm, kind and caring home care workers, and the ability to develop relationships by having continuity of workers.
1.4	**Importance of communication and 'being listened to'**
	There is very good evidence from a UK qualitative study (Cattan and Giuntoli, 2010, +) and two UK surveys (CQC, 2013, +; OPCW, 2012, +) that good communication, 'being listened to' and encouraged to express their views is important to service users and carers.

1.5	**Importance of having the same worker(s)**
	There is good evidence from a UK qualitative study (Sykes and Groom, 2011, +), one UK survey (OPCW, 2012, +) and a UK mixed methods study (London Assembly, 2010, +/+) that older people value having the same familiar workers, but that they are not always made aware of a change in personnel, causing anxiety and raising the need for training in that person's particular needs.
1.6	**Language as a barrier to good communication**
	There is good evidence from two UK qualitative studies (Walsh and Shutes, 2013, +; Sykes and Groom, 2011, +) that communication is hampered if the worker and the person they care for do not speak the same language.
1.7	**Home care workers reduce isolation, but may be too rushed to chat**
	There is good evidence from a survey done in Northern Ireland (DHSSPS, 2010, +) that contact with home care workers can reduce isolation and loneliness, but also good evidence from a UK qualitative study (Sykes and Groom, 2011, +) that some older people feel that care tasks are rushed and that some older people feel that care tasks are rushed and there is no time for conversation.
1.8	**Dignity, respect and ability to deliver culturally appropriate home care**
	There is good evidence from two UK surveys (DHSSPS, 2010, +; CQC, 2013, +), that, while most service users feel they are treated with dignity and respect, not everyone feels this way, and that there are particular shortcomings reported in a UK qualitative study (Cattan and Giuntoli, 2010, +), and in a UK mixed methods study; (London Assembly, 2010, +/+) in the delivery of culturally appropriate services, and matching care workers to users who speak the same language.
1.9	**Home care provision is not holistic and does not cover the identified needs of users**
	There is good evidence from a UK qualitative study (Clough et al, 2007, +) and a UK survey (PCC, 2012, +/+) that older people feel that home care should incorporate a wider variety of tasks. Some older people felt that definitions of care should be more holistic and take into account non-health and social care related tasks, 'odd jobs', management of personal affairs, shopping, socialising, recreation and leisure. Similarly, a further UK qualitative study (Seddon and Harper, 2009, +) found that some older people felt that home care should be more flexible, for example by allowing staff to take older people shopping rather than collecting it for them. People contributing to the cost of care were particularly dissatisfied with this inflexibility, according to a UK secondary data study (CSCI, 2006, +).
1.10	**Care plans are applied inflexibly and do not respond to changing needs**
	There was good evidence from a UK survey (CQC, 2013, +) a UK qualitative study (Sykes and Groom, 2011, +) and a UK secondary data study (CSCI, 2006, +) that users and carers felt that rigid adherence to care plans was unhelpful, and that these need to be responsive to fluctuating needs. They also felt that too much attention was given to record keeping (using time that could be used for responsive caring).

1.11	Users' and carers' views on allotted time slots
	There is good evidence from several UK studies, a secondary data study (CSCI, 2006, +), a mixed methods study (London Assembly, 2010 +/+) and two surveys (Netten, 2007, +; PCC, 2012, +/+) that many older people felt that short time slots compromised the quality and scope of home care. A lack of travel time between slots was noted by users and carers as a contributory factor in a survey (OPCW, 2012, +).
1.12	**Appointments may be missed, and times set may be unfit for purpose**
	There is good and moderate evidence from a UK qualitative study (Sykes and Groom, 2011, +); a less robust UK mixed methods study (Quince, 2011, -/+) and two UK surveys (CQC, 2013, +; OPCW, 2012, +) that care visits are not always made as arranged, causing distress to older people, and that the timing of visits, especially those designed to help with going to bed, could be at inappropriate times.
1.13	**Personal assistants may allow more choice and flexibility**
	There is moderate evidence from a UK qualitative study (Ekosgen, 2013, +) and a UK mixed methods study (Lakey and Saunders, 2011, -/+) that people arranging or funding their own care hope to benefit from greater continuity of care, better relationships and care tailored more precisely to their needs, but that many found the lack of support to employ carers caused them stress and anxiety, and might mean that their care was not good value.

1

2 **Included studies for these review questions**

3 Brannelly T and Matthews B (2010) When practical help is valued so much by

4 older people, why do professionals fail to recognise its value? Journal of

5 Integrated Care 18: 33 – 40

6 Callaghan L and Towers A M (2014) Feeling in control: comparing older

7 people's experiences in different care settings. Ageing and Society 13: 1427-

8 1451

9 Care Quality Commission (2013) Not just a number: home care inspection

10 programme - national overview. Newcastle: Care Quality Commission

11 Cattan M and Giuntoli G (2010) Care and support for older people and carers

12 in Bradford: their perspectives, aspirations and experiences. York: Joseph

13 Rowntree Foundation

14 Clough R, Manthorpe J, ORPSI et al. (2007) The support older people want

15 and the services they need. York: Joseph Rowntree Foundation

1 Commission for Social Care Inspection (CSCI) (2006) Time to care? Towards

2 excellence in adult social care. London: Commission for Social Care

3 Inspection

4 Department of Health, Social Services and Public Safety (DHSSPS) (2010)

5 Survey of Home Care Service Users Northern Ireland 2009. Belfast:

6 Department of Health, Social Services and Public Safety

7 Ekosgen (2013) The workforce implications of adults and older people who

8 self-fund and employ their own care and support workers. Leeds: Skills for

9 Care

10 Henderson C (2006) Time and other inputs for high quality social care:

11 Wanless social care review. London: King's Fund

12 Lakey L and Saunders T (2011) Getting personal? Making personal budgets

13 work for people with dementia. London: Alzheimer's Society

14 London Assembly (2010) Home truths: older Londoners' access to home care

15 services. London: Greater London Authority

16 Netten A, Jones K, Sandhu S (2007) Provider and Care Workforce Influences

17 on Quality of Home-Care Services in England. Journal of Aging & Social

18 Policy 19: 81-97

19 Older People's Commissioner for Wales (2012) My home, my care, my voice:

20 older people's experiences of home care in Wales. Cardiff: Older People's

21 Commissioner for Wales

22 Patient and Client Council (PCC) (2012) Care at Home. Older people's

23 experiences of domiciliary care. Belfast: Patient Client Council

24 Quince C (2011) Support. Stay. Save: care and support of people with

25 dementia in their own homes. London: Alzheimer's Society

26 Seddon D and Harper G (2009) What works well in community care:

27 supporting older people in their own homes and community networks. Quality

28 in Ageing 10: 8-17

1 Sykes W and Groom C (2011) Older people's experiences of home care in

2 England. Manchester: Equality and Human Rights Commission

3 Walsh K and Shutes I (2013) Care relationships, quality of care and migrant

4 workers caring for older people. Ageing and Society 33: 393-420

5 ## 3.2   *Practitioner views and experiences*

6 **Introduction to the review questions**

7 These review questions aimed to establish the views of home care held by

8 home care practitioners, managers, commissioners of home care and primary

9 healthcare staff (with whom home care staff might expect to liaise). In

10 particular, the questions sought to understand the aspects of their working

11 conditions which home care workers thought inhibited them from delivering

12 higher quality care to people using services; and to understand how this

13 impacted on their job satisfaction. In addition, research detailing the

14 experience of managers of home care services could identify the problems,

15 including recruitment, retention and absenteeism, which made it difficult at

16 times to deliver a reliable service. Some of these factors were expected to

17 derive from commissioning practices, including restrictions on time and tasks

18 which were written into care plans. Although commissioning itself was out of

19 scope, it was hoped that research material found would include the views of

20 commissioners. It was thought that evidence from this material would show

21 how and why the outcomes of home care which service users and carers

22 value were not always delivered, and what changes were required to support

23 service improvement

24 **Review question(s)**

25 2.1 What are the views and experiences of home care practitioners, service

26 managers and commissioners procuring or delivering services?

27 2.2 What do they think works well and what needs to change?

28 **Summary of review protocol**

29 The protocol sought to identify studies which would:

- describe the views and experiences of people delivering, organising and commissioning home care services;
- collect evidence on key workforce and practice issues which we may consider within the guidance;
- highlight aspects of home care which work well, as perceived by practitioners, managers and commissioners;
- highlight aspects of home care which providers and commissioners feel should change in order to improve the service;
- contextualise and compare findings from effectiveness questions on home care and consider the extent to which evidence of different kinds is mutually supportive to recommendations; and,
- collect the views of commissioners on what services should be provided to inform the guidance (although commissioning models were out of scope).

Population: Practitioners (home care workers), managers, social workers, care managers, coordinators, and commissioners of home care services for older people, aged 65 years and older. Primary and community healthcare staff who work with or liaise with home care service providers or with the older people using home care services were also included, as were views of personal assistants.

Intervention: Home care – personal care and practical support – provided by social care practitioners or by directly employed personal assistants.

Setting: Service users' home, including sheltered housing accommodation, extra care housing, Shared Lives Scheme living arrangement.

Outcomes: None specified in advance, but driven by the data, which concerns narrative or survey-based description of practitioners' views and experiences of home care services, their impact on outcomes for people using services and for organisations. It was anticipated that the likely outcomes (described or measured) would include: service user satisfaction; quality and continuity of home care; choice and control; involvement in decision-making; dignity and independence; quality of life; health status; safety and safeguarding. It was also expected that data would address employee and

organisational outcomes such as: productivity, consistency in care provision, staff retention rates job satisfaction; condition of work; organisational issues, perceived competency; work-related training and supervision issues; quality of home care provided (as per section 4.4 Scope).

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

- systematic reviews of qualitative studies on this topic;
- qualitative studies of provider, manager and commissioner views of home care;
- qualitative components of effectiveness studies;
- observational and cross-sectional survey studies of home care provided (e.g. NHSIC reports showing the distribution of home care hours).
- research-based findings from organisations representing providers (e.g. UKHCA) may also be considered as evidence.

Full protocols can be found in Appendix A.

Summary of how the literature was searched

Electronic databases in the research fields of social care, health and social science were searched using a range of controlled indexing and free-text search terms based on the setting "home care" and the populations: "care professional(s)"; "care provider(s)"; "care co ordinat*"; "social worker*"; "Care supervi*" "Care worker(s)"; "workforce", "social care organisation".

The search aimed to capture both journal articles and other publications of empirical research. Additional searches of websites of relevant organisations were also carried out.

The search for material on this topic was carried out within a single broad search strategy used to identify material which addressed all the agreed review questions on home care. The search strategy did not distinguish research of specific study designs, as filters are often unreliable, so these were to be differentiated at the screening stages of the review.

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

Summary of 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 which identified the included studies, excluding those outside scope. Formal exclusion criteria were developed and applied to each item in the search output:

- Language (must be in English),
- Population (must be practitioners, home care workers, managers, social workers, care managers, coordinators, or commissioners of home care services for older people, aged 65 years and older)
- Intervention (home care)
- Setting (home care delivered in person's home)
- 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 139 studies which appeared relevant to the review question. We ordered full texts of 34 papers, which appeared to apply to a UK setting and were therefore most relevant, and were of acceptable methodological quality. On receiving and reviewing the full texts, we identified 22 which fulfilled these criteria (see included

studies below). 14 of these were qualitative studies, 5 used survey studies and 3 used mixed methods. 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

Person-centred approaches to care

Seddon and Harper (2009, evidence level +) reported that care managers identified the importance of enabling older people living in their own homes to maintain community connections and draw on existing community facilities. To be effective, support needs to be underpinned by a person-centred approach which takes into account individual preferences and priorities, and is organised locally to where older people live.

Working conditions

In terms of job satisfaction, Hall and Wreford (2007, evidence level +) found that 88% of workers said that their job made them happy, whilst Rubery et al (2011, evidence level +) found that 83% (of a different study sample) intended to remain in the sector. Reasons given for satisfaction included the rewarding nature of the work and the chance to meet and talk with clients. However, Hall and Wreford also reported that care workers found cleaning up messes, challenging behaviour and the death of clients to be particularly difficult features of their work. Their survey also found that 63% of care workers felt that the public did not understand the work that they do, whilst only 39% felt that their work was valued.

Angel (2012, evidence level +), Rubery et al (2011, evidence level +) and Unison (2012, evidence level +) all highlighted dissatisfaction amongst workers at the low rates of pay they received. This was seen to be exacerbated by the lack of pay for travel time which could often result in unpaid overtime. The Unison survey (2012) also found that 41.7% of respondents were employed on 'zero hours' contracts which were identified as

1 a further barrier to securing an adequate wage. Fleming and Taylor (2007,

2 evidence level +) report that the three main reasons for dissatisfaction among

3 workers (in ranking order) are: irregular and antisocial hours; lack of

4 management support; and workload pressures.

5 Angel (2012, evidence level +) found that 74% of providers said that over the

6 last 12 months, the councils they traded with had become more interested in

7 securing a low price over the quality of service delivered. Over half (53%)

8 reported that the council that they traded with had stated a maximum price

9 which they were prepared to pay for home care services.

10 In terms of relationships with other professionals, Duff and Hurtley (2012,

11 evidence level –) reported that some workers experienced difficulties in

12 liaising with healthcare services due to: confidentiality procedures enforced by

13 receptionists; refusal to accept referrals from care assistants; and, difficulties

14 in contacting and coordinating visits with healthcare professionals. Hek et al

15 (2004, evidence level +) reported that a pilot 'generic worker' role (working in

16 collaboration with district nurses) improved communication with nursing staff.

17 The study also found that staff who took part in the pilot felt that they were

18 valued more by other professionals than they had been as social care

19 workers. Unison (2012) found that some home care workers felt isolated and

20 that only 43% of respondents saw colleagues on a daily basis at work. This

21 was perceived to negatively impact on morale and hinder learning and

22 development.

23 ***Qualifications, training and development***

24 Hall and Wreford (2007) found that the majority of workers they spoke to held

25 NVQ Level 2 qualifications, although 20% had no qualifications at all. The

26 survey also found that only 15% of care workers were seeking promotion in

27 the next two years, with 24% stating that they did not want the extra

28 responsibility.

29 Unison (2012) found that the majority of respondents were critical of the

30 standard and amount of training provided and that 41.1% of survey

31 respondents had not been given specialist training to deal with their clients'

1 specific medical needs, such as dementia and stroke. Duff and Hurtley (2012)

2 also found that both staff and managers felt that training in communication

3 with people with dementia, and in responding to anxiety and distress were

4 especially important. Some respondents suggested that this could be

5 delivered by healthcare professionals accompanying care workers on visits

6 and providing training in situ.

7 Francis and Netten (2004, evidence level +) found that some managers

8 believed that whilst caring skills are 'instinctive' they also thought that they

9 could be instilled, maintained and assessed through induction and training.

10 ***Time to care***

11 There were several studies which highlighted discontent amongst care

12 workers with the length of time which was allocated per visit. Figures from

13 both Unison (2012) and Duff and Hurtley (2012) suggested that staff believed

14 that the 15 minute visits commissioned did not allow enough time to provide

15 good quality care. Walsh and Shutes (2013, evidence level +) reported that

16 some interviewees felt that time constraints acted as a barrier to the

17 development of good relations between service users and care workers. This

18 was also an issue raised by service providers with Angel (2012) reporting that

19 34% of providers expressed concern that their councils required them to

20 undertake personal care in such short timeframes that the dignity of service

21 users was at risk. Wibberley (2013, evidence level +) suggests that time

22 pressures can mean that workers have to endure unclean workplaces and-

23 are unable to help their elderly clients with basic cleaning tasks.

24 Francis and Netten (2004) found that some managers felt that reliability of

25 service provision was not within their control. Appointments overrunning when

26 workers found that clients were ill or injured, and who therefore required more

27 care, and the impact of traffic were seen as especially problematic in this

28 regard. Some managers suggested that local authority commissioning

29 arrangements which do not factor in travel time costs also made it difficult to

30 deliver a reliable service.

1 Francis and Netten (2004) found that some managers recognised that

2 continuity of care was important for service users, particularly in the provision

3 of intimate personal care. In order to address this issue managers reported

4 attempts to create teams of workers who worked regularly with individual

5 service users. The study also found that other organisations had arranged

6 introductory visits to enable service users to meet their new home care worker

7 in advance of their assumption of the role. Similarly, Devlin and McIlfatrick

8 (2010; evidence level +) found that Community Nurses thought that continuity

9 of home care staff was a crucial and integral feature of high quality palliative

10 care. Francis and Netten (2004) also highlight practitioner concerns regarding

11 inadequate sick leave procedures and high staff turnover as factors which

12 could negatively impact on continuity of care.

13 Roberts (2011, evidence level +) drew attention to the importance of

14 timeliness for supporting people with dementia, with the need to build good

15 relationships early between paid carers and the person using services (before

16 a person's decline into poorer health or wellbeing inhibits this process).

17 Reviews should also occur at the right time to respond to the changing needs

18 of people with dementia.

19 ***Roles of home care workers***

20 Cooper and Urquhart (2005, evidence level +) found that some care workers

21 were uncomfortable with the lack of boundaries of the home care worker role,

22 reporting that they had sometimes been asked to assist with relatively simple

23 personal care tasks which uncovered more serious health problems that they

24 felt unqualified to deal with. This study also found that some care workers felt

25 that their visits could lead to further isolation of the older person as, once

26 relieved of caring responsibilities, some friends and family stopped visiting

27 altogether. Patmore (2004, evidence level +) found that there was a great deal

28 of variation in terms of what tasks home care workers are permitted to do, in

29 addition to the normal 'personal care tasks'.

30 Rubery et al (2011) found that the majority of care workers in the study were

31 not attracted to the role of personal assistant given its one-to-one nature and

32 the risk that caring for one service user could prove emotionally draining.

1 Some respondents also felt that the role would reduce the variety of tasks

2 which care workers carry out and value. Other respondents felt that this role

3 was likely to negatively impact on job security and create a barrier to the type

4 of support from colleagues which can usually be found through working in

5 teams. Ekosgen (2013, evidence level +) highlights that for personal

6 assistants (PAs) the lack of sick pay available is an area which can make their

7 working inflexible; specifically, this means that they are rarely able to take

8 days off, although an example is given of a local network of PAs who support

9 each other with these kind of situations.

10 *Migrant workers*

11 Cangiano et al (2009; evidence level ++/+) found that the majority of

12 employers in the study recruited migrant workers due to a shortage of 'UK

13 born' workers. This was generally attributed to low pay and poor working

14 conditions; issues also identified by respondents in Manthorpe et al (2010;

15 evidence level +). Irregular shift patterns, physically intense labour and low

16 status were seen as particularly discouraging features of home care work.

17 Cangiano et al (2009, evidence level ++/+) found that 80% of managers

18 believed that the recruitment of migrant workers had improved the quality of

19 service, with many regarding these staff as flexible, reliable and hard workers.

20 In contrast, Walsh and Shutes (2013) reported that only 30% of managers felt

21 that the employment of migrant workers had improved care quality.

22 Both Walsh and Shutes (2013) and Manthorpe et al (2010) reported that some

23 managers had concerns regarding the language skills of migrant workers and

24 felt that poor English could potentially cause difficulties when caring for older

25 people, particularly those with hearing impairments.

26 Cangiano et al (2009) and Manthorpe et al (2010, evidence level +) found that

27 some employers and agencies felt ill equipped to manage relationships

28 between older service users and migrant workers when cultural and racial

29 tensions arose. This was thought to be particularly difficult when older

30 people's negative perceptions were founded on concerns about care workers

31 language skills or knowledge of customs.

1 *Funding mechanisms*

2 Clark et al (2004; evidence level +) reported that most care managers

3 interviewed believed that Direct Payments (DPs) gave more independence,

4 control and flexibility to service users. These respondents also reported that

5 DPs alleviated time pressures on their own role as they did not have to deal

6 with 'day to day care issues' such as care assistants not arriving for scheduled

7 visits. However, the study also found that some managers felt that DPs were

8 unsuitable for service users who have dementia. Moran et al (2013, evidence

9 level +) found that care managers who work with older people struggled with

10 the implementation of IBs with their client groups (of all types of care

11 manager), due to concerns over whether older people would be capable of

12 using them and a higher fear of risk, so presented as being least able to

13 devolve control to users. Both Clark et al (2004) and Manthorpe and Stevens

14 (2010, evidence level +) point towards the potential for DPs and personal

15 budgets to enable people to purchase tailored, individual services which meet

16 their personal needs.

17 *Do practitioners take into account the views of service users?*

18 Service user views – A Northern Ireland Department of Health, Social

19 Services and Public Safety report (2009; evidence level +) found that 95% of

20 service providers had, in the 12 months prior to the survey, sought the views

21 of their service users or their representatives about the home care services

22 they receive, with 72% stating that they had made changes in response to this

23 information.

24 **Evidence statements**

2.1	**Practitioners' views of the importance of person-centred care**
	There is good evidence from one UK qualitative study (Seddon and Harper, 2009, +) that care managers recognised the importance of effective support that is underpinned by a person-centred approach which takes into account individual preferences and priorities, and is organised locally to where older people live.
2.2	**Job satisfaction and the 'value' attached to care work**
	There is good evidence from two independent UK surveys (Hall and Wreford, 2007, +; Rubery et al, 2011, +) of high levels of job satisfaction among care workers. 88% of respondents (Hall and Wreford, 2007) enjoyed their work, and 83% of respondents to the Rubery et al, 2011 survey said that they intended to stay in the sector because they found

	home care work rewarding. Hall and Wreford (2007) also found that the work fitted in with other caring responsibilities. However, 63% of care workers they surveyed felt that the public did not understand the nature of their work and 39% of care workers felt undervalued.
2.3	**Job dissatisfaction: Terms of employment and remuneration**
	There is good evidence from three UK surveys (Angel, 2012, +; Rubery et al, 2011, +; Unison, 2012, +) that dissatisfaction among home care workers relates to low wages because of 'zero hours' contracts and unpaid travel time. Over 41% of care workers were employed on 'zero hours' contracts Unison, 2012, +). There is good evidence from another UK study using mixed methods (Fleming and Taylor, 2007, +) to suggest that the main reasons for work dissatisfaction among care workers are organisational issues: irregular and antisocial hours; lack of management support and workload pressures.
2.4	**Job dissatisfaction: Relationships with other professionals**
	There is moderate evidence from two UK qualitative studies (Hek et al, 2004, +; Duff and Hurtley, 2012, -) that care workers experience difficulties in liaising and coordinating with healthcare services regarding home visits due to referral refusals and confidentiality issues. Care assistants working in collaboration with district nurses reported improved communication with nursing staff and felt valued by other professionals.
2.5	**Qualifications, career progression and training**
	There is moderate evidence from one UK survey (Hall and Wreford, 2007, +) that most care workers held NVQ Level 2 qualifications but 20% held no qualifications. Fifteen percent of care workers were seeking promotion in the next two years, whereas 24% said they did not want the extra responsibility.
2.6	**Standards of training, especially in specialist care**
	There is moderate evidence from one UK survey (Unison, 2012, +) to suggest that care workers were critical of the standard and amount of training provided and that 41% of care workers had not been given specialist training to deal with their clients' specific medical needs, such as dementia and stroke care. A further UK qualitative study (Duff and Hurtley, 2012, -) found that both staff and managers felt that training in communication with people with dementia, and in responding to anxiety and distress, was needed.
2.7	**Ability to care**
	There is good evidence from one qualitative study (Francis and Netten, 2004, +) that some managers believed that whilst caring skills are 'instinctive', they could be instilled, maintained and assessed through induction and training.
2.8	**Time to care: Duration of visit and impact on care**
	There is good evidence from a range of UK studies that care workers thought that time allowed for visits was insufficient. Moderately good evidence from one qualitative study (Duff and Hurtley, 2012, -) and one survey (Unison, 2012, +) suggests that care workers believed that the use of 15 minute visits was not enough time to provide good quality care. There is good evidence from one qualitative study (Walsh and Shutes, 2013, +) to suggest that time constraints acted as a barrier to the development of good relations between service users and care workers. Good evidence from a survey (Angel, 2012, +) found that 34% of providers expressed concern that undertaking personal care in such short timeframes was putting the

	dignity of service users at risk. There is good evidence from one qualitative study (Wibberley et al, 2013, +) that due to time pressures, care workers often endure unclean workplaces (users' homes) as they are not able to help their elderly clients with cleaning.
2.9	**Time to care: Flexibility and reliability of visiting times**
	There is good evidence from one UK qualitative study (Francis and Netten, 2004, +) that some managers believed they had little control over the provision of a reliable service when visits overran due to ill or injured clients who required more care, as well as the impact of traffic on travelling to the next client. Some managers suggested that local authority commissioning arrangements should factor in travel time costs.
2.10	**Time to care: Continuity of care**
	There is good evidence from one UK qualitative study (Francis and Netten, 2004, +) that managers recognised the importance of continuity of care and made attempts to create teams of workers who worked regularly with individual service users, arranged introductory visits to enable service users to meet their new home care worker in advance. Inadequate sick leave procedures and high staff turnover are concerns which could negatively impact on continuity of care. There is moderate evidence from one UK qualitative study (Devlin and McIlfatrick, 2010, +) that community nurses perceived continuity of home care staff as an integral feature of high quality palliative care.
2.11	**Dementia care**
	There is good evidence from one UK qualitative study (Roberts, 2011, +) that it is important to provide timely support to people with dementia, with the need to build good relationships early between carers and the user before a person's decline into poorer health.
2.12	**Roles and tasks of home care workers**
	There is good evidence from one UK qualitative study (Cooper and Urquhart, 2005, +) that care workers were uncomfortable when they uncovered potentially serious health problems which they felt unqualified to deal with. Care workers also felt that their visits could lead to further isolation of the older person, because friends and family stopped visiting in the belief that the person's needs were now met. One moderate qualitative study (Patmore, 2004, +) suggested that there was variation in terms of what tasks home care workers are permitted to do, in addition to the normal 'personal care tasks'. In dealing with individual clients, respondents to the UK survey conducted by Hall and Wreford (2007, +) said they found it difficult to deal with issues such as cleaning up messes, challenging behaviours and the death of the clients.
2.13	**Home care workers' views of the roles of Personal Assistants**
	There is evidence from one good UK qualitative study (Rubery et al, 2011, +) that care workers thought that the role of personal assistant could be emotionally draining, and lack variety, given its one-to-one nature of caring for one service user over a period of time. Working for one person might negatively impact on job security and there would be no support from colleagues. Evidence from another good UK qualitative study (Ekosgen, 2013, +) also suggested that, for personal assistants, there's a likelihood of lack of sick pay and not being able to take days off, making their working inflexible.

2.14	**Migrant care workers: Reasons for recruitment**
	There is very good evidence from one mixed methods UK study (Cangiano et al, 2009, ++/+) and one good UK qualitative study (Manthorpe et al, 2010, +) that migrant workers were recruited due to a shortage of 'UK born' workers, a shortage generally attributed to the low pay, irregular shift patterns, physically intense labour, low status and poor working conditions associated with the work.
2.15	**Migrant care workers: Impact on quality of** services
	There is evidence from one good UK mixed methods study (Cangiano et al, 2009, ++/+) to suggest that 80% of managers believed that the recruitment of migrant workers had improved the quality of service, with many regarding these staff as flexible, reliable and hard workers. However, there is also evidence from one good UK qualitative study (Walsh and Shutes, 2013, +) that only 30% of managers felt that the employment of migrant workers had improved care quality.
2.16	**Migrant care workers: Language and cultural barriers**
	There is evidence from two good UK qualitative studies (Walsh and Shutes, 2013, +; Manthorpe et al, 2010, +) that managers had concerns regarding the language skills of migrant workers and felt that poor English could potentially cause difficulties when caring for older people, particularly those with hearing impairments.
2.17	**Migrant care workers: Discrimination in the workplace**
	There is evidence from one very good UK mixed methods study (Cangiano et al, 2009, ++/+) and one good UK qualitative study (Manthorpe et al, 2010, +) that employers and agencies felt ill-equipped to manage relationships between older service users and migrant workers when cultural and racial tensions arose., It was recognised that older people's negative perceptions were sometimes founded on concerns about care workers' language skills or knowledge of customs.
2.18	**Response to service users' views by care providers**
	There is evidence from one good survey from Northern Ireland (DHSSPS, 2008, +) that 95% of service providers had, in the 12 months prior to the survey, sought the views of their service users or their representatives about the home care services they receive, with 72% stating that they had made changes in response to this information.
2.19	**Budgetary constraints**
	There is good evidence from one UK survey (Angel, 2012, +) that 74% of providers said that over the last 12 months, the councils they traded with had become more interested in securing a low price over the quality of service delivered. Over half (53%) reported that the council that they traded with had stated a maximum price which they would pay for home care services.
2.20	**Views on direct payments**
	There is good evidence from two UK qualitative studies (Clark et al, 2004, +; Manthorpe and Stevens, 2010, +) that care managers recognised the potential of IBs and DPs and believed they enabled people to purchase tailored, individual services which meet their personal needs, thus giving more independence, control and flexibility to service users. Managers felt that DPs were unsuitable for service users who have dementia. There is good evidence from one UK mixed methods study (Moran et al, 2013, +) which involved interviews with IB leads in sites where IBs had been piloted.

> IB leads suggested that care managers of older people may struggle the most with implementing IBs with their client groups due to concerns over whether older people would be capable of using them.

Included studies for this review question

Angel C (2012) Care is not a commodity. Sutton: United Kingdom Home care Association

Cangiano A, Shutes I, Spencer S et al. (2009) Migrant care workers in ageing societies: research findings in the United Kingdom. Oxford: ESRC Centre on Migration Policy and Society

Clark H, Gough H, Macfarlane A (2004) 'It pays dividends'. Direct payments and older people. Bristol: Joseph Rowntree Foundation

Cooper J and Urquhart C (2005) The information needs and information-seeking behaviours of home-care workers and clients receiving home care. Health Information and Libraries Journal 22: 107-116

Department of Health, Social Services and Public Safety (2009) Survey of Domiciliary Care Providers Northern Ireland 2008. Belfast: Department of Health, Social Services and Public Safety

Devlin M and McIlfatrick S (2010) Providing palliative care and end-of-life care in the community: the role of the home-care worker. International Journal of Palliative Care Nursing 16: 195-203

Duff P and Hurtley R (2012) Challenges facing domiciliary care agencies delivering person centred care. Working with Older People 16: 61-68

Ekosgen (2013) The workforce implications of adults and older people who self-fund and employ their own care and support workers. Leeds: Skills for Care

Fleming G and Taylor B J (2007) Battle on the home care front: Perceptions of home care workers of factors influencing staff retention in Northern Ireland. Health and Social Care in the Community 15: 67-76

1 Francis J and Netten A (2004) Raising the quality of home care: a study of
2 service users' views. Social Policy and Practice 38: 290-305

3 Hall L and Wreford S (2007) National survey of care workers: final report.
4 Leeds: Skills for Care

5 Hek G, Singer L, Taylor P (2004) Cross-boundary working: a generic worker
6 for older people in the community. British Journal of Community Nursing 9:
7 237-245

8 Manthorpe J, Hussein S, Charles N (2010) Social care stakeholders'
9 perceptions of the recruitment of international practitioners in the United
10 Kingdom - a qualitative study. European Journal of Social Work 13: 393-409

11 Manthorpe J and Stevens M (2010) Increasing care options in the
12 countryside: developing an understanding of the potential impact of
13 personalization for social work with rural older people. British Journal of Social
14 Work 40: 1452-1469

15 Moran N, Glendinning C, Wilberforce M et al. (2013) Older people's
16 experiences of cash-for-care schemes: evidence from the English Individual
17 Budget pilot projects UK. Ageing and Society 33: 826-851

18 Patmore C (2004) Quality in home care for older people: factors to pay heed
19 to. Quality in Ageing 5: 32-40

20 Roberts J (2011) Improving domiciliary care for people with dementia: a
21 provider perspective. Bristol: South West Dementia Partnership

22 Rubery J, Hebson G, Grimshaw D et al. (2011) The recruitment and retention
23 of a care workforce for older people. Manchester: Manchester Business
24 School

25 Seddon D and Harper G (2009) What works well in community care:
26 supporting older people in their own homes and community networks. Quality
27 in Ageing and Older Adults 10: 8-17

1   UNISON (2012) Time to care: A UNISON report into home care. London:

2   Unison

3   Walsh K and Shutes I (2013) Care relationships, quality of care and migrant

4   workers caring for older people. Ageing and Society 33: 393-420

5   Wibberley G (2013) The problems of a 'dirty workplace' in domiciliary care.

6   Health and Place 21: 156-162

7

3.3   *Care planning and delivery approaches*

Introduction to the review questions

Review questions around home care services reflect the fact that home care may be delivered, planned and commissioned in different ways. Home care may be organised and paid for by local authorities, or by people needing the service and their families, perhaps through the use of personal budgets. The 'content' of the home care intervention may be described as a series of tasks, an amount of time spent with the service user, or as a series of outcomes, such as ensuring that the person is enabled to visit a friend on a designated day. These variations in funding and identifying what is delivered may reflect the degree to which services feel 'person-centred' and responsive to the needs of the person using services. There was evidence from people using services and their families, and from practitioners, that variations in funding and determining the content of home care could have positive and negative effects on their perception of the quality of home care.

In addition, home care is often part of a package of health and social care, which may be overseen by a case manager or a care coordinator. Family carers may themselves take on this function when there is no designated coordinator. It was thought important that home care workers, who may be the most frequent visitor to a person's home, should be able to liaise with other practitioners involved in care. Case management, care coordination services, integrated health and social care service models and less formal models of

1   contact between practitioners were therefore included in our search for

2   evidence on home care practice.

3   We sought research evidence on both measurable impacts of different

4   approaches and service frameworks, and on their value to people using home

5   care services and their family carers. This evidence was designed to consider

6   how the quality of home care could be improved, what features of home care

7   might contribute to, or impede, delivery of high quality home care, and how

8   harmful effects could be minimised or eliminated.

9   **Review question(s)**

10   Q 3.1 What approaches to home care planning and delivery are effective in

11   improving outcomes for people who use services?

12   Q3.2 What are the significant features of an effective home care model?

13   Q3.3 Are there any undesired/harmful effects from certain types of home care

14   approaches?

15   Q3.4 What are the barriers to, and facilitators of, effective implementation of

16   approaches shown (3.1) to deliver good outcomes?

17   **Summary of review protocol**

18   The protocol sought to identify studies which would:

19   • identify and evaluate the effects of different models and frameworks for

20   care and support planning, including activities and interventions provided

21   as part of a home care service, and liaison and joint working with other

22   (formal and informal) care providers. Relevant approaches might include,

23   for example: person-centred care; outcomes-focused planning and

24   delivery; integrated care, delivered or coordinated with healthcare

25   practice/practitioners and with other providers of care and support e.g.

26   housing; case management; home care delivered by volunteers under

27   formal arrangements; home care organised and/or partly or wholly funded

28   by the person receiving care; shared lives schemes and other 'live-in' home

29   care.

- evaluate the components of an effective model of home care. This question anticipates that the approaches referred to in 3.1 may not be that different from each other, may not be compared with other approaches and are unlikely to show 'causal' relationships with aspects of the approach; we would need then to consider some of those service elements which seem to be evidenced across approaches as showing good outcomes.
- identify home care practices which could deliver harmful outcomes, e.g. rushed visits; lack of training in lifting and moving or continence care. Some overlap or continuity with the review question focusing on safety (4.1) was anticipated.
- identify the opportunities for and barriers to the implementation of models and practice identified as potentially effective.
- identify implementation and practice issues which might contribute to undesirable or harmful effects.
- contextualise the views of users, carers and practitioners (1.1, 1.2, 2.1, 2.2) by identifying barriers and facilitators to improved or changed practice they suggest would improve outcomes.
- consider feasibility and cost of implementing practice shown to deliver good outcomes to service users and carers.

Population: Older people, aged 65 years and older, who use home care services, and their families, partners and carers. Practitioners (home care workers), managers, social workers, care managers, coordinators, and commissioners of home care services for older people, aged 65 years and older. Personal assistants.

Intervention: Home care – personal care and practical support – provided by social care practitioners. Models and frameworks for delivering home care to older people (aged 65 years and older), implemented by practitioners, managers and commissioners of home care services. Models of self-funding and/or commissioning by service users and their families were also sought. Teams including primary healthcare staff who work alongside home care service providers in integrated practice were also included.

1 **Setting:** Service users' home, including sheltered housing accommodation,

2 extra care housing, Shared Lives Scheme living arrangement.

3 **Comparator:** None identified for home care, although it was expected that

4 there would be comparative studies of different models of providing home

5 care.

6 **Outcomes:** None specified in advance, but driven by the data. It was

7 anticipated that the likely outcomes (described or measured) would include:

8 service user satisfaction; quality and continuity of home care; choice and

9 control; involvement in decision-making; dignity and independence; quality of

10 life; health status; safety and safeguarding. It was also expected that data

11 would address employee and organisational outcomes such as: productivity,

12 consistency in care provision, staff retention rates job satisfaction; condition of

13 work; organisational issues, perceived competency; work-related training and

14 supervision issues; quality of home care provided (as per section 4.4 Scope).

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

16 • Systematic reviews of studies of different models of home care;

17 • RCTs of different models;

18 • Quantitative and qualitative evaluations of different home care models;

19 • Economic evaluations

20 • Cohort studies, case control and before and after studies;

21 • Mixed methods studies;

22 • Case studies of practice site implementation.

23 It was also thought that there might be qualitative or survey studies that

24 related to views around implementation issues.

25 Full protocols can be found in Appendix A.

26 **Summary of how the literature was searched**

27 Electronic databases in the research fields of social care, health and social

28 science were searched using a range of controlled indexing and free-text

29 search terms based on the setting "home care" and the populations: "care

1 professional(s)"; "care provider(s)"; "care co ordinat*"; "social worker*"; "Care

2 supervi*" "Care worker(s)"; "workforce", "social care organisation".

3 The search aimed to capture both journal articles and other publications of

4 empirical research. Additional searches of websites of relevant organisations

5 were also carried out.

6 The search for material on this topic was carried out within a single broad

7 search strategy used to identify material which addressed all the agreed

8 review questions on home care. The search strategy did not distinguish

9 research of specific study designs, as filters are often unreliable, so these

10 were to be differentiated at the screening stages of the review.

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

12 **Summary of how studies were selected**

13 Search outputs (title and abstract only) were stored in EPPI Reviewer 4 (a

14 software programme developed for systematic review of large search

15 outputs), and screened against an exclusion tool which identified the included

16 studies, excluding those outside scope. Formal exclusion criteria were

17 developed and applied to each item in the search output:

18 • Language (must be in English),

19 • Population (must be practitioners, home care workers, managers, social

20   workers, care managers, coordinators, or commissioners of home care

21   services for older people, aged 65 years and older)

22 • Intervention (home care)

23 • Setting (home care delivered in person's home)

24 • Country (must be UK, European Union, Denmark, Norway, Sweden,

25   Canada, USA, Australia and New Zealand)

26 • Date (not published before 2004)

27 • Type of evidence (must be research)

28 • 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 156 studies which appeared relevant to one or more of the review questions. We ordered full texts of 84 papers, which appeared to be either of a high methodological quality (study types identified above) or were qualitative and applied to a UK setting. On receiving and reviewing the full texts, we identified 25 which fulfilled these criteria (see included studies below). 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 evidence for:

Q 3.1 What approaches to home care planning and delivery are effective in improving outcomes for people who use services?

Q3.2 What are the significant features of an effective home care model?

We identified six papers that assessed the effectiveness of a different model/approach of home care services on improving service user outcomes (Glendinning et al, 2008a; Moran et al, 2013; Gethin-Jones 2012a; Davey et al, 2005; Onder et al, 2007, Ottmann and Mohebbi, 2014). Two of these papers (Glendinning et al, 2008a; Gethin-Jones 2012a) also provided cost-effectiveness evidence. A further four studies also provided economic evidence (Forder 2013; Jones et al 2012; Montgomery et al 2008 (a Cochrane

review); Netten and Forder 2007) and, in addition, authors of the IBSEN study made available primary data for further analysis.

Individual budget (IB) versus no individual budget

Effectiveness

A UK RCT (the 'IBSEN trial'; Glendinning et al, 2008a, evidence rating +/+; Moran et al, 2013; evidence level +/−) assessed the effectiveness of IBs on ASCOT outcomes on five different groups of social service users (N=959), including older people (n=263) using IBs to pay for social services, including home care. The IBs could be deployed in different ways e.g. through DP or a managed account (although it is unclear how results presented relate to different deployment options).

The data suggested that when older people were given the choice of having an IB they were more likely to replace traditional home care with care delivered by personal assistants. The study indicated a preference of some older people to exercise more choice and control over the activities provided by the person supporting their personal and home care needs.

At 6 months, subgroup analysis found no significant difference in the ASCOT outcomes between the IB (N=142) and non-IB group (N=121) of older people. Psychological ill-health was significantly higher in the IB group when compared with the non-IB group. However, regression analyses showed that IB users were associated with better ASCOT scores for those with access to support in planning IB. The long term effects on ASCOT outcomes were not reported. (Glendinning et al, 2008a; Moran et al, 2013).

Cost-effectiveness of self-directed support through Individual budgets

The IBSEN study included a cost-effectiveness analysis (Glendinning et al, 2008a, economic evidence rating ++). Jones et al (2012, economic evidence rating ++) analysed the cost data in more detail for N=268 in the IB group and N=250 in the non-IB group but did not present findings specifically for the group of older people. Study findings on differences in effects or costs were

1   not always presented with information about their significance (p-value or

2   similar.)

3   Weekly mean social care costs for older people were the same in the IB group

4   (N=73; £228) and in the non-IB group (N=66; £227) but the weekly mean cost

5   for care management (across all groups) was significantly higher in the IB

6   group (£18 vs. £11; p<0.001). In addition, the data indicated that when people

7   were given a choice of IB they were more likely to replace traditional home

8   care with use of personal assistants, which was reflected in lower costs of

9   home care (£57 vs. £90) and higher costs of using personal assistants (£66 vs

10   £31) in the IB group. Overall costs (including those of unpaid care) across all

11   groups were slightly higher in the IB group than in the Non-IB group due to

12   additional weekly costs for care management (as above) and unpaid care

13   (£579 vs. £508). Glendinning et al (2008a) reported incremental cost-

14   effectiveness results across all groups (including older people), which showed

15   that IB group was marginally less cost-effective than control; the cost per

16   incremental change in ASCOT was -£61 and per incremental change in GHQ

17   -£12.Home care vs other social care

18   We undertook additional economic analysis as part of this evidence review

19   using primary data from the same (IBSEN) study. Full details can be found

20   under PSSRU, Technical report for NICE Home care Guideline development

21   [unpublished], 2014 in Appendix C3. This analysis found that, among the

22   different components provided to older people (N= 400) as part of a wider

23   home care package (such as personal assistant services, telecare, care

24   management, meals on wheels etc), home care appeared to have a

25   significant impact on costs and outcomes for older people (controlling for all

26   other factors). Older people using home care were more likely to have higher

27   psychological wellbeing scores (measured via the GHQ, p<0.05) at a cost per

28   unit increase (on the GHQ scale) of £51 in 2012/13 prices.

29   Certain groups of older people who used social care in their own home

30   (including home care) were more likely to report worse psychological

31   wellbeing (GHQ) and/or some unmet social care needs (ASCOT): people with

32   cognitive impairment were significantly more likely to have overall higher

1 unmet social care-related quality of life needs (p<0.05); people living alone

2 reported significantly more unmet needs in regards to 'personal care/comfort'

3 (p<0.05) and 'social participation and involvement' (p<0.05); people using

4 equipment or adaptations were significantly more likely to report lower

5 psychological wellbeing (p<0.05) and higher unmet needs in regards to

6 'safety' (p<0.05).

7 Older people using home care reported lower unmet needs in regards to

8 'control over daily lives' (p<0.05), but higher unmet needs in regards to

9 'accommodation cleanliness and comfort' (p<0.05) compared to people with

10 otherwise similar characteristics, needs and service use. Older people who

11 used personal assistant services tended to have higher unmet 'meals and

12 nutrition' needs (p<0.05); the small group of people who moved during the

13 time of the study from having home care to personal assistant services

14 reported higher unmet needs in regards to 'safety' (p<0.05).

15 In terms of social care related quality of life (measured via the ASCOT),

16 findings were therefore more difficult to interpret as older people using home

17 care seemed to have less unmet needs in some domains and higher unmet

18 needs in other domains than other older people using social care (controlling

19 for all other factors). It was thus not possible to construct a robust ICER on the

20 ASCOT. In addition, findings suggest that certain sub-groups of older people -

21 in particular those with cognitive impairment and those living alone - were

22 more likely to report worse psychological wellbeing and/or higher unmet

23 needs in regards to the social care package they used in their homes

24 (including home care) than people with otherwise similar characteristics and

25 needs.

26 ***Cost-effectiveness of self-directed support through use of personal***

27 ***assistants***

28 A systematic Cochrane review (Montgomery et al 2008, economic evidence

29 rating moderate +, as studies are not recent and from US) assessed

30 effectiveness and cost- effectiveness of personal assistants (paid long-term

31 support, >20hrs/wk.) for older people. They present findings from one RCT

1 and three non-randomised studies with a combined sample of N=1,642

2 participants. All studies were from the US, and the RCT (N=938) was of a

3 more recent date (from 2007); studies used different comparison groups.

4 Findings of the review and specifically the RCT suggested that use of

5 personal assistants had probable health benefits including a reduction in falls

6 (13% vs 20%, p=0.01), a significantly reduced risk of contractures (18% vs

7 27%, p<0.01) and a significantly lower proportion with unmet needs

8 concerning activities of daily living (44% vs. 58%, p<0.01). Furthermore, there

9 were some likely benefits to carers, and use of personal assistants possibly

10 substituted for unpaid care. The RCT showed that compared with usual care,

11 there were greater direct costs associated with organising and providing

12 personal assistants ($20,236 vs $20,015 in 1st year; $19,407 vs $17,975 in

13 2nd year). Findings have to be interpreted with caution as studies have design

14 problems due to the complexity of evaluation in this area. However, the

15 studies indicated a preference of some older people to exercise more choice

16 and control over the activities provided by the person supporting their

17 personal and home care needs.

18 **Outcomes-focused care versus time-task care**

19 *Effectiveness*

20 A small UK cohort study (Gethin-Jones, 2012a, evidence level +; economic

21 evidence rating -) examined the effectiveness of outcome-focused home care

22 on subjective wellbeing of older people (N=40). At 18 months, older people in

23 the outcomes-focused group (N=20) reported improved concern scores and

24 significant improvement in their subjective wellbeing when compared with

25 older people in the time-task group (N=20). Gethin-Jones highlights as a

26 feature of outcomes-focused care, the 'aim to achieve the aspirations, goals

27 and priorities identified by service users – in contrast to services whose

28 content and/or forms of delivery are standardised or solely determined by

29 those who deliver them' (Gethin-Jones, 2012a, p 53).

30 This study also reported some cost relevant information, focusing on the

31 contact or visiting time of home care workers, but the study had only limited

32 applicability so that the findings could not be used to inform recommendations

1 about cost-effectiveness. This study presented limited details of the

2 intervention and analysis and the sample size is small.

3 *Cost-effectiveness*

4 Gethin-Jones (2012a) collected information about the time home care worker

5 spent with (N=8) service users. They reported that contact time reduced in the

6 outcome-focused group (n=4) and increased in the time-task group (n=4) and

7 that the time-task group was 17 per cent more expensive. No further detail is

8 provided on how cost figures were derived and the effectiveness analysis

9 presented in this paper lacked detail (see above), so that no conclusions can

10 be drawn from this study about costs and cost-effectiveness of outcome-

11 focused versus time-task approach.

12 ***Stepped, capacity-building approach to self-directed care***

13 A small Australian cohort study (Ottmann and Mohebbi, 2014, evidence level

14 +/+) comparing outcomes of a stepped approach to taking on care planning

15 responsibilities and IBs examined outcomes at 11 months for 98 older people

16 (intervention) and 87 older people (usual care management). 59 and 50 older

17 people respectively completed outcome measures of satisfaction with

18 treatment, care options, level of ability to influence care, and on what could be

19 achieved. Participants in the intervention group "were likely to be more

20 satisfied with the way they were treated ($P = 0.013$), their care options ($P =$

21 0.014), the 'say' they had in their care ($P < 0.001$), the information they

22 received regarding their care ($P = 0.012$), what they were achieving in life ($P =$

23 0.031), that the services changed their view on what could be achieved in life

24 ($P = 0.020$) and with their standard of living ($P = 0.008$)." (p598) As one

25 commented: "Well, it's there are huge benefits. You feel as though you can

26 organise your life instead of having it organised for you." (Level 3 client, p

27 607)

28 ***Co-location of social and primary care workers versus no co-location***

29 A UK cohort study (Davey et al, 2005; evidence level +) assessed the

30 effectiveness of joint working between social and primary care by co-location

31 vs no co-location on older people receiving home care, in terms of admission

1 (or lack thereof) to residential care. At 6 months, there was no significant

2 difference between the 2 groups (co-location=40; no co-location=39) in the

3 proportion of older people remaining in the community

4 ***Case management versus no case management***

5 A cohort study (Onder et al, 2007; evidence level +) of 11 European countries

6 (including the UK) assessed the effectiveness of case management vs no

7 case management (traditional home care) on older people (N=3292) receiving

8 home care service. At 1-year, there was significantly lower admission to

9 nursing home in the case management group (n=1184) when compared with

10 the no case management group (n=2108) (6.8% vs 13%, P<0.001, adjusted

11 odds ratio=0.56, 95% confidence interval 0.43-0.63). One-year mortality was

12 16% in both groups. Onder highlights as features of a case management

13 approach: 'a multidisciplinary team (responsible for managing cases and

14 dispensing services), which comes into contact with the patient and develops

15 and implements individual care plans for each patient…Case managers

16 performed the initial assessment of the patients…and were available to

17 manage problems that arose, monitor the provision of services, and provide

18 additional services as requested…In addition they designed and implemented

19 a 'personalised' care plan, and determined the services that each person was

20 eligible for. A multidisciplinary team then provided the approved services, with

21 the case manager facilitating the integration of services provided by social and

22 healthcare professionals.' (Onder, 2007, p441)

23 ***Emotional and social support***

24 A national UK evaluation of the Partnership for Older People Projects (POPP)

25 examined the costs and outcomes of low level support including emotional

26 and social support interventions for N=244 older people (Windle et al 2009,

27 economic evidence rating +). The study found that emotional and social

28 support was likely to be effective in reducing anxiety and depression but not in

29 improving overall health-related quality of life, and led to small but significant

30 reduction in health care costs of £30 over a period of 6 months (p=0.04). Per

31 person cost of running those kind of primary prevention projects was £4 per

32 week, so that it was unlikely that costs of the intervention were offset. In

1 addition, emotional and social support had other positive effects such as

2 helping older people to claim the benefits they were entitled to. It was

3 indicated from the overall findings of the study that there were other low level

4 projects that were likely to be more cost-effective than emotional and social

5 support in particular those that were exercise focused.

6 *Intensity of home care provision*

7 The weekly mean costs for home care (including personal assistant services)

8 for older people were reported in Glendinning et al (2008a) at £120/wk in 2007

9 prices; Forder et al (2013, economic evidence rating -) evaluated slightly lower

10 costs of £96/wk. Nationally collected expenditure data showed that the mean

11 cost of home care in 2012/13 was £17 per hour; the hourly cost of council

12 provided home care was £37 and those provided by other providers £15

13 (HSCIC 2013).

14 Research on the most cost-effective intensity of home care is in development

15 which aims to generate Incremental Cost-Effectiveness Ratios (ICER) derived

16 from national and survey data that can inform resource allocations in the

17 future (Netten and Forder, 2007, economic evidence rating -, Forder et al,

18 2013, economic evidence rating -). Only the costs of home care were included

19 in these studies (i.e. impact and potential savings on unpaid care and health

20 and social care were not considered), and methodologies still need to be

21 tested. Thus, evidence from these studies cannot be used to derive final

22 conclusions about the most cost-effective number of hours of home care

23 provision for different needs groups. However, some findings are reported

24 about relative cost-effectiveness between different needs groups that can –

25 with some caution - be used to inform recommendations. Weekly mean costs

26 for home care was £159 for high needs groups and £69 for moderate/low

27 needs groups; ICERs on the ASCOT were much higher for high needs than

28 for moderate/low needs groups (£53,205 vs. £35,146). Based on different

29 willingness-to-pay thresholds (£20,000, £30,000 and £40,000), calculated in

30 Forder et al, 2013, optimal provision for low/moderate needs groups ranged

31 from £12/wk. to £49/wk (mean £28/wk) and for high needs from £23/wk. to

32 £90/wk (mean £51/wk). In the other study by the same group of researchers

1. (Netten and Forder, 2007), cost- effective home care - at a willingness-to-pay

2. threshold of £20,000 - was estimated at up to 14 hours for people unable to

3. perform one ADL or IADL and up to 20hrs for people with higher needs.

4. Although these findings should be treated with caution, they appear to indicate

5. that home care could be employed more cost-effectively if it was allocated

6. more equally between different needs groups with a shift from people with

7. severe towards people with low to moderate needs.

8. ***Supplementary evidence from service users and practitioners***

9. In addition to effectiveness and cost-effectiveness evidence, studies of service

10. user and carer views identified specific characteristics of home care

11. approaches that were deemed to be important in terms of outcomes. While

12. these studies were not designed to answer questions of effectiveness,

13. consistent themes emerged and informed GDG discussion about what

14. approaches 'work' for people using services. Nineteen service user and carer

15. views studies were included, comprising:

16. • 7 UK mixed-methods studies (Bowers, 2006; Gethin-Jones, 2012b,Part

17.   Two; Glendinning et al, 2008b; Lakey and Saunders, 2011; Moran et al,

18.   2013; Patient Council of Northern Ireland, 2012 and Quince, 2011)

19. • 6 UK qualitative studies (Clark et al, 2004; Duff and Hurtley, 2012;

20.   Ekosgen, 2013; Manthorpe and Stevens, 2010; McNulty and Patmore,

21.   2005; and Roberts, 2011)

22. • 4 surveys (Venables et al, 2006; Netten et al, 2007; Angel, 2012;

23.   UNISON,2012)

24. • 2 studies which analysed secondary data (Commission for Social Care

25.   Inspection, CSCI, 2006; Henderson, 2006).

26. For full findings tables, see Appendix B.

27. ***Outcomes-focused, person-centred care***

28. Person-centred care relies on addressing a person's wider needs, by

29. commissioning services that can improve quality of life (e.g. leisure activities:

30. Henderson 2006, evidence level + citing Patmore, 2005) and that address

1 explicitly the priorities and aspirations defined by the person using the service

2 (Gethin-Jones, 2012b, Part Two, evidence level +). Bowers (2006, evidence

3 level –) noted that services provided by volunteers can be particularly

4 outcome-focused as volunteers start with the task that needs completing

5 rather than the time available. A number of papers noted that person-centred

6 care ensures the person is treated with respect, courtesy and in a dignified

7 manner, with their confidentiality ensured (CSCI, 2006; evidence level +;

8 Manthorpe and Stevens, 2010; evidence level +)

9 ***Choice and control***

10 IBs and/or DPs can give people a greater sense of control over their service

11 provision, and lead to better self-reported social outcomes and/or satisfaction

12 with services (Glendinning et al, 2008b, evidence level +/+; Lakey and

13 Saunders, 2011, evidence level -/+; Clark, 2004, evidence level+;

14 Glendinning, 2007 cited in Clark, 2004). People needing services can, for

15 example, help ensure they have support workers who understand and can

16 respond to their cultural needs through DPs (Clark, 2004) or IBs (Manthorpe

17 and Stevens 2010). Self-funders also reported satisfaction with their care in

18 the Ekosgen study (2013, evidence level +), reporting feeling in control and

19 well-supported.

20 ***Skilled, experienced workforce***

21 Netten et al (2007, evidence level +) found that service users perceive higher

22 quality home care to be related to having care workers who: are older

23 (specifically over 40 years); have received more hours of workforce training;

24 and, who have worked for the provider for more than five years.

25 ***Time to spend with the person using services***

26 Henderson (2006, citing Patmore, 2001 and 2004) provided, as an example of

27 good quality practice, a visit that allowed time for the worker to complete the

28 required tasks, as well as having some time to chat to the person or help with

29 other household tasks (e.g. washing up or pet care). The Gethin-Jones study

30 (2012b, evidence level –) findings supported this: service users reported

benefits as a result of being able to form a relationship with their home care workers. The self-funders in the Ekosgen (2013, evidence level +) study also highlighted the importance of building trust, and a positive relationship with the care worker. Continuity of care – to build positive relationships - was also noted in McNulty & Patmore (2005, evidence level +).

Flexibility of support

Service users associate higher quality home care to be related to flexibility (Gethin-Jones, 2012, Part Two, evidence level –) as do managers (Duff & Hurtley, 2012, evidence level –) with providers able to: vary the hours given and how the time is spent, within agreed limits; and, ensure workers have at least 10 or more minutes of travel time allowed between visits (Netten et al, 2007, evidence level +). Moran et al (2013, evidence level +) and Manthorpe and Stevens (2010, evidence level +) highlighted the opportunity IBs provide for increased flexibility of support (though there was no evidence that IBs improved service flexibility in Lakey and Saunders' 2011 study).

Consistent, reliable service

People using home care services want to be able to rely on the service (Patient Client Council Northern Ireland, PCC, 2012, evidence level +). Clark et al, (2004 evidence level +) found that some people chose DPs to ensure that they had staff employed when they needed it.

Narrative summary of evidence for:

Q 3.3 Are there any undesired/harmful effects from certain types of home care approaches?

We identified 14 UK qualitative studies which addressed this question. There were:

- 2 UK surveys (Angel 2012; UNISON 2012)
- 4 UK qualitative studies (Duff & Hurtley 2012; Ekosgen 2013; Manthorpe and Stevens, 2010; Roberts 2011)

1. - 6 UK mixed methods studies (Gethin-Jones 2012a; Glendinning et al,

2.   2008a; Lakey and Saunders, 2011; Moran et al, 2013; Patient Client

3.   Council of Northern Ireland 2012; Quince 2011)

4. - 2 UK secondary analyses (Henderson; CSCI 2006)

5. *Visits too short to address people's needs sufficiently well*

6. Survey data indicated that 15-minute and 30-minute appointment booking is

7. commonplace (Angel, 2012, evidence level +) and that home care workers

8. can feel the service they offer is compromised as a result of this and/or too

9. many appointments being booked too closely together (Henderson, 2006,

10. evidence level+; Angel, 2012, evidence level +; UNISON, 2012, evidence

11. level +; PCC, 2012, evidence level +). People using services reported feeling

12. rushed when visits were commissioned by time (Gethin-Jones, 2012b,

13. evidence level +).

14. *Inadequate workforce competence*

15. CSCI (2006) found nearly two- fifths (39 per cent) of providers were not

16. compliant with basic requirements for staff recruitment. The CSCI (2006)

17. study raised particular concerns about safe processes for managing

18. medication, reporting and preventing accidents, noting a need for providers to

19. improve procedures and training in this respect. There is also a particular

20. need for home care workers to have specialist training in dementia care (Duff

21. and Hurtley, 2004, evidence level –; Quince, 2011, evidence level –/+;

22. Roberts, 2011, evidence level +).

23. *Lack of required support leading to social isolation*

24. Not being able to go out, socialise and perform everyday tasks independently

25. were among the main sources of concern for older people in the Gethin-Jones

26. study (2012b, evidence level +) which also found that where services were not

27. commissioned for outcomes, people could feel disengaged and socially

28. isolated. Related to this, PCC (2012) found that unreliable home care services

29. were those in which staff did not turn up when expected, sometimes without

30. notice, leaving people alone and without the required support.

Lack of support when using individual budgets, direct payments or when self-funding

When people do not receive sufficient information about the options available to them, or about how to access or manage their care, this can be stressful, confusing or limiting, particularly in respect of IBs (Glendinning, 2008a, evidence level +; Lakey and Saunders, 2011, evidence level –) Moran et al, 2013, evidence level +). Moran et al (2013) found that services to enable older people and people with disabilities to use IBs were under-resourced. Similarly, self-funders can find the employment-related administration stressful (Ekosgen, 2013, evidence level +). There can be particular challenges for people using IBs in rural areas where the available workforce may require additional training (Manthorpe and Stevens, 2010, evidence level +).

Fragmented, unreliable care

Duff and Hurtley (2012, evidence level –) found weaknesses in inter-agency working resulting in care being fragmented or uncoordinated. This could result, for example, in delays or difficulties addressing health care needs or poor handovers between health and social care staff (Duff and Hurtley,2012, evidence level –; Roberts, 2011, evidence level +).

Narrative summary for Q3.4 What are the barriers to, and facilitators of, effective implementation of approaches shown to deliver good outcomes?

Three studies provided supplementary evidence on this question (Glendinning et al 2008a; Baxter et al, 2008; Glendinning et al, 2008b).

Barriers and facilitators

The IBSEN study (Glendinning et al, 2008a, +) suggested that the main barriers to implementation of IB could be: High workloads, poor information and training and lack of clarity about IBs in the workforce; a perceived lack of commitment to change at national level and cynicism about new initiatives, a barrier to the success of training. There were sector differences in performance management, managerial priorities and organisational targets,

1 which were cited as creating further barriers. Low take-up of IBs among older

2 people may be due to care managers, with overly risk averse. Older people

3 were reported to be reluctant to change as they were satisfied with their

4 current care arrangements – particularly when this involved an established

5 relationship with a current care worker.

6 Another study (Baxter et al, 2008) suggested that the main barriers are a lack

7 of knowledge and experience in local authorities of DPs or personalised

8 budgets system; problems people using services intermittently with late or

9 non-payment; agencies lose out on care workers who can earn more per hour

10 by working privately for personalised budget holders; and concerns about the

11 quality of home care provision with the employment of unqualified carers.

12 Glendinning et al (2008b) suggested that the understanding of 'outcomes' to

13 be a barrier as it had different definitions and meanings for medical and social

14 care professionals, which could impede the development of integrated

15 outcomes-focused day services. The study also suggested facilitators such as

16 establishing good and trusting relationships with a wide range of external

17 partners with a range of professional skills working together to meet the

18 priorities and needs of individual older people.

19 We did not identify any studies which investigated the facilitators and barriers

20 to implementing the case-management approach of home care reported by

21 Onder et al (2007).

22 **Expert witness evidence**

23 The GDG found that the research literature on current models of home care

24 was inadequate (possibly because research and evaluation tended to lag

25 behind implementation). Although 11 systematic reviews and some controlled

26 studies on care planning approaches were considered, most of the studies

27 reviewed were about healthcare delivered at home, rather than social care

28 approaches. In particular, the evidence on outcomes-focussed care, which is

29 strongly associated with person-centred care, was sparse. There was also a

30 belief that the private sector might be providing standards of home care to

31 which all providers might aspire, but little evidence was available. It was

1 therefore decided to invite two directors of apparently successful outcomes-

2 focussed services for older people (one from public and one from private

3 sector) to provide expert testimony to the GDG. A summary of the expert

4 testimony is provided below. For full testimonies, see Appendix D.

5 ***James Cawley, Wiltshire Council, England, UK***

Job title:	Associate Director - Adult Care Commissioning, Safeguarding and Housing
Subject of expert testimony:	Home care for older people living in the community – planning, commissioning and delivering for outcomes.

Expert witness testimony:

Wiltshire Council acknowledged a consensus that the care system was characterised by poor recruitment, poor outcomes for service users, and increased cost. The council decided to change financial incentives and to tie payment to outcomes which had the potential to maximise customers' independence, improve cost-efficiency and improve pay and working conditions for care providers.

Wiltshire introduced Help to Live at Home (HTLAH), which has a focus on personalisation, recovery and prevention. People who need support receive a person-centred assessment that focuses on outcomes – particularly outcomes that will leave them better able to live well with less care. HTLAH pays providers for the results they achieve, rather than the work they do – namely improved or preserved independence. The council applies financial penalties when outcomes are not achieved, and it rewards providers when people recover faster than planned.

Wiltshire's "payable outcomes" are about simple activities of daily living– getting up, bathing, dressing, cooking and eating, shopping, seeing friends.

The system introduced in 2011 has simplified the council's trading relationship with providers. Ninety separate domiciliary contracts worth £14 million have been reduced to eight payment-by-results contracts worth £11 million with 4 providers.

Results at April 2014 include:
- Numbers of people placed in residential care has reduced.
- Hourly rate for care reduced from £18.78 to £16.06
- Initial assessments are completed in 20 days rather than 20 weeks
- 1,523 customers accessing HTLAH care and support a week
- 320 self-funders are using HTLAH
- Number of people going into nursing care reduced from 905 to 872
- Number of people going into residential care reduced from 1126 to 872 between 2010/2011 and 2013/2014
- 48% of those receiving the reablement service had no further need for care
- 23.7% needed less care after reablement.

Further detail is given in Appendix D.

6

1   *Trevor Brocklebank, Home Instead Senior Care, England, UK*

Job title:	Chief Executive Officer
Subject of expert testimony:	An international perspective – what does good home care delivered to older people in the community look like?

Q 3.1: What approaches to home care planning and delivery are effective in improving outcomes for older people who use services?

Home Instead Senior Care provides an innovative and effective care model, operating in 18 countries. The service promotes active and healthy living and aims to extend life by delivering person cantered and relationship-based care. The focus is on relationships, not tasks. Personalized care packages, which often include care coordination, are devised in collaboration with the client, their family and often involved health or social care professionals.

Assistance with healthy behaviour, staying physically active, eating well, and staying socially engaged and intellectually curious is provided. Continuity of care is valued, and caregivers are matched to clients based on shared experiences, backgrounds or interests. Social interaction, the ability to sustain valued interests and activities, and improved nutrition all help to prolong independent living.

Special care is taken in reassuring people living with dementia through providing familiar activities and personnel, and family members are reassured to find that their loved ones are active and well supported.

Q 3.2: What are the significant features of an effective model of home care?

The most important feature is putting the client and their needs first. The collaborative development of a care plan which is needs based rather than task oriented is the foundation stone.

Continuity of care and calls which last a minimum of one hour are also significant features of effective home care. Building strong relationships between workers and clients who are matched has many benefits, including preserving a sense of independence and "self", all which can help reduce loneliness.

Regular assessment and feedback to family members is also important as clients' needs can change, reduce or increase with chronic conditions, over time.

Q 3.3: Are there any undesired/harmful effects from certain types of home care approaches?

An annual client survey is carried out to monitor performance and ensure that outcomes are delivered.

Short or rushed visits (under thirty minutes long) encourage focus upon delivery of tasks rather than building a relationship, and can cause anxiety and stress for worker and client, especially if the person mobility issues or dementia.

Short task based visits, coupled with no continuity of care, can increase social isolation, leaving little time for social interaction, and leaving the person being cared for feeling unimportant, which puts them at risk of depression. A focus on delivery of tasks can facilitate a reduction in the ability of clients to do things for themselves, leading to more and more dependence upon the care services, and risk of needing residential care.

1 **Evidence statements**

Effectiveness, cost-effectiveness and acceptability of different approaches (RQ 3.1)	
3.1	**Individual budgets, self-directed care and need for support for older people**
	There is good evidence from one UK Randomised Controlled Trial) (Glendinning 2008a, +) and one related mixed methods study (Moran et al, 2013, +) that older people who were offered IBs for social services (including home care) achieved similar ASCOT outcomes as those who were not offered IBs. Older people who were offered IBs were significantly less likely to improve psychological wellbeing than those who were not offered IBs after six months. Improved ASCOT outcomes were associated with users who had access to support in planning the IB scheme.
	An economic evaluation (cost effectiveness analysis) carried out as part of this trial (Glendinning 2008a +) suggests that IBs provided to older people were marginally less cost-effective on ASCOT and GHQ at the time when they were piloted. This finding is likely to be reflective of a substantial effort that is required from councils in order to implement IBs (cost-) effectively.
3.2	**Older people's preference for personal assistants over traditional home care**
	Good evidence from two studies - one UK randomised trial which evaluated IBs (Glendinning et al 2008a, +), one systematic Cochrane review (Montgomery et al 2008, +) - suggested that older people might prefer employing a personal assistant (or someone who takes on a similar role) rather than traditional forms of home care when given the choice.
3.3	**A stepped approach to introducing self-directed care to older people**
	There is good evidence from one good quality comparison evaluation of self-directed care (Ottmann and Mohebbi, 2014, +) that a 'stepped' approach to providing support to manage self-directed care– i.e. one which enables the person to take increasing control, over time – is experienced positively by older people, and can contribute helpfully to delivering the outcomes they want to achieve.
3.4	**Outcomes-focused home care**
	There is moderate evidence from one small UK cohort study (Gethin-Jones, 2012a, +) that older people who received outcome-focused home care were significantly more likely to achieve improvements in their subjective wellbeing than those who received time-tasked home care after 18 months.
3.5	**Home care delivered through case management**
	There is good evidence from one European cohort study (Onder et al, 2007, +) to suggest that a case management approach to deliver home care to older people resulted in significantly lower admission to nursing homes when compared with the traditional home care approach after 12 months.

3.6	**Intensity of home care for people with different levels of need**
	Two early economic studies (Netten and Forder, 2007, economic evidence rating -, Forder et al, 2013, economic evidence rating -) suggest that home care could be employed more cost-effectively if it was allocated more equally between different needs groups with a shift from people with severe towards people with low to moderate needs.
3.7	**Co-location as a means to integrate health and social care**
	There is good evidence from one UK cohort study (Davey et al, 2005, +) that joint working between social and primary care services by co-location to deliver home care resulted in the same proportion of older people remaining in the community, when compared with joint working between social and primary care services with no co-location after six months.

Significant features of an effective model of home care (RQ 3.2)

3.8	**Time to spend conversing with service users**
	There is moderate evidence from one secondary data analysis (Henderson 2006 + citing Patmore 2005) that good quality practice allows time for the workers to complete the required tasks as well as having time to chat or help with household task (such as washing up or pet care). Moderate evidence from one UK mixed methods study (Gethin-Jones, 2012b, +) showed that service users reported benefits as a result of being able to form a relationship with their care workers. In a UK qualitative study (Ekosgen, 2013, +), self- funders highlighted the importance of building trust, a positive relationship with their care workers, thus ensuring continuity of care.
3.9	**Reliability of home care support**
	There is good evidence from one UK mixed methods studies (PCC, 2012, +) that service users want a reliable service. Good evidence from one UK qualitative study (Clark et al, 2004, +) found that service users chose DPs to ensure that they could employ staff for the hours and times when they need support
3.10	**Social and emotional support within care planning**
	Evidence from one national mixed methods study that followed a case study approach (Windle et al, 2009, -) showed that emotional and social support for older people, such as emotional and social support can reduce depression and anxiety but did not confirm that it was likely to be cost-effective; interventions of this type could be provided at relatively small costs and there were likely to be wellbeing and wider outcomes that had not been captured in the cost-effectiveness findings. The study was broadly applicable and had only minor limitations so that findings could be used to inform recommendations.
3.11	**Flexibility of home care support**
	There is moderate evidence from one UK mixed methods study (Gethin-Jones, 2012b, +), one UK survey (Netten et al, 2007, +) and one UK qualitative study (Duff and Hurtley, 2012,-) that service users and care managers associate high quality care to be related to flexibility with providers able to: vary the hours given and how the time is spent, and ensure workers have sufficient travel time between visits. Good evidence from one UK mixed methods study (Moran et al, 2013, +) and one UK qualitative study (Manthorpe and Stevens, 2010, +)

	highlighted the opportunity IBs provide for increased flexibility of support.
3.12	**Personalised care and better outcomes in user control and satisfaction through Individual Budgets and Direct Payments**
	There is very good evidence from two UK mixed methods studies (Glendinning et al, 2008a, +; Lakey and Saunders, 2011, +), three UK qualitative studies (Clark et al, 2004, +); Ekosgen, 2013, +; Manthorpe and Stevens 2010, +) and one secondary data analysis (CSCI, 2006, +) that IBs and/or DPs can give people a sense of control over their service provision and lead to better social outcomes and satisfaction because they help to ensure users have support workers who understand them and respond to their cultural needs. Self-funders felt satisfied with their care, reporting feeling in control and well-supported.
3.13	**Characteristics of workforce linked to quality of home care service**
	There is moderate evidence from one UK survey (Netten et al, 2007, +) that service users perceived higher quality home care to be related to having care workers who are older (over 40 years), have received more hours of training and who have worked for the provider for more than five years.
3.14	**Volunteer support in the home**
	There is poor evidence from one UK mixed methods study (Bowers et al, 2006, -) that service users found the service provided by volunteers can be particularly outcome-focused as they start with the tasks that need completing rather than the time available.
Undesired or harmful effects from approaches to home care (RQ 3.3)	
3.15	**Unreliable home care services (visits missed or late)**
	Unreliable home care services left older people alone and without the required support. There is evidence from two UK qualitative studies (Duff and Hurtley, 2012, -; Roberts, 2011, +) that fragmented and uncoordinated inter-agency working resulted in delays and difficulties addressing health care needs or poor handovers between health and social care staff.
3.16	**Barriers to good home care: need for reliable care that addresses outcomes such as social participation**
	There is good evidence from two UK mixed methods studies (Gethin-Jones, 2012b, +; PCC, 2012, +) to suggest that older people can feel disengaged and socially isolated where services were not commissioned for outcomes.
Barriers to, and facilitators of, effective implementation of home care with good outcomes (RQ 3.4)	
3.17	**Barriers to implementing individual budgets**
	There is supplementary good evidence from one UK RCT (Glendinning et al, 2008a, +) and one UK mixed methods study (Baxter et al, 2008, +) to suggest that service providers'lack of knowledge and experience with IBs could be a barrier to implementation of this model. Some older people were reluctant to change. There were also concerns about the quality of home care provision with the employment of unqualified carers.

3.18	**Barriers to adopting individual budgets and direct payments**
	There is good evidence from three UK mixed methods studies (Glendinning et al, 2008b, +; Moran et al, 2013, +; Lakey and Saunders, 2011, -) that receiving insufficient information about how to take up options for self-directed care can be stressful and limiting to older people.
3.19	**Barriers and facilitators to outcomes-focused home care**
	There is supplementary good evidence from one UK mixed methods study (Glendinning et al, 2008b, +) to suggest that the different definitions and meanings of 'outcomes' among health and social practitioners to be a main barrier to implement integrated outcomes-focused day services. Facilitators included good and trusting relationships with external partners working together to meet the needs of individual older people.
3.20	**Barriers to good home care: rushed care slots**
	There is good evidence from two UK surveys (Angel, 2012, +; UNISON, 2012, +) and two UK mixed methods studies (Gethin-Jones, 2012b, +; PCC, 2012, +) and one secondary analysis study (Henderson, 2006, +) to suggest that care workers felt the service they offered was compromised due to 15-minute and 30-minute appointment, or appointments being booked too closely together. Users reported feeling 'rushed'.
3.21	**Barriers to good home care: need for training in particular areas**
	There is moderate evidence from two UK qualitative studies (Duff and Hurtley, 2004, -; Roberts, 2011, +) and one UK mixed methods study (Quince, 2011, -/+) that home care workers needed to have specialist training in dementia care. Evidence forom a secondary data analysis study (CSCI, 2006, +) reported particular concerns about safe medication management and reporting and preventing accidents.

1

2 **Included studies for this review question**

3 Angel C (2012) Care is not a commodity. Sutton: United Kingdom Home care

4 Association

5 Baxter K, Glendinning C, Clarke S, et al. (2008) Domiciliary Care Agency

6 Responses to Increased User Choice: Perceived Threats, Barriers and

7 Opportunities from a Changing Market. Social Policy Research Unit (SPRU),

8 University of York.

9 Bowers H, Macadam A, Patel M (2006) Making a difference through

10 volunteering: The impact of volunteers who support and care for people at

11 home. London: Community Service Volunteers

Clark H, Gough H, Macfarlane A (2004) 'It pays dividends'. Direct payments and older people. Bristol: Joseph Rowntree Foundation

Commission for Social Care Inspection (CSCI) (2006) Time to care? Towards excellence in adult social care. London: Commission for Social Care Inspection

Davey B, Levin E, Iliffe S et al. (2005) Integrating health and social care: Implications for joint working and community care outcomes for older people. Journal of Interprofessional Care 19: 22-34

Duff P and Hurtley R (2012) Challenges facing domiciliary care agencies delivering person centred care. Working with Older People 16: 61-68

Ekosgen (2013) The workforce implications of adults and older people who self-fund and employ their own care and support workers. Leeds: Skills for Care

Forder J, Malley J, Towers A M et al. (2013) Using cost-effectiveness estimates from survey data to guide commissioning: An application to home care. Health Economics 8: 979-992

Gethin-Jones S (2012a) Outcomes and well-being part 1: a comparative longitudinal study of two models of home care delivery and their impact upon the older person self-reported subjective well-being. Working with Older people, Vol. 16 No. 1, pp. 22-30.

Gethin-Jones S (2012b) Outcomes and well-being part 2: a comparative longitudinal study of two models of home care delivery and their impact upon the older person self-reported subjective well-being. A qualitative follow up study paper. Working with Older People 12: 52-61

Glendinning C, Challis D, Fernández J-L et al. (2008a) Evaluation of the Individual Budgets Pilot Programme: Final report. York: Social Policy Research Unit, University of York

1 Glendinning C, Clark S, Hare P et al. (2008b) Progress and problems in

2 developing outcomes-focused social care services for older people in

3 England. Health and Social Care in the Community 16: 54-63

4 Henderson C (2006) Time and other inputs for high quality social care:

5 Wanless social care review. London: King's Fund

6 Jones K, Netten A, Fernández JL et al. (2012) The impact of individual

7 budgets on the targeting of support: findings from a national evaluation of pilot

8 projects in England. Public Money & Management 32: 417-424

9 Lakey L and Saunders T (2011) Getting personal? Making personal budgets

10 work for people with dementia. London: Alzheimer's Society (Linked to Quince

11 2011)

12 Manthorpe J and Stevens M (2010) Increasing care options in the

13 countryside: Developing an understanding of the potential impact of

14 personalization for social work with rural older people. British Journal of Social

15 Work 40: 1452-1469

16 McNulty A and Patmore C (2005) Caring for the whole person: home care for

17 older people which promotes well-being and choice. York: Wellbeing and

18 Choice

19 Montgomery P, Mayo-Wilson E, Dennis J A et al. (2008) Personal assistance

20 for older adults (65+) without dementia. Cochrane Database of Systematic

21 Reviews: Reviews 2008; Issue 1.

22 Moran N, Glendinning C, Wilberforce M (2013) Older people's experiences of

23 cash-for-care schemes: Evidence from the English Individual Budget pilot

24 projects. Ageing and Society 33: 826-851 Linked to the IBSEN study by

25 Glendinning 2008a.

26 Netten A, Forder J (2007) The costs of what? Measuring services and quality

27 of care. Social Policy and Society 6:397-409

1 Netten A, Jones K, Sandhu S (2007) Provider and Care Workforce Influences
2 on Quality of Home-Care Services in England. Journal of Aging and Social
3 Policy 19: 81-97

4 Onder G, Liperoti R, Soldato M (2007) Case Management and Risk of Nursing
5 Home Admission for Older Adults in Home Care: Results of the Aged in Home
6 Care Study. Journal of the American Geriatrics Society 55: 439-444

7 Ottmann G and Mohebbi M (2014) Self-directed community services for older
8 Australians: a stepped capacity-building approach. Health & Social Care in the
9 Community, 22: 598–611.

10 Patient and Client Council (2012) Care at Home. Older people's experiences
11 of domiciliary care. Belfast: Patient Client Council

12 PSSRU (2014) Technical report for NICE Home care Guideline development
13 [unpublished]

14 Quince C (2011) Support. Stay. Save: Care and support of people with
15 dementia in their own homes. London: Alzheimer's Society (Linked to Lakey
16 2011)

17 Roberts J (UKHCA) (2011) Improving domiciliary care for people with
18 dementia: a provider perspective. Bristol: South West Dementia Partnership

19 UNISON (2012) Time to care: A UNISON report into home care. London:
20 Unison

21 Venables D, Reilly S, Challis D (2006) Standards of care in home care
22 services. A comparison of generic and specialist services for older people with
23 dementia. Aging and Mental Health 10: 187-194

24 Windle K, Wagland R, Forder J et al. (2009) National Evaluation of
25 Partnerships for Older People Projects: Final Report. PSSRU Discussion
26 Paper 2700, University of Kent.Woolham J, Benton C (2012) The costs and
27 benefits of personal budgets for older people: Evidence from a single local
28 authority. British Journal of Social Work 1-20.

3.4   Safe care

Introduction to the review question

This question was potentially very broad given that the safety and security of older people (both perceived and actual) encompasses a wide range of factors. Although safety is not solely the responsibility of home care workers, they may be the only regular visitors to a person's home, and so may recognise signs of physical or other abuse, household hazards and the absence of safeguards such as smoke alarms. Home care staff may also be involved in prompting or supporting clients to take vital medication, and to know what to do if doses of medication are missed or serious side effects are spotted. The cleanliness and safety of the home of the service user is important if the person is to be able to remain in their home, and to the worker for whom it is the workplace. Inability to keep the home clean may be an issue of increasing importance as home care often does not encompass household tasks. Finally, the home care worker, as well as the service user, may be at risk from physical aggression or abuse from members of the household.

Review question(s)

Q4.1   What are the effects of approaches to promote safe care?

Summary of review protocol

The protocol sought to identify studies which would:

- identify aspects of home care organisation and delivery which promote the safety (alongside dignity, choice, control and other desirable outcomes) of the service user, their carers and the practitioners working within the home.

- identify evidence of policy and practice to support safe delivery of specific home care services in relation to safeguarding (from neglect or abuse); and systems to support lone workers.

- identify aspects of care delivery which users and carers say contribute to their sense of safety (e.g. reliability of service, consistency of care staff and good communication with provider agencies).

1 • inform the question on training effects (5.1) and the question on information

2   and support needed to enable service users and carers to play a full role in

3   planning their own care (7.1 and 7.2).

4 **Population:** Older people, aged 65 years and older, who use home care

5 services, and their families, partners and carers.

6 **Intervention:** Aspects of home care – personal care and practical support –

7 provided by social care practitioners that support the safety of service users,

8 carers and practitioners. This may include models, protocols, etc. Material on

9 personal services commissioned by service users and their families will also

10 be sought, as there is some concern that these services are not regulated and

11 carers will not, for example, be CRB (Criminal Records Bureau) checked.

12 Barriers and facilitators to the delivery of safe care may be identified within

13 papers which describe or evaluate models and frameworks (3.1, 3.2, 3.3, and

14 3.4) or their implementation, or safety issues may be considered

15 independently.

16 **Setting:** Service users' home, including sheltered housing accommodation,

17 extra care housing, Shared Lives Scheme living arrangement.

18 **Comparator:** There may be comparative studies of different models of

19 providing or implementing home care.

20 **Outcomes:** None specified in advance, but driven by the data. It was

21 anticipated that the likely outcomes (described or measured) would include:

22 sense of security, safety and safeguarding of users and carers; service user

23 satisfaction; quality and continuity of home care; choice and control;

24 involvement in decision-making; dignity and independence; quality of life;

25 health status (as per section 4.4 of the Scope).

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

27 • Systematic reviews of studies of different models of home care and their

28   implementation which highlight safety and safeguarding issues within the

29   described models;

- RCTs of different models which describe safety and safeguarding issues;

- Quantitative and qualitative evaluations of different home care models or safety aspects of home care delivery;

- Observational and cross-sectional survey studies of home care provided;

- 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

Electronic databases in the research fields of social care, health and social science were searched using a range of controlled indexing and free-text search terms based on the setting "home care" and the populations: "older people", "carers", "workforce", "social care organisation". The search aimed to capture both journal articles and other publications of empirical research. Additional searches of websites of relevant organisations were also carried out.

The search for material on this topic was carried out within a single broad search strategy used to identify material which addressed all the agreed review questions on home care. The search strategy did not distinguish research of specific study designs, as filters are often unreliable, so these were to be differentiated at the screening stages of the review.

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:

1. • Language (must be in English),
2. • Population (must be older people receiving home care, however organised,
3.   or their carers)
4. • Intervention (home care)
5. • Setting (home care delivered in person's home)
6. • Country (must be UK, European Union, Denmark, Norway, Sweden,
7.   Canada, USA, Australia and New Zealand)
8. • Date (not published before 2004)
9. • Type of evidence (must be research)
10. • Relevance to (one or more) review questions.
11.
12. Title and abstract of all research outputs were screened against these
13. exclusion criteria. Those included at this stage were marked for relevance to
14. particular review questions and retrieved as full texts.

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

21. This review question asks 'what works to make services safer', and we
22. therefore looked for studies of an experimental design, e.g. those which
23. compared one way of working with another. We identified 56 papers from an
24. initial review of the search outputs (title and abstracts only) which appeared to
25. consider safe care. Within these were two small controlled (US) studies
26. Ganong et al, 2013; Gershon et al, 2012) of approaches to improve the
27. domestic safety of older people, although they did not directly involve home
28. care workers or social care services. Consequently, we looked at the studies
29. which concerned aspects of safe care, used an acceptable transparent
30. research methodology, and/or were based in the UK and gave an overview of
31. issues. Eight studies met these criteria. Two of the studies were from the
32. USA, though neither were directly on our research topic: Ganong et al (2013),

an RCT (which was not directly on our topic, concerning training of family carers); and Gershon et al (2012), a 'pre- and post- quantitative evaluation of healthcare workers. All other studies - 4 qualitative studies, one evidence review and one survey - were from UK research. Some of the eight studies described here then are not directly relevant to this question, or to older people, but do raise issues where the GDG thought guidance on safeguarding was needed.

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 of the evidence

Recognising and reporting abuse

In terms of the prevalence of abuse, a rapid evidence review (using Civil Service methodology) by the Institute for Public Care (IPC, 2013, evidence level +/+) found that, compared to care provided in a care home or residential setting, home care was less likely to yield cases of reported abuse by a factor of around 6:1. Where abuse did take place in domiciliary settings, the review found that financial abuse was the type most frequently reported.

The IPC (2013) found that there was 'some evidence' to suggest that staff understanding of abuse can vary. The review states that whilst many staff was aware of physical, psychological, financial and sexual abuse of service users, issues of neglect, and the possible nature of abuse by service users, are not well understood. Simic et al (2012, evidence level +) included 26 home care workers in a telephone survey (a sub-set of the total sample). While initially 77% rated themselves as confident in their ability to recognise abuse and distinguish it from good/bad practice, less than half were satisfied with the training and support which they received on this issue, and those who had been involved in investigations were particularly dissatisfied.

1 A survey by Bell et al (2004, evidence level +), using vignettes of social care

2 staff working with older people, found that practitioners were more likely to

3 endorse formal action (the form of which was not described) if they had

4 received training, if the caregiver was male or if a higher level of abuse was

5 presented. The survey also found that home care assistants were less likely

6 than social workers to report abuse, especially if the suspected abuser was

7 male. Simic et al (2012) held a focus group with 10 home care workers, and

8 found that respondents had no means to share concerns with colleagues or

9 local authority staff without triggering the full formal inquiry process, which

10 focused on attributing 'blame'. The study also reported that some participants

11 felt that being able to spend more time with their clients and being able to

12 access support from more highly trained colleagues would help to improve

13 their safeguarding practice. It was also thought that perverse drivers

14 prevented reporting of concerns: "both CQC and the LA interpret incident

15 reporting as a negative outcome (a measure of bad care) rather than a

16 positive one (a measure of commitment to tackle poor care)" (Simic et al

17 (2012, p 30). Participants noted that service user consent and involvement

18 was not always sought when reporting abuse.

19 ***Impact of reporting abuse and safeguarding concerns on staff***

20 Both Simic et al (2012) and the IPC (2013) reported concerns from some staff

21 regarding the impact of formal safeguarding processes on staff. A number of

22 participants in the Simic et al study (2012) felt that local authorities did not

23 understand the impact that inquiries and their timescale in particular, had on

24 staff. Similarly, whilst the IPC (2013) noted that the impact of safeguarding

25 procedures is an under-explored research area, the report noted that there is

26 'some evidence' of a lack of support for workers, including those exonerated

27 following an accusation.

28 ***Making the home safer***

29 Ganong et al (2013, evidence level +/-) evaluated an intervention designed to

30 train support network members (e.g. family members or close friends) to help

31 older adults in rural areas maintain their independence and live safely in their

32 own homes. Significantly more behavioural and environmental changes were

1 made by older adults whose support network members received the

2 intervention of two training sessions on hazard identification and how to

3 address them. Changes included implementing daily calling plans, buying a

4 fire extinguisher, removing loose rugs, and learning to use a mobile phone.

5 Gershon et al (2012, evidence level +/-) evaluated a training programme and

6 checklist designed to be used by home healthcare paraprofessionals (a role

7 assumed to be comparable to home care workers) in older people's homes

8 focusing on identifying domestic risks. The study found that use of the 50 item

9 checklist significantly improved the ability of these staff to identify domestic

10 risks such as chemical, fall and fire hazards; poor medication management;

11 insanitary conditions and security issues. The study also found that training

12 made small but significant improvements in the ability of these staff to identify

13 household hazards.

14 A person's home is not just the place where they live, but also a place of work

15 for home care (and other) workers. Taylor and Donnelly (2006, evidence level

16 +) found that some home care workers in Northern Ireland, particularly those

17 in deprived rural areas, reported a range of hazards which they faced in their

18 daily work. These included access problems and hygiene and infection issues,

19 as well as risk of injury through manual handling, service user aggression or

20 harassment, domestic or farm animals, or unsafe home infrastructure. Some

21 service managers and providers reported instances where compromise had

22 been reached, for example by tailoring care packages to take account of

23 issues such as lack of running water. Other agencies reported that they used

24 the threat of withdrawal of service as a means of encouraging service users or

25 carers to make changes. Wibberley (2013, evidence level +) also considered

26 the environmental hazards of the home and found that some home care

27 workers reported that they often had to work in insanitary conditions.

28 Problems included general squalor, as well as non-functioning toilets, fridges

29 filled with rotting food and fleas and animals in the home. The study found that

30 some staff felt that home care was too often limited to personal care, and that

31 there was little if any time to undertake cleaning work. If the client could not or

would not pay for cleaning services, it was unclear who had responsibility for necessary domestic chores.

Medication in the home

McGraw et al (2008, evidence level -) found that some home care workers are increasingly involved in medication management in domestic settings. Interview participants reported that the tasks which home care workers carry out include collecting prescriptions, reminding people to take medication, as well as administering medication and loading medication compliance devices. Some participants cited difficulties which they had encountered in these tasks, such as resistance from service users and their family members, and lack of clinical support in explaining the medication and its use to service users. A number of respondents suggested that high staff turnover and poor communication with primary services resulted in a home care workforce who often had little knowledge of their client's medication regime.

Supplementary evidence

Overall, there was a lack of cost-effectiveness evidence in this area. However, 'feeling safe' was considered as an outcome in the review of care planning approaches; the additional analysis of primary data of the IBSEN study (PSSRU 2014, evidence level +, N=381) measured this outcome as part of the Adult Social Care Outcomes Tool (ASCOT). Findings indicated that older people felt significantly less safe ($p<0.05$) when they moved from traditional home care to using personal assistant services. This effect might be short-term but it could suggest that changes in home care arrangements were linked to an increased risk to the older person's safety. The need for changes in home care provision should be considered carefully and planned together with the older person and their carers. Furthermore, it was suggested that older people who used equipment and adaptations were more likely to feel less safe ($p<0.05$). Home care providers could consider ensuring that safety arrangements for people who use equipment and adaptations are appropriate.

1 **Evidence statements**

4.1	**Abuse concerns reported by home care services**
	There is moderate evidence from a UK evidence review (Institute of Public Care or IPC, 2013, evidence level +/+) that home care services are less likely to report abuse and safeguarding concerns than are staff working in care home settings. Financial abuse (by whom is not stated) is thought to be the most common type of abuse reported in home care.
4.2	**Training and awareness of abuse among home care workers**
	There is moderate to good evidence from a UK evidence review (IPC, 2013, evidence level +/+); from a UK qualitative study (Simic et al, 2012, +) and from a UK survey (Bell et al, 2004, +) that understanding, awareness and training concerning abuse among home care staff is uncertain in scope and quality, and may be reported by staff as not satisfactory. Staff who had been involved in abuse inquiries were particularly dissatisfied with the training and support given.
4.3	**Reasons for not reporting concerns about abuse**
	There is moderate to good evidence from a UK evidence review (IPC, 2013, evidence level +/+) and a UK qualitative study (Simic et al, 2012, +) that home care and other social care staff may be discouraged from reporting concerns because: - There is poor support for staff involved in abuse allegations, which may be very protracted, and may affect present and future employment even if they are exonerated; - Home care staff may have no access to an independent source of advice if they have concerns, and therefore fear that any concern may quickly accelerate into a heavy-handed enquiry by the local authority; - Local authorities' enquiries are thought to be aggressive in their handling of concerns, and inclined to attribute blame; - CQC and local authorities regard reporting as a negative measure of bad care, rather than a positive commitment to tackle bad care and neglect.
4.4	**Home care workers could help improve environmental safety in service users' homes**
	There is moderate evidence from two US studies (an RCT, Ganong et al, 2013, +/-; a quantitative before and after evaluation, Gershon et al, 2012, +/-) that safety in service users' homes could be improved by training paid and unpaid carers to recognise hazards in the home (chemical, fall, fire, security and health), and to respond to them (e.g. through installing fire alarms, making pre-arranged calls, fixing rugs, teaching older people to use mobile phones).
4.5	**Evidence of hazardous and dirty homes**
	There is evidence of moderate quality from two UK qualitative studies (Taylor and Donnelly, 2006, on Northern Ireland, +; Wibberley 2013, +) that home care workers face a number of hazards and deficiencies in the workplace, many of which can impact negatively on service users and carers. In rural settings especially (Taylor and Donnelly, 2006 on Northern Ireland), these may include lack of running water, heating and functioning

		toilets. Both studies reported general squalor and filth, and rotting food. Comments from home care workers and managers reiterate the difficulty of balancing the client's preferences and privacy with their view of what is acceptable and healthy; and the problem that home care commissioners concentrate on personal care, although many older people cannot manage housework and laundry tasks.
4.6		**The home as a hazardous workplace**
		There is qualitative evidence of moderate quality from Northern Ireland (Taylor and Donnelly, 2006, +) that home care workers are themselves vulnerable to infection while working in insanitary conditions, as well as to risk of injury through manual handling, aggression or harassment from users and family members, and hazardous environmental conditions and equipment (e.g. electrical). It is not clear that home care workers have knowledge and strategies to deal with these difficulties (which may include refusal to continue the service).
4.7		**Medication management**
		There is UK qualitative evidence of poor quality (McGraw et al, 2008, -, in which no raw data was reported) that home care workers are increasingly involved in medication management, and that they encountered difficulties when users or carers refused the medication; did not know what they were for or how vital they were; and had no support from primary care clinicians to enable them to promote adherence.

1 **Included studies for this review question**

2 Bell B, Oyebode J, Oliver C (2004) The physical abuse of older adults: The

3 impact of the carer's gender, level of abuse indicators, and training on

4 decision making. Journal of Elder Abuse and Neglect 16: 19-44

5 Ganong L H, Coleman M, Benson J et al. (2013) An intervention to help older

6 adults maintain independence safely. Journal of Family Nursing 19: 146-170

7 Gershon R M, Dailey M, Magda L A et al. (2012) Safety in the home

8 healthcare sector: Development of a new household safety checklist. Journal

9 of patient safety 8: 51-9

10 Institute of Public Care (IPC) (2013) Evidence review: Adult safeguarding.

11 Leeds: Skills for Care

12 McGraw C, Drennan V, Humphrey C (2008) Understanding risk and safety in

13 home health care: The limits of generic frameworks. Quality in Primary Care

14 16: 239-48

Simic P, Newton S, Wareing D (2012) "Everybody's business": Engaging the independent sector. An action research project in Lancashire. Journal of Adult Protection 14: 22-34

Taylor B J and Donnelly M (2006) Risks to home care workers: Professional perspectives. Health, Risk and Society 8: 239-256

Wibberley G (2013) The problems of a 'dirty workplace' in domiciliary care. Health and Place 21: 156-162

3.5 Training

Introduction to the review question

The purpose of this review question was to seek evidence which would guide recommendations about the induction, training, supervision and support given to home care staff providing care to older people in their own homes, with a view to improving home care. Home care staff are a specific workforce, who usually work alone and take responsibility for visiting people within set time-slots, which may limit their ability for shared learning. We were also interested in the need for training of personal assistants, that is, those home care workers who are directly employed by the person receiving care or their family, and are not supported by an external agency. It was expected that home care agencies would be primarily responsible for providing training and supervision, as local authorities now directly provide very few home care services.

The population in question concerned was older people, many of whom may have long-term conditions and complex needs. The outcomes prioritized in relation to evidence on training were the satisfaction of users and carers and their perception of choice and control in the way care was provided, and indicators of improved quality and reliability of the home care service as a result of staff training and support.

1 **Review question(s)**

2 Q.5.1 What are the effects of workforce training, supervision and support on

3 outcomes for people who use home care services and their family carers?

4 **Summary of review protocol**

5 The protocol sought to identify studies which would:

6 • identify core induction and training needs of home care workers and

7   managers.

8 • identify and evaluate training programmes and approaches which, when

9   delivered to home care workers and managers, demonstrate improved

10 outcomes for people who use services and their family carers, sustainable

11 service quality improvements and worker job satisfaction.

12 • identify good practice in the provision of supervision and support to home

13 care workers and managers.

14 • identify approaches which benefit from cross-disciplinary working, training

15 or work shadowing (e.g. with colleagues involved in delivering healthcare in

16 homes).

17 • describe the implementation costs of training, and if possible any effects on

18 recruitment and retention.

19 • inform questions on significant features of effective home care (3.1), safety

20 and safeguarding (4.1), and evidence relating to the views and experiences

21 of users, carers, and practitioners (1.1, 1.2, 2.1, 2.2).

22 **Population:** Social care practitioners and workers delivering home care to

23 older people (aged 65 years and older). The training of personal assistants

24 who are commissioned by service users and their families were also within

25 scope. Training and support delivered by community health personnel (GPs,

26 district nurses) to home care workers was also within scope.

27 **Intervention:** Training, supervision and support to home care workers and

28 managers.

29 **Setting:** In the practice setting (service users' home, including sheltered

30 housing accommodation, extra care housing, Shared Lives Scheme living

1   arrangement), in the agencies managing home care support, or in other

2   settings.

3   **Comparator:** Comparative studies could compare organisations receiving

4   training with those who do not, or before/after designs.

5   **Outcomes:** Primary outcomes are improved home care for service users' and

6   their families, such as; service user satisfaction; quality and continuity of home

7   care; choice and control; involvement in decision-making; dignity and

8   independence; quality of life; health status; safety and safeguarding of users

9   and carers; (4.4 Scope).

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

11   • Systematic reviews of studies of different models of training for home care
12   staff and managers;

13   • RCTs of different models of training (or cluster randomised trials or before
14   and after evaluations);

15   • Quantitative and qualitative evaluations of different models of training with
16   demonstrable outcomes over time;

17   • Observational and cross-sectional survey studies of training provided;

18   • Mixed methods studies.

19   Full protocols can be found in Appendix A.

20   **How the literature was searched**

21   Electronic databases in the research fields of social care, health and social

22   science were searched using a range of controlled indexing and free-text

23   search terms based on the setting "home care" and the populations: "older

24   people", "carers", "workforce", "social care organisation". The search aimed to

25   capture both journal articles and other publications of empirical research.

26   Additional searches of websites of relevant organisations were also carried

27   out.

The search for material on this topic was carried out within a single broad search strategy used to identify material which addressed all the agreed review questions on home care. The search strategy did not distinguish research of specific study designs, as filters are often unreliable, so these were to be differentiated at the screening stages of the review.

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 receiving home care, however organised, or their carers)
- Intervention (home care)
- Setting (home care delivered in person's home)
- 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 did not find any material which directly responded to this question, because there were no experimental studies, and no reporting of outcomes of training for users and carers, with the exception of Netten et al (2007), which is a large survey (an observational study) of older service users' views of the quality of home care delivered by different providers, with some reference to workforce training and how this correlates with satisfaction (see below). We therefore included studies which must be considered of lesser relevance and lesser research credibility, but may at least identify some of the areas and effects of training thought important by home care workers, managers, commissioners, and other stakeholders.

From 63 studies which appeared relevant (by title and abstract), we ordered full texts of those which appeared to concern either UK studies of training and workforce support, and/or were of acceptable methodological quality (n=29). On receiving and reviewing the full texts, we identified 8 which fulfilled these criteria (see included studies below): all were based on UK research. Most of these concentrated on prevalence of, and additional needs for, training and support. 5 of the included studies are surveys, two employ mixed methods, and one is a scoping review.

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

Impact of training on the quality of home care

Only one paper (Netten et al, 2007, evidence level +) explored the links between care quality and workforce training. This study surveyed 7935 older users of home care services and linked responses to the workforce characteristics, including training, of workers in 121 home care provider

1 services. The survey found that on the whole, older people associated higher

2 levels of service quality with a more highly trained workforce (hours of

3 training) (p<0.01). However, training for the NVQ2 qualification was negatively

4 associated with service quality (p<0.001). Higher quality ratings by service

5 users were also associated with a stable workforce with guaranteed hours and

6 allotted travel time. Unfortunately, the data is not current.

7 ***Recruitment and induction***

8 Rubery et al (2011, evidence level +) found that recruitment was rarely

9 influenced by prior completion of the NVQ2, and that employment was more

10 likely to be offered on the basis of a positive attitude and availability during

11 antisocial hours. This is consistent with findings from Cangiano et al (2009,

12 evidence level ++/+) that migrant workers are recruited into care work on the

13 basis of caring attitudes, and willingness to work antisocial hours, rather than

14 qualifications or experience.

15 A study by the Department of Health, Social Services and Public Safety of

16 Northern Ireland (DHSSPS, 2009, evidence level +) found that 76% of

17 respondents reported that they did not (in the last year) send staff who had

18 not completed induction training out on home care visits. However, this is self-

19 reported data from a survey of providers in Northern Ireland to which 25% did

20 not respond.

21 ***Home care workers' qualifications***

22 In a survey for Skills for Care of the entire social care workforce (not just the

23 home care sector), Hall and Wreford (2007, evidence level +) found that whilst

24 the majority of respondents to the survey were qualified to at least a Level 2

25 qualification, 20% had no qualifications at all. The qualifications most often

26 achieved were a NVQ Level 2 (23%), with a further 11% having reached NVQ

27 Level 1. Social care workers in the care home sector were more likely to have

28 had training than those working in home care, as were younger respondents.

29 Around a quarter of respondents to the DHSSPS (2009) survey from Northern

30 Ireland reported that their workers were not undergoing external training

31 towards qualification in areas relevant to home care. 50% of those providers

1   with workers undertaking qualifications gave them time off to do so, but it was

2   not clear whether the worker was paid for this time.

3   Workers who responded to the Hall and Wreford survey (2007) gave a variety

4   of motives for undertaking qualifications. These included prompts from

5   employers, increasing their chances of securing a better job (11%), increasing

6   their chances of promotion (10%), and increasing their ability to secure a

7   higher wage (9%). Just 15% reported intention to seek internal promotion

8   through training; 27% said there was no pathway for progression, and 24%

9   did not want additional responsibility.

10   ***The influence of regulation on training provision***

11   Only one study (DHSSPS, 2009,) considered training and support of home

12   care workers in relation to regulatory requirements. The survey found that

13   between 2/3rds and 100% of registered home care providers who responded

14   said that they had provided training to their workers in all six areas highlighted

15   by the regulatory body the Regulation and Quality Improvement Authority

16   (RQIA). Over a third (36%) said that they had trained 100% of their workers in

17   all six areas. Most respondents stated that they scheduled staff appraisals

18   either at six month intervals or annually given RQIA requirements for regular

19   appraisals.

20   ***Does provider type influence provision of training?***

21   Rubery et al (2011) found that the shift towards a mixed economy in the

22   provision of home care was associated with difficulties in providing and

23   resourcing training for home care workers. The survey found that 10% of

24   Independent Domiciliary Providers (IDPs) who responded required applicants

25   to undertake training in their own time, whilst 25% did not pay for induction

26   training. Zero hours contracts were common in nearly 70% of IDPs, so the

27   incentive to invest (by the provider or by the potential home care recruit) in

28   training may not be strong. The survey also found that perceptions of

29   adequate training times varied between provider types. Over one quarter of

30   IDP managers believed that new recruits would be able to do the job as well

31   as existing staff in one week or less, compared to none of the Local Authority

1 Domiciliary Providers (LADP) managers, who felt that induction could take

2 between one and six months.

3 Rubery et al (2011) found that only one of fourteen interviewed local authority

4 commissioning managers included incentives to providers for training staff.

5 A study by the DHSSPS (2009) found that 90% of providers who responded

6 reported that they had appointed a qualified supervisor for new recruits: but

7 supervision did not necessarily include 'on the job' joint visits. The study also

8 found that 94% of service providers who responded said that the domiciliary

9 care workers they employed were formally appraised by a suitably qualified

10 person.

11 Manthorpe and Martineau (2008, evidence level +/+) found that directly

12 employed personal assistants were likely to have little or no training other than

13 instruction given by service users. This issue was also highlighted by Rubery

14 (2011), with some providers expressing concerns that these workers are

15 unlikely to be trained or have CRB checks.

16 ***Training needs identified by the workforce***

17 Hall and Wreford (2007) reported demand for more training amongst some

18 social care staff, with dementia awareness being mentioned most frequently

19 (14% of respondents). Twelve per cent wanted first aid training, 10% an NVQ

20 of some kind, 8 % any other training related to their job, 6% manual handling

21 or lifting training, and 5% mental health or medication training. The study also

22 found that only 64% of home care workers (compared to 86% in other care

23 settings) said that they had an annual training and development review. In a

24 study exploring the role of the home care worker in palliative and end of life

25 care, Devlin and McIlfatrick (2010, evidence level +/+) found that two-thirds of

26 respondents did not have training in palliative care, but that half wanted

27 training in this field. Respondents to their questionnaire identified emotional

28 support for themselves, and training which focused on specific conditions, as

29 issues which training programmes should cover in detail.

1   *Support for migrant workers*

2   Cangiano et al (2009, evidence level ++/+) found that language difficulties

3   were a significant issue for both service users and employers. The study also

4   reported that it was often difficult for migrants to find the time to attend

5   language classes, and interviewees suggested that they had poorer access to

6   training, particularly when working in home care (rather than residential care)

7   settings, which then impacted upon their prospects of promotion. The authors

8   also suggest that induction training for migrant workers should cover everyday

9   customs and the colloquialisms that older people may use to refer to their

10 health and personal needs.

11 Cangiano et al (2009) also reported that some employers identified NVQ

12 eligibility rules as a barrier to high quality care. The requirement for non-EEA

13 staff to have been resident in the UK for three years before accessing NVQ

14 courses was seen as particularly problematic by some respondents.

15 *Training and support through 'integrated working'*

16 A scoping study by Manthorpe and Martineau (2008) found a number of

17 studies reporting that support workers employed by healthcare organisations

18 are more likely to receive structured training on healthcare tasks than those

19 employed in independent domiciliary care organisations, although they may

20 be undertaking similar tasks (such as infection control, medication prompting).

21 Nancarrow et al (2005, evidence level -) investigated provision of training to

22 unqualified support workers and found that the majority of intermediate care

23 teams – employed through the NHS - who responded reported that they did

24 have arrangements in place for support worker supervision. The most

25 common models of doing so were: provision of a mentor; team supervision; or

26 direct formal or informal supervision from a line manager or team leader.

27 Devlin and McIlfatrick (2010) found that home care workers respondents to

28 their survey were commonly providing palliative and end of life care, and were

29 often involved in quasi-medical tasks such as catheter and pressure area care

30 as well as medication administration. However, the study found that 'training'

31 was largely dependent on working alongside community nurses. The study

32 also reported from a focus group with community nurses that nurses felt that

1 home care workers should be able to provide physical care and to identify

2 deterioration in skin condition and mobility (although there was no formal or

3 informal structure suggested for training them).

4 **Evidence statements**

5.1	**Impact of workforce characteristics on users' perceptions of service quality**
	There is moderate evidence from one UK survey study (Netten et al, 2007, +) which suggests that older people's perception of good quality home care is positively associated with an older and more highly trained workforce (but the negative association between workers with NVQ2 qualification was an exception to this rule).
5.2	**Decline in training opportunities for home care workers**
	There is moderate evidence from two UK survey studies (Rubery et al 2011, +; Hall and Wreford, 2009, +) that the shift of provision from local authority in-house home care services to a mixed economy of providers is associated with difficulties in providing and resourcing training to the home care workforce. Social care workers delivering home care are less likely than those in residential settings to receive adequate induction and additional training (possibly because it is more difficult to organise and release staff time for training).
5.3	**Home care workers' perception of need for training in particular areas**
	There is good quality evidence from three UK studies, a survey (Hall and Wreford, 2009, +), a mixed methods study (Cangiano et al,2009, ++/+) and a qualitative study (Devlin and McIlfatrick, 2010, +) that home care staff feel they would benefit from more training in specific topics, such as dementia care and working with families facing death and bereavement.
5.4	**Training for migrant care workers**
	There is good evidence from one UK mixed methods study (Cangiano et al, 2009, ++/+) that migrant workers need more support from employers to improve language skills and cultural awareness, delivered in ways which do not compromise their ability to work.
5.5	**Need for some training in health-related areas**
	There is moderate to good evidence from three UK studies, a scoping review (Manthorpe and Martineau, 2008, +/+), a survey (Nancarrow et al, 2005, -) and a mixed methods study (Devlin and McIlfatrick, 2010, +) that social care practitioners working in such services as intermediate care and home-based palliative care often do not receive training and supervision that supports their delivery of basic healthcare for older people living at home with complex needs. There is a need for strategic solutions at all levels to ensure that social care staff and qualified clinical (mainly nursing) practitioners collaborate and complement each other's work.
5.6	**Lack of cost-effectiveness studies on training of home care workforce**
	No studies were identified on the cost-effectiveness of workforce training, and the lack of effectiveness studies that used standardised measures on health and wellbeing meant it was not possible to derive any conclusions about likely cost-effectiveness of different training programs.

5

1 **Included studies for this review question**

2 Cangiano A, Shutes I, Spencer S et al. (2009) Migrant care workers in ageing

3 societies: research findings in the United Kingdom. Oxford: ESRC Centre on

4 Migration Policy and Society

5 Department of Health, Social Services and Public Safety Northern Ireland

6 (2009) Survey of domiciliary care providers Northern Ireland 2008. Belfast:

7 Department of Health, Social Services and Public Safety Northern Ireland

8 Devlin M and McIlfatrick S (2010) Providing palliative care and end-of-life care

9 in the community: the role of the home-care worker. International Journal of

10 Palliative Care Nursing 16: 195-203

11 Hall L and Wreford S (2007) National survey of care workers: final report.

12 Leeds: Skills for Care

13 Manthorpe J and Martineau S (2008) Support workers: Their role and tasks. A

14 scoping review. London: Social Care Workforce Research Unit

15 Nancarrow S, Shuttleworth P, Tongue A et al. (2005) Support workers in

16 intermediate care. Health and Social Care in the Community 13: 338-344

17 Netten A, Jones K, Sandhu S (2007) Provider and Care Workforce Influences

18 on Quality of Home-Care Services in England. Journal of Aging & Social

19 Policy 19: 81-97

20 Rubery J, Hebson G, Grimshaw D et al. (2011) The recruitment and retention

21 of a care workforce for older people. Manchester: Manchester Business

22 School

23

24

3.6 Telecare

Introduction to the review question

This review question sought to identify which types of telecare were used as part of a home care package to support older people to live at home, and how these interventions supported or dovetailed with home care provision. A further concern was how acceptable telecare interventions, particularly those which might intrude on privacy and dignity, were to service users, and whether telecare could offer reassurance and resolve anxiety for older people living at home and their (often distantly located) carers.

Difficulties in addressing this question were not only the lack of agreed definition of telecare, but the failure of many studies, including the Whole Systems Demonstrator study (Hirani et al (2014); Davies et al (2013); Steventon et al (2013); Sanders et al (2012) and Henderson et al, (2014) to specify exactly what the intervention, that is what type or combination of telecare, was included. Our question had intended to identify only the telecare interventions that are used as part of a home care package, but there were few studies which referred explicitly to home care. The economic cost-effectiveness review encountered similar difficulties.

Review question(s)

Q.6.1 What elements of telecare that could be used in planning and delivering home care are effective in improving outcomes for people who use services & their carers?

Q 6.2 What are the views of users and family carers on the use of telecare as part of the home care package?

Summary of review protocol

The protocol sought to identify studies which would:

- identify and evaluate elements of telecare that are used or could be used effectively in home care planning, practice and delivery.

- identify the outcomes – for service users and carers, and for the home care workforce and agencies - of using telecare in home care practice.
- consider how useful and acceptable telecare is from the perspective of home care users and carers.
- Inform questions on: what users, carers and practitioners (1.1.1 – 1.2.2) identify as aspects of good and poor practice; barriers to implementation of good home care practice (2.2); safety (2.3); and workforce (2.4), specifically to understand whether workforce development could be wholly or partially addressed by investment in telecare.

Population: Older people (aged 65 years and older) receiving home care and people who care for those using services. Home care practitioners delivering home care to older people.

Intervention: Telecare which contributes directly to the organisation and effectiveness of home care.

Setting: Service users' homes, including sheltered housing accommodation, extra care housing, Shared Lives Scheme living arrangement, and organisations delivering home care.

Comparator: There may be comparative studies of agencies using/not using telecare, or of outcomes of different types of telecare.

Outcomes: None specified in advance, but driven by the data. It was anticipated that the likely outcomes (described or measured) would include service user outcomes such as: service user satisfaction; quality and continuity of home care; choice and control; involvement in decision-making; dignity and independence; quality of life; health status; safety and safeguarding (4.4 Scope). It was also anticipated that organisational outcomes would be relevant, including, for example: productivity, consistency in care provision, staff retention rates job satisfaction; condition of work; organisational issues, perceived competency; work-related training and supervision issues; quality of home care provided.

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

1   • Systematic reviews of studies of different models of telecare;

2   • RCTs or cluster randomised trials of telecare;

3   • Before and after evaluations of telecare;

4   • Cost effectiveness studies of telecare, or other economic studies;

5   • Qualitative evaluations of telecare, including studies concerning user, carer
6   and practitioner views of telecare;

7   • Mixed methods studies.

8   Full protocols can be found in Appendix A.

9   **How the literature was searched**

10   Electronic databases in the research fields of social care, health and social
11   science were searched using a range of controlled indexing and free-text
12   search terms based on the setting "home care" and the populations: "older
13   people", "carers", "workforce", "social care organisation". The search aimed to
14   capture both journal articles and other publications of empirical research.
15   Additional searches of websites of relevant organisations were also carried
16   out.

17   The search for material on this topic was carried out within a single broad
18   search strategy used to identify material which addressed all the agreed
19   review questions on home care. The search strategy did not distinguish
20   research of specific study designs, as filters are often unreliable, so these
21   were to be differentiated at the screening stages of the review.

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

23   **How studies were selected**

24   Search outputs (title and abstract only) were stored in EPPI Reviewer 4 - a
25   software programme developed for systematic review of large search outputs
26   - 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 receiving home care, however organised, or their carers)
- Intervention (home care)
- Setting (home care delivered in person's home)
- 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%.

A large number of full texts were retrieved to check the exact details of the intervention and then subsequently excluded if they did not meet the definition. Another common problem within this set of studies was that 'telecare' was not defined at all, and that – as in the Whole Systems Demonstrator trial - several technologies were bundled together, so that no clear findings on their effectiveness emerged. Finally we excluded papers based on poor methodologies if they did not have relevant findings.

Ten (10) papers were included in our analysis, and a further two papers (Clifford et al, 2012; Henderson et al, 2014) were used in the economic

analysis (total 12 studies). We identified 3 high quality papers which were part of the same programme of research, the Whole Systems Demonstrator, which used a cluster randomised controlled trial design to assess the impact of telecare: Hirani et al (2014) which measured impact on wellbeing and quality of life; Steventon et al (2013) which measured impact on use of health and social care, and Sanders et al (2012), a small qualitative study. A fourth paper (Henderson et al, 2014) relating to this trial, and an unrelated cost-effectiveness study (Clifford et al, 2012), were assessed for cost-effectiveness evidence by NCCSC economists. In addition, we included 2 systematic reviews (on fear of falling, Stewart and McKinstry, 2012; and outcomes for carers, Davies et al, 2013), one small controlled study (Brownsell et al, 2008), 2 surveys (Beale et al, 2009; Rainbow, 2008) and 2 qualitative studies (Clark and McGee-Lennon, 2011; Jarrold and Yeandle, 2008).

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

Outcomes for older people

Hirani et al (2014, evidence level ++/+) found that telecare interventions produced a small statistically significant improvement in the mental health quality of life and psychological wellbeing of a group of 430 older people with social care needs. Similarly, Beale et al (2009, evidence level -) and Rainbow (2008, evidence level -) both reported from (poorly reported) survey data that telecare interventions can increase the independence and social functioning of older people with social care needs, as well as reduce their levels of anxiety and fear. Brownsell et al (2008, evidence level +/+) also reported that telecare interventions produced an 8% increase in the social function of older people but this may have been attributable to the provision of an internet café rather than the telecare intervention itself.

1 Beale et al (2009), Brownsell et al (2008) and Rainbow (2008) all found that

2 telecare interventions increased the sense of independence and safety

3 amongst older people with social care needs. Beale et al (2009) reported that

4 93.3% of participants in the study felt safer, 69.7% felt more independent and

5 87.2% thought that their families now worried about them less. Similarly,

6 Brownsell et al (2008) found that telecare enabled people to spend more time

7 out of the home, made them feel safer (particularly during the night), and

8 made them less fearful of crime (10% decrease in fear), although these

9 findings were not statistically significant. Rainbow (2008) reported that 96% of

10 participants agreed with the statement that telecare had 'made a positive

11 addition to my life'. However, only 47% agreed that it had helped them to

12 remain in their own home.

13 A systematic review (self-defined as 'critical') by Stewart and McKinstry (2012,

14 evidence level +/+) concluded that there is no clear link between use of

15 telecare and a reduction in fear of falling. The authors note that many of the

16 conclusions drawn in the included studies are unconvincing and that the

17 included papers were limited by unsound methodologies. Similarly, an

18 evaluation of second and third generation telecare devices by Brownsell et al

19 (2008) found that there was no significant difference between the control and

20 intervention groups in relation to fear of falling. However, 77% of participants

21 in a study by Rainbow (2008) said that their fear of falling and not being able

22 to get help had been reduced; although 22% said that their level of concern

23 had not changed at all.

24 Hirani et al (2014) found that telecare interventions did not have any

25 significant effects on the physical quality of life of older people with social care

26 needs. Brownsell et al (2008) reported no significant difference between the

27 two arms in 8 out of 9 SF36 domains (physical functioning; physical role

28 limitation; emotional role limitation; mental health; energy/vitality; pain; health

29 perception; change in health).

30 Clark and McGee-Lennon (2011, evidence level -) found that some older

31 people had concerns regarding the type of telecare which was installed in

32 their homes, with a number suggesting that sensors were more appropriate

1 than video surveillance. Beale et al (2009) reported that some older people

2 felt that telecare devices worn on the person such as pendant alarms and fall

3 detectors were uncomfortable, restrictive or too sensitive; and a review by

4 Stewart and McKinstry (2012) recommended that automatic fall detectors

5 should be designed to be wearable. Beale et al (2009) also found that wrist

6 pendants were generally more popular than those worn around the neck.

7 *Outcomes for carers*

8 A systematic review by Davies et al (2013, evidence level ++/+) concluded

9 that many studies which evaluated the effectiveness of telecare had such poor

10 methodologies that it was not possible to reach a definitive conclusion on the

11 benefits for carers. However, the study cited evidence from one UK paper

12 which reported that 82% of carers in the study said that telecare had made 'a

13 lot' or 'a little', as opposed to 'no', difference to them as a carer. Similarly,

14 Rainbow (2008) reported that 86% of family carer participants in the study

15 stated that telecare was of benefit to them.

16 Jarrold and Yeandle (2011, evidence level +) found that the majority of carers

17 in the study found telecare to be beneficial, most often because it led to a

18 reduction in stress and anxiety for them as carers. They also perceived the

19 people whom they cared for to have increased feelings of security, confidence

20 and independence. Several carers reported feeling more freedom to leave the

21 house for short times, delegate care to other people or spend time alone in

22 their own houses, rather than constantly in the company of the person they

23 care for. Several carers also stated that they felt their relationship with the

24 person they cared for had improved as a result of telecare. Similarly, Rainbow

25 (2008) found that family carers of older people receiving home care felt that

26 telecare interventions reduced the stress and anxiety of the caring role.

27 Jarrold and Yeandle (2011) found that although family carers reported less

28 time spent worrying about the person they cared for, and that many felt that

29 telecare was beneficial to them, installation had not reduced the amount of

30 support which these carers received from paid home care services or the

31 amount of time which they themselves spent caring. Beale et al (2009) found

32 that whilst 32.8% of older people in the study felt that telecare equipment had

1   reduced the amount of help they needed, but 40.8% said that the equipment

2   had not affected the amount of help which they needed from their

3   family. However, Jarrold and Yeandle (2011) did report that telecare enabled

4   some carers in the sample to engage in paid work alongside their caring role.

5   ### *Service outcomes*

6   Two studies explored the effect of telecare on hospital admissions. Steventon

7   et al (2008, evidence level ++/+) found that there was a small difference in the

8   number of hospital admissions within 12 months in the intervention and

9   control groups of the Whole Systems Demonstrator trial (46.8% and 49.2%

10   respectively and only statistically significant when adjusted for baseline

11   characteristics). However, the study found no convincing significant

12   differences in outcomes such as admission to nursing or residential care,

13   rates of mortality or length of hospital stay. In contrast, Beale et al (2009)

14   found that many partnerships who participated in the study reported fewer

15   hospital and care home admissions as well as reduced lengths of stay, but it

16   should be noted that these outcomes were self-reported by agencies

17   participating in the Scottish Telecare Development Programme, and that no

18   baseline or follow up detail was provided.

19   ### *Barriers to the use of telecare*

20   ### *Older people's perceptions of and introduction to telecare*

21   Clark and McGee-Lennon (2011) found that some older people rejected the

22   idea that they needed help at all; and a number of studies cited in a review by

23   Stewart and McKinstry (2012) reported similar findings. Sanders et al (2012,

24   evidence level +) also found that some participants who had declined to

25   participate or had withdrawn from the Whole Systems Demonstrator trial felt

26   that their autonomy would be undermined by the installation of telecare

27   equipment within their home.

28   Clark and McGee-Lennon (2011) found that although carers and professionals

29   who participated in the study perceived older people's 'technophobia' to be a

30   barrier to the uptake of telecare, this was not a concern mirrored by older

31   participants. Sanders et al (2012) did report that many respondents had a

general distrust of modern technologies or lacked confidence in their abilities to use telecare devices. Similarly, Jarrold and Yeandle (2011) found that some carers had concerns about the capacity of the person they cared for and their ability to operate telecare equipment. This was a relatively common concern amongst carers of people with cognitive impairments such as dementia, or worsening health conditions which impinged upon their ability to use alarms correctly or respond to alarm or sensor enquiries.

Sanders et al (2012) found that some older people who had withdrawn from the Whole Systems Demonstrator trial felt that the introduction to telecare, and the information, which they had received did not encourage or enable them to use the equipment. The author states that discussion of issues such as cost had in some cases worried the person so much that they had decided to leave the trial. In contrast, Jarrold and Yeandle (2011) found that all carers in the study felt that the equipment had been adequately explained to them at installation. However, the study also found that some carers felt that they lacked access to information about new or recent developments in telecare.

Other factors affecting take-up

Both Jarrold and Yeandle (2011) and Sanders et al (2012) reported concerns from some participants that the person they cared for was too ill for telecare to be of any benefit, or that telecare was potentially harmful for very ill people, for example by further confusing an individual with cognitive issues (Jarrold and Yeandle, 2011).

Beale et al (2009) also reported that the decreasing prevalence of telephone landlines, particularly in urban areas, was a further barrier to uptake of telecare.

Economic evidence

A cost utility analysis of telecare was carried out from data of the Whole Systems Demonstrator (Henderson et al 2014, economic evidence rating ++). The trial compared second-generation in addition to standard care (telecare group, n=375) with standard care (comparison group, n=378). Standard care included social and healthcare packages (including home care) and first-

generation telecare, and the comparison group had a significantly greater use of first generation telecare at follow up (difference of 13%, $p<0.05$). The study found a small positive, non-significant health effect (measured with EQ-5D) in the telecare (second generation) group at 12 months (0.003, standard difference 3.7%). Costs at 12 months were higher in the telecare group (£8,909 vs. £7,329; 95% CI -£525, £2,553) which was mainly due to the costs of telecare (£791), greater use of home care (£42 vs. £33), social work and community nursing. The probability that telecare was cost-effective was under 16% at a willingness-to-pay threshold of £30,000 and sensitivity analysis showed that this was robust against changes of parameters such as cost of telecare and different willingness-to-pay thresholds.

Two UK cost savings study reported that there could be substantial cost savings linked to telecare. Clifford et al (2012, economic evidence rating -) applied a mixed methods design based on case descriptions and presented weekly cost savings per older person (n=52) which ranged from £29 to £39 for individuals with high needs and from £6 to £35 for people with low needs. Beale et al (2009, economic evidence -) carried out a survey that asked representatives of 32 partnerships of the National Telecare Development Programme in Scotland to provide estimates of cost savings. The study reported total cost savings across the partnerships of £11.2m which included those linked to improved hospital discharge (£1.7m), reduced unplanned hospital admission (£3.3.m), reduced care home admission (£3.4m), reduced night care (£0.6m), reduced home check visits (£1.8m), other efficiencies (£0.3m). Both studies failed to report details about types of telecare provided.

Based on existing cost-effectiveness evidence there was a low probability that second-generation telecare was cost-effective. However, this evidence came from only one trial and a replication of the trial might be required to confirm findings. In the absence of further evidence the GDG might decide to recommend the use of first-generation telecare. Further economic evaluations should include the carers' perspective - in particular carers' health and wellbeing outcomes and the hours of unpaid care- as well as out-of-pocket expenditure by service users and carers.

1 **Evidence statements**

6.1	**Impact of telecare support on wellbeing of older people**
	There is good evidence from one UK cluster RCT (Hirani et al, 2014, ++/+) to suggest that older people who received home-based telecare support were significantly more likely to achieve a small improvement in mental health-related quality of life and psychological wellbeing than those who received usual health and social care at 12 months. There is moderate evidence from one UK controlled study (Brownsell et al, 2008, +) that older people in older people's housing who were offered a telecare package improved social function by 8% at 12 months.
6.2	**Impact of telecare on hospital use and care home admissions**
	There is good evidence from one UK cluster RCT (Steventon et al, 2008, ++/+) that demonstrates a small decrease in the proportion of hospital admissions for older people using telecare when compared with no telecare support at 12 months (46.8% and 49.2%). The study found no evidence of a difference between the two arms in admission to nursing or residential care, rates of mortality or length of hospital stay.
	There is poor, self-reported evidence from one Scottish survey (Beale et al, 2009, -) that partnerships participating in the National Telecare Development Programme (NTDP) found that use of telecare reduced hospital and care home admissions as well as lengths of stay.
6.3	**Impact of telecare on independence and perception of safety**
	There is good evidence from one UK controlled study (Brownsell et al, 2008, +/+) that older people offered telecare were more likely to report going outdoors and spending more hours out of the home. They were also more likely to feel safe during the day and night and to be less fearful of crime. Two poorly described UK surveys (Beale et al, 2009, -) (Rainbow, 2008, -) reported that older people in the National Telecare Development Program felt safer, and more independent, and perceived that their families now worried about them less. There is poor evidence from one UK survey (Beale et al, 2009, -) that older people felt that telecare equipment had reduced the amount of paid help they needed but that the equipment had not affected the amount of help which they needed from their family.
6.4	**Lack of impact of telecare on physical functioning and wellbeing**
	There is good evidence from one UK cluster RCT (Hirani et al, 2014, ++/+) that telecare interventions did not have any significant effects on the physical quality of life of older people with social care needs when compared with no telecare.
	There is good evidence from one UK controlled study (Brownsell et al, 2008, +/+) that SF36 domains (physical functioning; physical role limitation; emotional role limitation; mental health; energy/vitality; pain; health perception; change in health) did not differ between older people offered a telecare package or no telecare package.
6.5	**Lack of impact of telecare on falls and fear of falling**
	There is good evidence from one UK controlled study (Brownsell et al, 2008, +) which found no significant difference in the reported fear of falling among older people offered a telecare package and those who were not offered a telecare package. This is consistent with poor evidence from one systematic review (Stewart et al, 2012, +/+) of ten poor quality studies to suggest that there is no clear link between telecare support and a reduction in fear of falling.

6.6	**Little evidence of impact of telecare on carers and caring**
	There is good evidence from one systematic review (Davies et al, 2013, ++/+) that the benefits of telecare on burden or quality of life for family carers cannot be established due to the poor quality of the seven studies included. However, one UK study included in this review reported that 82% of carers in the study said that telecare had made 'a lot' or 'a little' difference to them as a carer (although it is unclear whether this finding is reliable).
6.7	**Perceived impact of telecare on carers and caring**
	There is poor evidence from two UK qualitative studies (Jarrold and Yeandle, 2011, +; Rainbow, 2008, -) that carers agreed that telecare had led to a reduction in stress and anxiety for them as carers, and perceived that the people they cared for had increased feelings of security, confidence and independence. Telecare had enabled some carers to engage in paid work alongside their caring role and that their relationship with the person they cared for had improved as a result of telecare.
6.8	**Acceptability of telecare devices to older people**
	There is poor evidence from one UK qualitative study (Clark and McGee-Lennon, 2011, -) that some older people had concerns regarding the type of telecare which was installed in their homes, with a number suggesting that sensors were more appropriate than video surveillance. One poor quality survey (Beale et al, 2009, -) reported that older people found telecare devices worn on the person such as pendant alarms and fall detectors to be uncomfortable, and were concerned about activating them unintentionally.
6.9	**Reasons for older people not wanting telecare: loss of autonomy**
	There is good evidence from one UK qualitative study (Sanders et al, 2012, +) that older people who declined to participate or had withdrawn from the Whole Systems Demonstrator project felt that their autonomy would be undermined by the installation of telecare equipment within their home. Another poor quality survey (Clark and McGee-Lennon, 2011, -) found some older people rejected the idea that they needed telecare help.
6.10	**Reasons for not wanting telecare: lack of confidence**
	There is moderate evidence from three UK qualitative studies (Sanders et al, 2012, +; Jarrold and Yeandle, 2011, +; Clark and McGee-Lennon, 2011, -) that some older people had a general distrust of modern technologies or lacked confidence in their abilities to use telecare devices. Carers had concerns about the capacity of the person they cared for and their ability to operate telecare equipment. In particular, carers of people with cognitive impairments such as dementia feared that telecare would not be of benefit and could be potentially harmful for very ill older people by further confusing an individual with cognitive impairment.
6.11	**Information about, and preparation for, telecare**
	There is good evidence from one UK qualitative study (Sanders et al, 2012, +) that older people felt that the introduction to telecare which they had received did not encourage or enable them to use the equipment and they were worried by the discussion of cost of telecare. Another good qualitative UK study (Jarrold and Yeandle, 2011, +) found that carers felt that the equipment had been adequately explained to them at installation, although some carers felt that they lacked access to information about new or recent developments in telecare services.

6.12	**Reliance on telephone landlines**
	There is poor evidence from one UK survey (Beale et al, 2009, -) that the decreasing prevalence of telephone landlines, particularly in urban areas, was a further barrier to uptake of telecare.
6.13	**Cost-effectiveness of telecare**
	There is one robust UK study on cost-effectiveness and cost-utility, which is an economic evaluation carried out alongside a RCT by Hirani and colleagues, ++/+ (Henderson et al, 2014, ++) which did not confirm that second-generation telecare was likely to be cost-effective, if only health outcomes and government costs were considered. It showed that second-generation telecare might slightly increase the costs of home care. This study was not designed to provide cost-effectiveness evidence for first-generation telecare. Studies that reported positive cost-effectiveness findings or cost savings of telecare (Beale et al, 2009, -; Clifford et al, 2012, -) used inappropriate designs which did not allow attributing effects and associated cost savings to telecare in a robust manner so that findings could not be used to inform recommendations.

1

2 **Included studies for this review question**

3 Beale S, Sanderson D, Kruger J (2009) Evaluation of the Telecare

4 Development Programme: Final report. Edinburgh: Scottish Government

5 Brownsell S, Blackburn S, Hawley M S (2008) An evaluation of second and

6 third generation telecare services in older people's housing. Journal of

7 Telemedicine and Telecare 14: 8-12

8 Clark J S and McGee-Lennon M R (2011) A stakeholder-centred exploration

9 of the current barriers to the uptake of home care technology in the UK.

10 Journal of Assistive Technologies 5: 12-25

11 Clifford P, Padda K, Brown O et al. (2012) Investing to save: Assessing cost-

12 effectiveness of telecare. FACE Recording and Measurement Systems Ltd.

13 Davies A, Rixon L, Newman S (2013) Systematic review of the effects of

14 telecare provided for a person with social care needs on outcomes for their

15 informal carers. Health and Social Care in the Community 21:582-97

16 Henderson C, Knapp M, Fernández JL et al. (2014) Cost-effectiveness of

17 telecare for people with social care needs: The Whole Systems Demonstrator

18 cluster randomised trial. Age and Ageing 0:1-7

1 Hirani SP, Beynon M, Cartwright M et al. (2014) The effect of telecare on the
2 quality of life and psychological well-being of elderly recipients of social care
3 over a 12-month period: The Whole Systems Demonstrator cluster
4 randomised trial. Age and Ageing 43: 334-341

5 Jarrold K and Yeandle S (2011) 'A weight off my mind': Exploring the impact
6 and potential benefits of telecare for unpaid carers in Scotland. Glasgow:
7 Carers Scotland

8 Rainbow D (2008) Telecare service report for Herefordshire. Journal of
9 Assistive Technologies 2: 53-56

10 Sanders C, Rogers A, Bowen R et al. (2012) Exploring barriers to participation
11 and adoption of telehealth and telecare within the Whole System
12 Demonstrator trial: A qualitative study. BMC Health Services Research 12:
13 220

14 Steventon A, Bardsley M, Billings J et al. (2013) Effect of telecare on use of
15 health and social care services: Findings from the Whole Systems
16 Demonstrator cluster randomised trial

17 Stewart L and McKinstry B (2012) Fear of falling and the use of telecare by
18 older people. British Journal of Occupational Therapy 75: 304-312

19 ## *3.7 Information*

20 **Introduction to the review question**

21 These questions sought to understand the need for and provision of
22 information and support to people seeking access to home care - for
23 themselves or others - and to consider whether their information and support
24 needs while receiving home care were met. The quality of information and
25 support, the formats and languages in which it was made available, and how it
26 was accessed were all important to the evidence. Access to information for
27 people in different stages and circumstances is now critical; people may now
28 be applying for local authority funding, or may be partly or wholly self-funding,
29 and they may be potentially 'new' customers of social services, or may by-

1 pass local authorities altogether. The Care Act 2014 has placed a mandatory

2 duty on local authorities to make information about social care accessible and

3 appropriate, and this entails a wide range of strategies which might have been

4 evaluated, either formally or through the views and experiences of service

5 users.

6 This topic also acknowledges that people already receiving home care may

7 choose, given the appropriate information and support, to change the way it is

8 delivered, perhaps taking on an IB or DP to employ a personal assistant; and

9 that knowing how to complain is an important aspect of consumers having

10 some choice and control.

11 **Review question(s)**

12 Q 7.1 What information and support is helpful to people seeking access to

13 home care services?

14 Q 7.2 What information and support should be provided to people who use

15 home care services to enable them to be aware of their options, and play a full

16 role in reviewing their care and making decisions?

17 **Summary of review protocol**

18 In respect of people seeking access to home care services, the protocol

19 sought to elicit studies which:

20 • describe the information and support needs of people (and their families)

21   seeking access to home care services, and whether such information and

22   support is helpful and accessible to different populations.

23 • identify whether improvement in information provision has an impact on

24   choice, control and other outcomes for people seeking access to home

25   care and their families.

26 • consider the issues of good or poor practice identified by users, carers and

27   practitioners (RQs 1.1.1 – 1.2.2) concerning initial access to information.

28 In respect of people using home care services and their carers, the protocol

29 sought to elicit studies which:

1 • identify the information and support needs of people who are receiving

2   home care services and those of their families, and whether such

3   information is helpful and accessible to different populations.

4 • consider the effects and outcomes of information provided during a period

5   of home care, including the impact on:

6   − the empowerment of people who use services and their carers

7   − ability to participate in and influence decision-making, including full

8   participation in regular reviews of care

9   − increased choice and control

10   − the ability of users and family carers to consider options for self-directed

11   care and use of personal budgets

12   − ability to make complaints and suggestions

13   − safety and safeguarding, where users and carers have concerns about

14   care or about limitations of care.

15 • consider whether issues of good or poor practice identified by users, carers

16   and practitioners (RQs 1.1.1 – 1.2.2) concern access to information during

17   receipt of home care services.

18 **Population:** Older people (aged 65 years and older) seeking access to home

19 care and their families; older people (aged 65 years and older) receiving home

20 care and their families. The experience of agencies providing and

21 commissioning care (including local authorities who have a duty to provide

22 information and assessment) will also be relevant.

23 **Intervention:** Information provided to the public generally and to older people

24 about home care (functions, criteria, funding options, self-directed care,

25 assessment, etc.) Information may be in the form of text products, internet

26 material, face to face advice, telephone consultation, etc.

27 **Setting:** Community contexts where information is provided or coordinated

28 (including local authorities); the potential service users' homes, including

29 sheltered housing accommodation, extra care housing, Shared Lives Scheme

30 living arrangement; organisations delivering home care.

1 **Comparator:** There may be comparative studies of agencies that have a

2 strong versus weak communication strategy.

3 Outcomes: None specified in advance, but driven by the data. It was

4 anticipated that the likely outcomes (described or measured) would include

5 service user outcomes such as: service user satisfaction with the process of

6 information seeking and provision; perceptions of choice and control;

7 involvement in decision-making; and, dignity and independence (4.4 Scope). It

8 was also anticipated that organisational outcomes would be relevant,

9 including, for example relationships between people who use services and

10 providers.

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

12 • Qualitative studies of users' and carers' experience of seeking or receiving

13 information about home care.

14 • Qualitative studies of practitioners and social services' staff experience of

15 providing information to people receiving home care, including routes for

16 complaints.

17 • Before and after evaluations where a new communication strategy has

18 been introduced, e.g. by a local authority;

19 • Mixed methods studies;

20 • Self-reported returns to Health and Social Care Information Centre,

21 illustrating demand for and supply of information provision, with possible

22 links to number of service reviews, take up of self-directed care, etc.

23 Full protocols can be found in Appendix A.

24 **How the literature was searched**

25 Electronic databases in the research fields of social care, health and social

26 science were searched using a range of controlled indexing and free-text

27 search terms based on the setting "home care" and the populations: "older

28 people", "carers", "workforce", "social care organisation". The search aimed to

29 capture both journal articles and other publications of empirical research.

1 Additional searches of websites of relevant organisations were also carried

2 out.

3 The search for material on this topic was carried out within a single broad

4 search strategy used to identify material which addressed all the agreed

5 review questions on home care. The search strategy did not distinguish

6 research of specific study designs, as filters are often unreliable, so these

7 were to be differentiated at the screening stages of the review.

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

9 **How studies were selected**

10 Search outputs (title and abstract only) were stored in EPPI Reviewer 4 - a

11 software programme developed for systematic review of large search outputs

12 - and screened against an exclusion tool informed by the parameters of the

13 scope. Formal exclusion criteria were developed and applied to each item in

14 the search output, as follows:

15 • Language (must be in English),

16 • Population (must be older people receiving home care, however organised,

17   or their carers)

18 • Intervention (home care)

19 • Setting (home care delivered in person's home)

20 • Country (must be UK, European Union, Denmark, Norway, Sweden,

21   Canada, USA, Australia and New Zealand)

22 • Date (not published before 2004)

23 • Type of evidence (must be research)

24 • Relevance to (one or more) review questions.

25 Title and abstract of all research outputs were screened against these

26 exclusion criteria. Those included at this stage were marked for relevance to

27 particular review questions and retrieved as full texts.

28 Full texts were again reviewed for relevance and research design. If still

29 included, critical appraisal (against NICE tools) and data extraction (against a

30 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 screening on title and abstract, we found 30 research papers that appeared to address these questions, and full text versions were acquired for review. There were no studies of high quality design with a comparator (possibly because it would be unethical to withhold available information from some people). Nine (9) were selected for in-depth review and analysis: three were qualitative studies, three surveys, one a study of secondary data, and the other used mixed methods. The research papers concern the views and experiences of service users, carers and providers, including home care workers, in UK countries.

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

Types of helpful information and support

A report by the Commission for Social Care Inspection (CSCI, 2006, evidence level +) emphasised the importance of the provision of basic information about entitlement to services, what services are available and how they will be provided. Whilst 91% of local authorities who responded to a survey by the Equality and Human Rights Commission (EHRC, 2013, evidence level +) reported that they had taken action to better support older people who directly employ personal assistants, nearly half (49%) had not provided a register of these workers as recommended by the 'Close to Home' inquiry (on which the survey was based). Similarly, a survey by the Department of Health, Social Services and Public Safety of Northern Ireland (DHSSPS, 2010, evidence level +) found that 38% of service users had not been given a written guide to home care services in their area.

1   A report by the CSCI (2006) referenced the 'National Minimum Standard 1'

2   which includes detailed guidance on what should be communicated to service

3   users. Requirements included what service users can expect from a service,

4   what they will have to pay, contact details which can be used in the event of a

5   problem, and how to make a complaint. The survey noted that only 66% of

6   agencies had achieved this standard in inspections.

7   A report by the London Assembly (2010, evidence level +/+) found that some

8   participants felt that the assessment process was confusing; and a number of

9   people suggested that accurate information was especially important for

10 service users with IBs given the increasing complexity of service provision.

11 Similarly, Ekosgen (2013, evidence level +) reported that some self-funders

12 needed information to help them to understand the flexibilities of care and

13 what they could expect to pay.

14   A survey by the DHSSPS (2010) explored what information older people had

15 been given about the role of their care worker, and found that almost a fifth

16 (19%) of respondents reported that they had not been provided with an

17 explanation of what their care worker was supposed to do for them. Similarly,

18 Ekosgen (2013) found that some self-funders lacked the information they

19 needed to help them to recruit a personal assistant, with employment law

20 being cited by some as an issue on which they needed assistance. Some

21 respondents reported that they had approached people receiving DPs as a

22 means of accessing information.

23 A study by the London Assembly (2010) reported that some service users

24 found complaints procedures to be confusing and unclear. A report by the

25 EHRC (2013) stated that their 'Close to Home' inquiry had prompted local

26 authorities to review whether people using home care services were aware of

27 how to make a complaint. The report included examples of how some local

28 authorities had addressed this issue by producing a film and distributing

29 comments and complaints forms more widely.

30 A report by the EHRC (2013) recommended that local authorities should

31 provide advice, advocacy and brokerage services for those considering

1   employing personal assistants and to ensure that older people can benefit, if

2   they choose, from the 'greater autonomy inherent in personalised homecare.'

3   In response to this, three local authorities had specifically (self) reported their

4   efforts to develop Independent Mental Capacity Act services.

5   ***Features of good information and support***

6   A report by the London Assembly (2010) identified a number of groups for

7   whom accessing information and advice was likely to prove problematic.

8   These included people with dementia and those who had suffered a health

9   crisis, older people who are housebound and older people who do not qualify

10   for council-funded services. A report by the CSCI (2006) suggested that

11   resources should be widely publicised to ensure that as many people as

12   possible can access them, whilst Cattan and Giuntoli (2010, evidence level +)

13   found that some respondents felt that they would only be aware of their

14   entitlements in certain circumstances. Examples given included: after being

15   hospitalised; because they have a relationship with someone who works for a

16   provider; and, because a community or recreational centre which they

17   attended provided this information. A report by Ekosgen (2013) found that

18   some interviewees disliked having to use the internet to find information, and

19   a survey by the EHRC (2013) reported that one local authority had created an

20   'ambassador network' to disseminate information in order to reach older

21   people who were not digitally literate. The report also suggested that local

22   authorities monitor internet usage of web-based resources to ensure that they

23   are fit for purpose.

24   Both Cattan and Giuntoli (2010) and the CSCI (2006) highlighted the

25   importance of providing materials in languages other than English, and the

26   CSCI report (2006) stated that there was evidence that cultural or language

27   barriers had led to 'people slipping through the net'. Similarly, Cattan and

28   Giuntoli (2010) reported that women from Bangladeshi and Pakistani

29   communities in particular often had difficulties understanding English and

30   relied on their children to contact service providers for them. Both studies

31   (Cattan and Giuntoli, 2010; CSCI, 2006) also noted that translation could be

32   problematic, with the CSCI (2006) citing the confusion which the term 'help

1   with daily living' had caused amongst a group of Yemeni community

2   members, and Cattan and Giuntoli (2010) discussing the misunderstanding of

3   care information translated for the Ukrainian community.

4   Cooper and Urquhart (2005, evidence level +) recommends that information

5   resources should be succinct and written in plain English. A survey by the

6   DHSSPS (2010) found that 96% of respondents who had received a written

7   guide to home care services understood what it told them.

8   Cattan and Giuntoli (2010) found that some older people felt that providing

9   information in the period immediately after a health crisis was inappropriate.

10   The study also found that older people needed more time to process

11   information, particularly during face-to-face assessments. The paper also

12   reported that some family carers of people with dementia preferred to be

13   present when their relative was given new information, as they were

14   concerned that their relative would say things to please the worker and not

15   always understand the information given to them.

16   Ekosgen (2013) found that some self-funders were concerned about the lack

17   of information aimed specifically towards them, noting that they were often

18   provided with information intended for those who receive DPs. The study

19   sampled 15 local authority social care enquiry lines to investigate this issue

20   and found that a number suggested that callers contact the local Direct

21   Payments Support Officer.

22   A report by the London Assembly (2010) reported that older people are more

23   likely to trust information provided by independent charities as local authorities

24   may have a vested interest in concealing entitlements.

25   ***Information and support services in practice***

26   Cattan and Giuntoli (2010) found that some participants preferred to access

27   information and advice services in person. Suggestions included the

28   attendance of officers from adult social care services at GP practices, or by

29   accessing information at community or recreational centres. A report by the

30   London Assembly (2010) noted the frustration felt by some older people and

31   their carers regarding the variety of organisations which provide information

1   services and the report makes the recommendation that information should be

2   provided on a pan-London basis.

3   A report by the Older People's Commissioner for Wales (OPCW, 2012,

4   evidence level +) investigated the role that care workers can play in

5   signposting to other sources of support. While more than a third of older

6   people who responded to this survey said that they had 'always' or 'often'

7   received useful information from their care workers, a similar proportion said

8   that this 'rarely' or 'never' happens. Similarly, both Cattan and Giuntoli (2010)

9   and Cooper and Urquhart (2005) noted that older people and their families

10 often need information on a variety of issues not directly related to home care.

11 These included eligibility for benefits and services (e.g. Carer's Allowance) as

12 well as the provision of medical devices or adaptations for the home.

13 Cattan and Giuntoli (2010), Ekosgen (2013) and the London Assembly (2010)

14 all cited concerns from some service users on the standards of social care

15 enquiry lines. Cattan and Giuntoli (2010) reported that some service users

16 found voice message menus to be frustrating, while Ekosgen (2013) reported

17 that these did not adequately signpost to other services, relying too heavily on

18 Age Concern and local Direct Payments Supports Officers. A report by the

19 London Assembly (2010) cited one example of poor practice where a local

20 authority had only one phone line dedicated to answering social care queries.

21 **Economic evidence**

22 Windle et al (2009, economic evidence rating -) found that information,

23 signposting and access to health and social care provided to N=91 older

24 people – either by home care workers as part of care planning or as single

25 point of information - had a probability of 83% to be cost-effective at a

26 willingness-to-pay threshold of £30,000 and of 75% at a willingness-to-pay

27 threshold of £20,000. However, findings were based on non-significant

28 changes in health-related quality of life (measured with the EQ-5D) and

29 potential cost savings that were likely to present overestimations as

30 investigated in subsequent research of a small sample of projects (Steventon

31 et al 2011, see Windle, 2009). Costs of the intervention were £4 to £7 per

32 person and week, in 2008 prices.

1   **Evidence statements**

7.1	**Local authorities' duty to provide information on home care**
	There is good evidence from two UK surveys (EHRC, 2013, +; DHSSPS, 2010, +) that some local authorities had not met minimum requirements to provide information for service users such as a register of personal assistants and a written guide to home care services in their area.
	Secondary data from a UK CSCI report (2006, +) found that only one-third of agencies had achieved the requirement of informing users about what service users can expect from a service, what they will have to pay, contact details which can be used in the event of a problem, and how to make a complaint.
7.2	**Service users' experience of information at the time of assessment**
	There is good evidence from a UK mixed methods study (London Assembly, 2010, +) that service users found the assessment process for social care eligibility was confusing, and that there were no adequate sources of information and advice to help them.
7.3	**Information for people funding and/or arranging their own care**
	There and good evidence from a UK qualitative study (Ekosgen, 2013, +) that accurate information is especially important for self-funders and those wishing to employ personal assistants, to help them understand the complexities of individual budgets and employment law. A UK survey (EHRC, 2013, +) recommended that local authorities should provide advice, advocacy and brokerage services to ensure that older people can benefit, if they choose, from the 'greater autonomy inherent in personalised homecare.'
7.4	**Information on home care roles**
	There is good evidence from a Northern Ireland survey (DHSSPS, 2010, +) and from a UK qualitative study (Ekosgen, 2013, +) that older people had not been provided with information about the role and tasks that their care workers would undertake.
7.5	**Additional information requirements**
	There is good evidence from two UK qualitative studies (Cattan and Giuntoli, 2010, +; Ekosgen, 2013, +) that older people and their families require information on a variety of issues not directly related to home care such as eligibility for benefits and services (e.g. Carer's Allowance, television licences, etc) as well as the provision of medical devices or adaptations for the home.
7.6	**Information on complaints procedures**
	There is good evidence from a UK mixed methods study (London Assembly, 2010, +) that service users found complaints procedures confusing. Evidence from a UK survey (EHRC, 2013, +) reported that some local authorities had produced a film and distributed comments and complaints forms more widely.
7.7	**Sources of information**
	There is good evidence from two UK qualitative studies (Cattan and Giuntoli, 2010, +; Ekosgen, 2013, +) that users were most likely to access information on entitlements after being hospitalised or from a community recreation centre. Some users disliked having to use the internet to find information. Users preferred having an officer from adult services department to attend their GP practice to answer questions.
	There is good evidence from a UK mixed methods study (London Assembly, 2010, +) that some older people and their carers felt frustrated that one single organisation is not able to give them all the information they need to know and felt that information should be provided on a pan-London basis.

7.8	**Need for information in a variety of languages**
	There is good evidence from one UK qualitative study (Cattan and Giuntoli, 2010, +) and one UK secondary data analysis (CSCI, 2006, +) that information should be provided in languages other than English, in particular for people from ethnic minority groups, as cultural or language barriers had led to 'people slipping through the net'.
7.9	**Need for information to be concise and clear**
	There is good evidence from one UK qualitative study (Cooper and Urquhart, 2005, +) that information resources should be succinct and written in plain English.
7.10	**Information tailored to older people's needs**
	There is very good evidence from one UK qualitative study (Cattan and Giuntoli, 2010, +) that older people need more time to process information, and providing information only in the period immediately after a health crisis was often inappropriate. Some family carers of people with dementia preferred to be present when their relative was given new information to support the person in giving and recalling information.
7.11	**Independent information**
	There is good evidence from a UK mixed methods study (London Assembly, 2010, +) that older people are more likely to trust information provided by independent charities, as they think local authorities may have a vested interest in concealing entitlements.
7.12	**Home care worker's role in providing useful information**
	There is evidence from a good UK survey (OPCW, 2012, +) that some older people 'often' received useful information from their care workers.
7.13	**Dislike of phone menus**
	There is good evidence from two UK qualitative studies (Cattan and Giuntoli, 2010, +; Ekosgen, 2013, +) and a UK mixed methods study (London Assembly, 2010, +) that service users found voice message menus to be frustrating as the menus did not adequately signpost to the required services; and there were insufficient phone lines dedicated to answering social care queries.
7.14	**Cost-effectiveness of information**
	There was a lack of cost-effectiveness evidence in this area with the exception of one national mixed-method evaluation (Windle et al 2009, -) which showed a relatively high probability that information and support was cost-effective and led to cost savings but results were afterwards found to be too optimistic. However, interventions in this area were of relatively low cost. Effective information and support should be delivered to older people irrespective of an economic rationale.

1

2 **Included studies for this review question**

3 Cattan M and Giuntoli G (2010) Care and support for older people and carers

4 in Bradford: their perspectives, aspirations and experiences. York: Joseph

5 Rowntree Foundation

1   Commission for Social Care Inspection (2006) Time to care? Towards

2   excellence in adult social care. London: Commission for Social Care

3   Inspection

4   Cooper J and Urquhart C (2005) The information needs and information-

5   seeking behaviours of home-care workers and clients receiving home care.

6   Health Information and Libraries Journal 22: 107-116

7   Department of Health, Social Services and Public Safety (2010) Survey of

8   Home Care Service Users Northern Ireland 2009. Belfast: Department of

9   Health, Social Services and Public Safety

10   Ekosgen (2013) The workforce implications of adults and older people who

11   self-fund and employ their own care and support workers. Leeds: Skills for

12   Care

13   Equality and Human Rights Commission, Adams L, Koerbitz C, Murphy L et al

14   (2013) Older people and human rights in home care: local authority responses

15   to the 'Close to home' inquiry report. Manchester: Equality and Human Rights

16   Commission.

17   London Assembly (2010) Home truths: older Londoners' access to home care

18   services. London: Greater London Authority

19   Older People's Commissioner for Wales (2012) My home, my care, my voice:

20   older people's experiences of home care in Wales. Cardiff: Older People's

21   Commissioner for Wales

22   Windle K, Wagland R, Forder J et al. (2009) National Evaluation of

23   Partnerships for Older People Projects: Final Report. PSSRU Discussion

24   Paper 2700, University of Kent.

25

3.8 Evidence to recommendations

This section of the guideline details the links between the guideline recommendations, the evidence reviews, expert witness testimony and the GDG discussions. Section 3.8.1 (see below) provides a summary of the evidence source(s) for each recommendation. Section 3.8.2 provides substantive detail on the evidence for each recommendation, presented in a series of linking evidence to recommendations (LETR tables).

3.8.1 Summary map of recommendations to source(s) of evidence

Recommendation	Evidence statement(s) and other supporting evidence (expert witness testimony GDG consensus)
1.1 Ensuring care is person-centred	
Recommendations for home care providers and commissioners	
1.1.1 Ensure services support the aspirations, goals and priorities of each person, rather than providing one size fits all' services.	1.4, 1.11, 1.12, 1.13, 2.1, 2.20 and GDG consensus
1.1.2 Ensure support focuses on what people can or would like to do to maintain their independence, not only on what they cannot do. Recognise: • that people have aspirations and potential throughout their lives and, • that people with cognitive impairment and those living alone might be at higher risk of having unmet social care-related quality of life needs or worse psychological outcomes.	1.1, 1.4, 1.11, 1.12 and GDG consensus
1.1.3 Ensure everyone working with people using home care services and their carers treats them with empathy, courtesy, respect and in a dignified way by: • agreeing mutual expectations • always respecting confidentiality and privacy • providing a reliable service that people and their carers can trust • regularly seeking feedback (both positive and negative) about the quality and suitability of care from people using the service, including those who do not have a carer or advocate.	1.4, 1.12, 2.9, 2.18 and GDG consensus
1.1.4 Prioritise continuity of care, using a core team of care workers, so that the person becomes familiar with them.	1.3, 1.5, 1.13, 2.10 and 2.11
1.1.5 Ensure that there is a transparent process for 'matching' care workers to people, taking into account:	1.6, 1.8, 2.11 and GDG consensus

Recommendation	Evidence statement(s) and other supporting evidence (expert witness testimony GDG consensus)
• the person's needs, and • the care workers' skills, and • if possible and appropriate, both parties' interests and preferences.	
1.2 Providing information	
Recommendations for local authorities	
1.2.1 In line with the requirements of the Care Act, local authorities must establish a service that gives people: information about how to access care and support, what support is available and who provides it; independent financial advice; and, details of how to raise concerns. Local authorities should give people who use or who are planning to use home care services and their carers details of: • Different funding mechanisms including the options available for people with personal budgets, for example having a managed budget, an individual service fund or direct payment, and ways to influence or manage them. • How home care services are paid for. • Where to find information about the range and quality of services available, the activities they offer and how much they cost. • What needs the home care services are expected to address, for example, personal care (help with tasks such as getting in and out of bed, washing and bathing, going to the toilet, dressing or eating and drinking) and help with housework and other services to help people remain safely at home and in their community. • Other options, such as: - saving allocated hours to be used at a later date (sometimes known as 'timebanking') - options such as a live-in carer or 'shared lives' (where the person stays in the community by living with another person or a family) - employing personal assistants.	7.1, 7.2, 7.3, 7.4 and 7.5
1.2.2 Offer people and their carers information about local and national support groups and networks.	7.11

Recommendation	Evidence statement(s) and other supporting evidence (expert witness testimony GDG consensus)
Recommendations for home care providers and commissioners	
1.2.3 Ensure people using services and their carers have information that supports them to make informed choices about their care, including: • what to expect from the home care service, and • their rights, and • what they should do if they are not happy with the service. Consider presenting this as part of a 'welcome pack' (or equivalent).	7.1, 7.2, 7.4 and 7.6
1.2.4 Offer the person a written summary of the information that has been provided to them (or provide this summary in another format that meets the person's needs). Be aware that the circumstances that lead people to need home care can be traumatic and people may find it difficult to take in a lot of information.	7.4, 7.10 and 7.12
1.2.5 Tailor all information for different audiences to ensure it is accessible and understandable. Ensure information is: • easy to read and in plain English • available in the person's language if needed • available in different formats and media (including information packs, telephone hotlines and electronic media) • made available in different venues, such as community centres or GP surgeries, as well as through face-to-face meetings with a social care practitioner • provided in formats that suit people with different communication or capacity needs, for example, large-print, braille or audio versions.	7.7, 7.9, 7.8 and 7.11
1.2.6 Ensure that information is updated regularly. Consider designing information in a way that allows it to be updated easily.	GDG consensus

Recommendation	Evidence statement(s) and other supporting evidence (expert witness testimony GDG consensus)
1.3 Planning and reviewing home care support	
Coordinating and planning home care as part of a multidisciplinary team	
Recommendations for commissioners	
1.3.1 Ensure integrated care and support is delivered to the person through a multidisciplinary team, where required. The team might include: • healthcare practitioners • social care practitioners, including home care workers • people from voluntary and community organisations, befriending and specialist services • advocates, including those appointed by the Court of Protection.	2.4 and GDG consensus
Recommendations for multidisciplinary teams	
1.3.2 Ensure the person using services and their carers are involved in multidisciplinary team discussions about their care.	2.4, 2.12 and GDG consenus
1.3.3 Consider identifying a lead practitioner from among the people involved in delivering support to lead care planning and coordinate care for each person.	2.4 and GDG consensus
Recommendations for home care and health service providers	
1.3.4 Ensure that support is delivered in cooperation with a multidisciplinary team, recognising the expertise, knowledge and commitment of all professionals.	2.4, 2.12 and GDG consensus
Recommendations for commissioners	
1.3.5 Support home care as an important component of a care package for older people living in their own home, given that is likely to have a positive impact on psychological wellbeing at a relatively low cost, and that it can help people to feel more in control over their daily lives.	1.1, additional economic analysis and GDG consensus
1.3.6 Consider offering home care support to older people with low-to-moderate needs. This is because it may mean that they need less intensive support later on or may delay the time at which such support is needed.	3.6, GDG consensus and expert witness testimony

Recommendation	Evidence statement(s) and other supporting evidence (expert witness testimony GDG consensus)
1.3.7 Ensure home care packages address social care-related quality of life and the person's wider wellbeing in addition to practical support, (for example home cleanliness and comfort). Recognise that people who use home care services often need support that goes beyond their personal care needs.	1.1, 1.9, 3.10, additional economic analysis and GDG consensus
1.3.8 If a person chooses to take direct payments for home care, give them the support and information they need to manage the payments effectively. This should be regardless of whether they buy care through a regulated provider, directly employ a personal assistant or choose another way to meet the agreed need.	3.2, 3.17 and 3.19
1.3.9 Consider asking people with experience of using a direct payment for home care to help provide training, support or advice to others thinking of doing so.	3.19, 3.19 and GDG consensus
1.3.10 Aligned with the recommendations in Ensuring care is person-centred, ensure that lead practitioners and others involved in home care and support planning: • understand the principles and importance of involving the person using services, and their carers if relevant, as an equal partner in designing the support and services they receive • know how to work in a way that maximises choice, control, dignity and respect for the person using services • have an awareness of common conditions affecting people using home care services, for example, sensory loss, dementia, physical and learning disabilities, and stroke • know about local organisations that provide specialist support • know about the funding options available for care and support • understand different funding mechanisms including the options available for people with personal budgets, for example having a managed budget, an individual service fund or direct payment.	1.1, 1.9, 3.2, 3.17 and 3.19
1.3.11 Give lead practitioners relevant information about a person's circumstances before the care and support planning takes place.	3.2, 3.17 and 3.19

Recommendation	Evidence statement(s) and other supporting evidence (expert witness testimony GDG consensus)
Recommendations for lead practitioners (or other practitioners planning care)	
1.3.12 Before meetings to plan home care and support, give the person using services and their carer information about the process of care planning, how the home care plan will be developed, negotiated and reviewed and the options available to them. Ensure people have enough time to understand this information.	7.10
1.3.13 Ask people if they want carers or advocates involved in their home care planning and support, and respect their choice.	GDG consensus
1.3.14 Consider planning support that enables the person to take more responsibility, including for the financial arrangements, to increase their independence over time.	3.3
1.3.15 Ask people about their aspirations, needs and priorities, as well as what gives them peace of mind, and makes them feel safe and unsafe. Ensure the care plan: - empowers the person as much as possible, by recognising what they can and want to do - explicitly addresses safety, wellbeing, independence and any specialist needs - is informed by the experience, skills and insight of carers, as appropriate - addresses the range of practical support needed to help the person to live how they choose, as far as possible, rather than addressing only personal care needs (this could include, for example, support to help a person manage their own financial and personal affairs, do their own shopping and cooking, or socialise, or other help, depending on the person's needs and preferences) - describes how success and outcomes will be measured - is clear, concise and easy to navigate - has a summary at the start, with links to more detailed information.	1.1, 1.9, 3.3 and 3.10
1.3.16 When assessing risk, balance the risk of a particular behaviour or activity with how it is likely to benefit the person's wellbeing and help improve their quality of life. The lead practitioner should:	GDG consensus

Recommendation	Evidence statement(s) and other supporting evidence (expert witness testimony GDG consensus)
- complete a risk plan with the person as part of the care planning process and include this I the home care plan - ensure the risk plan includes strategies to minimise risk, for example specialist equipment; use of verbal prompts; use of support from others - ensure the risk plan includes the implications of taking the risk for the person and the care worker - carry out risk assessments as part of care planning and at relevant intervals, such as when significant factors change.	
1.3.17 Liaise with healthcare practitioners and other professionals to ensure the home care plan promotes wellbeing, particularly for medicines management, pain management and pressure sore and moisture lesion prevention and care.	GDG consensus
1.3.18 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.	GDG consensus
1.3.19 Always discuss with the person and their carer whether telecare could complement their home care package (and any other services they are using).	6.10 and 6.11
1.3.20 Discuss the potential benefits of telecare, such as how it can provide reassurance to the person and their carer, while bearing in mind the rights of a person, particularly in relation to privacy, choice and control.	6.10 and 6.11
1.3.21 Consider addressing the potential negative effect social isolation on people's health and consider including voluntary sector and community organisations to maintain family and local community links, working with the carer as appropriate.	GDG consensus
Recommendations for home care providers	
1.3.22 Ask people: - which elements of their home care service are a priority for them and - whether some home care time may be used flexibly (that is, used for a variety of jobs according to what is needed).	3.3, 3.11, 3.14, GDG consensus and expert witness testimony

Recommendation	Evidence statement(s) and other supporting evidence (expert witness testimony GDG consensus)
1.3.23 Give people and their carers if appropriate, a copy of their home care plan in a format that meets their needs.	GDG consensus
1.3.24 Ensure all practitioners providing support complete the home care plan, and deliver support in an integrated way according to the plan.	3.15
1.3.25 Undertake an initial review of the home care plan after about 6 weeks, then review regularly at least annually. This should involve the person and their carers (if appropriate) in a meaningful way.	3.11, GDG consensus and expert witness testimony
1.3.26 Consider working with other agencies to ensure that people who use home care services have a single home care and support plan rather than separate plans from each service or provider.	3.15
Planning telecare	
Recommendations for lead practitioners (or other practitioners planning care)	
1.3.27 If the person wishes to use telecare, work with them to identify their preferred telecare options, that maximise dignity and help them live in the way that they choose.	GDG consensus
1.3.28 Ensure telecare does not replace personal contact, unless the person using services wants it to.	GDG consensus
1.3.29 Record in the care plan how the telecare equipment meets the person's needs and will help them achieve their desired outcomes.	GDG consensus
1.3.30 Offer people using home care services information about options for telecare that could help them. Include information on potential risks and benefits, so they can make an informed decision.	6.10 and 6.11

Recommendation	Evidence statement(s) and other supporting evidence (expert witness testimony GDG consensus)
1.4 Delivering home care	
Recommendations for commissioners	
1.4.1 Ensure contracts allow home care workers enough time to provide a good quality service including having enough time to talk to the person and their carer. They should ensure that workers have time to do their job without being rushed or compromising the dignity of the person who uses services.	1.4, 1.11, 2.8, 2.9, 3.8 and 3.20
1.4.2 Home care visits shorter than half an hour should be made only if: • the home care worker is known to the person and • the visit is part of a wider package of support and • it allows enough time to complete specific, time limited task or to check if someone is safe and well, for example.	1.11, 2.8, 2.9, 3.8, GDG consensus and expert witness testimony
1.4.3 Consider contracting and monitoring in a way that allows services to be delivered flexibly to ensure the person can identify what is a priority for them. This might include, for example, allowing providers (with the person's agreement or at their request) to use time flexibly.	1.4, 3.11, expert witness testimony and GDG consensus
Recommendations for home care managers and providers	
1.4.4 Ensure home care visits are long enough for home care workers to complete their work without compromising the quality of their work or the dignity of the person, including scheduling sufficient travel time between visits. Take into account that people with cognitive impairments, communication difficulties or sensory loss may need workers to spend more time with them to ensure they have the support they need.	1.11, 2.9, 3.8, 3.20 and GDG consensus
1.4.5 Ensure there is a complaints procedure in place. Tell people about how they can make a complaint either in writing or in person.	7.6
1.4.6 Make the complaints procedure available on your website and in other ways appropriate to people using the service and their carers. Give information about escalating complaints if necessary (to the commissioning body and Ombudsman) or ensure that this information is readily available.	7.6

Recommendation	Evidence statement(s) and other supporting evidence (expert witness testimony GDG consensus)
1.4.7 Prioritise continuity of care (so that the person knows the home care practitioners and they are familiar with how that person likes support to be given) – particularly given that this can ensure any risks or concerns are identified early – by: • introducing people to new care workers and • building teams of workers around a person and their carer and • informing people in advance if staff will be changed and explaining why and • working with people to negotiate any changes to their care plan, for examples when visits will be made and • recognising that major changes (for example moving from home care to use of personal assistants) can make people feel unsafe.	1.5, 2.10 and 3.15
1.4.8 Ensure home care workers are able to deliver home care in a way that meets the person's cultural and language needs.	2.10
1.4.9 Consider the need for independent advocacy if a person lives alone, has difficulty expressing their views and aspirations or routinely lacks capacity.	2.10
1.4.10 Closely monitor risks associated with missed or late visits and take prompt remedial action. Recognise that people living alone (without carers or advocates) or those who lack capacity may be particularly vulnerable if visits are missed or late.	1.5, 2.10 and 3.15
Recommendations for home care workers	
1.4.11 Ensure the person who uses services (or their carer) is contacted if you will be late or unable to visit, as well as informing your manager, if appropriate.	1.5, 3.15 and GDG consensus
1.4.12 Make every effort to avoid missed calls because these can cause major concern or have serious implications for people's health or wellbeing.	3.15 and GDG consensus
1.4.13 Ensure the record you complete routinely on each visit is detailed enough to keep people their carers and practitioners fully informed about what has been provided. Record any incidents or changes. The record could form an additional part of the home care plan or could be a separate 'care diary'.	3.15 and GDG consensus

Recommendation	Evidence statement(s) and other supporting evidence (expert witness testimony GDG consensus)
Delivering telecare	
Recommendations for the lead practitioner	
1.4.14 Ensure that the telecare provider gives the person and their carer information about how to use the equipment, and confirm that the person can confidently use it.	6.3, 6.7 and 6.8
1.4.15 Review a person's use of telecare to ensure they find it useful. Involve the person in the review and seek feedback from others, such as carers or call centres. During the review, tell the person about any new telecare options available.	6.1, 6.3, 6.7 and 6.8
1.4.16 Provide telecare call centres with all relevant information about a person's circumstances (if the person agrees).	GDG consensus
1.4.17 If providing alarm-based telecare, ensure response systems are in place. For example, the alarm can be linked to a warden, live-in carer, family member or contact centre.	6.8
1.4.18 If the alarm is set to alert a carer who does not live near the person, consider ensuring there is a 24-hour, 7-days-a-week contact close by who is able to provide assistance.	GDG consensus
1.5 Ensuring safety and safeguarding people using home care services	
Recommendations for health care practitioners	
1.5.1 Consider regularly liaising with home care workers about the person's medication.	4.7
1.5.2 Write information and guidance for home care workers about medication in the home care plan.	4.7
Recommendations for home care managers	
1.5.3 Ensure there is a written process to follow in the event of a safeguarding concern and ensure that the process is aligned with local authority procedures. The process should include key contacts such as:	4.5 and 4.6

Recommendation	Evidence statement(s) and other supporting evidence (expert witness testimony GDG consensus)
- emergency services - the registered manager of the home care provider - the local authority vulnerable adults or safeguarding helpline - other sources of support, for example, the Care Quality Commission, Action on Elder Abuse, the local Healthwatch.	
1.5.4 Ensure home care workers are aware of the process.	4.5 and 4.6
1.5.5 Build a culture in which reporting of safety and abuse concerns is understood as a marker of good care, not just as a negative outcome of poor care. Build such a culture by, for example: - stating explicitly, as part of induction training, that safeguarding alerts are part of delivering a responsible home care service and that home care workers play a vital role in helping to safeguard a person using services and - providing case studies that demonstrate the far-reaching effects of not acting on safeguarding concerns.	4.1, 4.2 and 4.3
Recommendations for commissioners	
1.5.6 Recognise that safeguarding alerts can be a responsible element of providing home care, given that the home care worker may be the first person to spot abuse and should respond proportionately.	4.1, 4.3 and GDG consensus
Recommendations for home care providers	
1.5.7 Put policies in place that ensure home care workers are supported through any safeguarding process.	4.1, 4.2 and 4.3
1.5.8 Home care providers must have a medicines management policy.	4.7
Recommendations for home care providers and home care workers	
1.5.9 Ensure the person using the service, and their carers (if the person has involved them in their care), can direct the way home care is delivered. This is so that the person's safety, comfort, independence and sense of security are always promoted.	4.1 and 4.6

Recommendation	Evidence statement(s) and other supporting evidence (expert witness testimony GDG consensus)
1.6 Recruiting, training and supporting home care workers	
Recommendations for home care providers	
1.6.1 Have a transparent and fair recruitment and selection process that: • uses values-based interviews and approaches to identify the personal attributes and attitudes essential for a caring and compassionate workforce and • ensures workers have the necessary literacy and numeracy skills to do the job.	1.3, 1.2.7 and GDG consensus
1.6.2 Consider involving people who use home care and their carers in recruiting and training home care workers.	2.7 and GDG consensus
1.6.3 Ensure that new home care workers are observed at work more than once during their probationary period.	1.2, 2.7 and GDG consensus
1.6.4 Ensure home care workers 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.	2.6, 2.12, 5.3 and 5.5
1.6.5 Make provision for more specialist support to be available to people who need it – for example, in response to complex health conditions – either by training their own home care workers or through partnerships with specialist organisations.	2.6 and 5.5
1.6.6 Ensure home care workers have the knowledge and skills needed to perform their duties safely by providing, as part of the full induction and ongoing training package, specific training on: • what constitutes 'safe' care • identifying and responding to possible or actual abuse or neglect • identifying and responding to environmental risks • safe care policies and procedures.	2.7, 2.12, 5.2, 5.3 and 5.5

Recommendation	Evidence statement(s) and other supporting evidence (expert witness testimony GDG consensus)
1.6.7 Use feedback from people using the service and their carers to assess training needs for the workforce.	1.2, 2.7 and 5.1
1.6.8 Ensure home care workers have opportunities to refresh and extend their knowledge and skills.	1.2, 2.7, 5.2 and 5.4
Recommendations for home care managers	
1.6.9 Managers should: • respond promptly to workers when they request support to deal with difficult situations • supervise workers in a timely, accessible and flexible way, at least every 3 months and ensure an agreed written record of supervision is given to the worker • observe workers' practice regularly, at least every 3 months and identify their strengths and development needs • appraise workers' performance regularly and at least annually. The annual appraisal should include a review of workers' learning and development needs, and feedback from people who use the service and their carers.	1.2
Recommendations for local authorities	
1.6.10 Develop workforce plans for the home care sector, in collaboration with providers, identifying current and future workforce needs. Include training and how such needs might be met by prioritising available local authority resources in the plans.	1.2, 5.2 and 5.4
Recommendations for healthcare professionals working in primary and secondary care	
1.6.11 Liaise with home care workers to provide integrated, person-centred support that promotes wellbeing, particularly for medicines management, pain management and tissue viability care. Recommendations for commissioners	2.6 and 5.5
1.6.12 Consider commissioning training to ensure health and social care practitioners understand how they should collaborate to provide integrated planning and delivery of home care.	2.6 and 5.5

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1 ### 3.8.2   Linking Evidence to Recommendations (LETR) tables

Topic/section heading	Ensuring care is person centred
Recommendations	**Recommendations for home care providers and commissioners** 1.1.1 Ensure services support the aspirations, goals and priorities of each person, rather than providing 'one size fits all' services. 1.1.2 Ensure support focuses on what people can or would like to do to maintain their independence, not only on what they cannot do. Recognise: • that people have aspirations and potential throughout their lives and • that people with cognitive impairment and those living alone might be at higher risk of having unmet social care-related quality of life needs or worse psychological outcomes. 1.1.3 Ensure everyone working with people using home care services and their carers treats them with empathy, courtesy, respect and in a dignified way by: • agreeing mutual expectations • always respecting confidentiality and privacy • providing a reliable service that people and their carers can trust • regularly seeking feedback (both positive and negative) about the quality and suitability of care from people using the service, including those who do not have a carer or advocate.
Research recommendations	The GDG considered there were no important gaps in the evidence to make research recommendations on.
Review questions	1.1 What are users' and carers' experiences of home care? 1.2 What do they think works well and what needs to change? 2.1 What are the views and experiences of home care practitioners, service managers and commissioners procuring or delivering services? 2.2 What do they think works well and what needs to change?
Quality of evidence	The quality of research evidence in respect of users' and carers' views of services is of moderate to good quality. It is predominantly qualitative with some surveys and mixed methods studies. Much of the evidence is recent. The reported methodology does not always make clear what data can be directly attributed to service user or carer opinion rather than researcher interpretation. However, there was consistency across studies in relation to the approaches to home care which users and carers valued, and consistency with practitioners'

	views on what constituted good home care. Surveys suggested that most users and carers had positive experiences of home care, but that there was variation in experience, and shortcomings which could be addressed.
Relative value of different outcomes	These recommendations were informed predominantly by data on views and experience. However, the outcome of 'person-centred care', though not easily measured, underpins all the recommendations in this section.
Trade-off between benefits and harms	No effectiveness evidence was identified: it would be unlikely that a suitable and ethical comparator to person-centred care could be identified. Views data and GDG experience indicated that care which does not take into account the person's views and aspirations may result in poor experience of services, and poorer quality of life for people who use home care support and their carers.
Economic considerations	The recommendations were predominantly based on data on views and experience of home care. Recommendation 1.1.2, however, was also informed by the additional analysis conducted by PSSRU from the IBSEN study data (see appendix C3), specifically, the findings which suggested that certain sub-groups of older people – in particular those with cognitive impairment and those living alone – were more likely to report worse psychological wellbeing and/or higher unmet needs in regards to the social care package they used in their homes (including home care) than people with otherwise similar characteristics and needs.
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	Person-centred care runs throughout the recommendations and views data informed all aspects of the guideline. The data informing these over-arching recommendations in particular is as follows: **1.1 Value of home care to users in promoting independence** There is moderate and good evidence from two UK mixed methods studies (Quince, 2011, -/+; Lakey and Saunders, 2011, -/+), and one Northern Ireland survey (DHSSPS, 2010, +). that home care users, including those with dementia (Quince, 2011, -/++; Lakey and Saunders, 2011, -/+), value home care because it enables them to live at home independently. There is also good evidence from a UK survey (PCC, 2012, +/+) that some people feel that more practical support, such as help with household tasks, would help them achieve greater independence and control over their lives. **(REC 1.1.2)** **1.4 Importance of communication and 'being listened to'** There is very good evidence from a UK qualitative study (Cattan and Giuntoli, 2010, ++); and two UK surveys (CQC, 2013, +; OPCW, 2012, +) that good communication, 'being listened to' and encouraged to express their views is important to service users and carers. **(REC 1.1.1, 1.1.2 & 1.1.3)**

1.11 Users' and carers' views on allotted time slots

There is good evidence from several UK studies, a secondary data study (CSCI, 2006, +), a mixed methods study; (London Assembly, 2010 +/+); and two surveys (Netten, 2007, +; PCC, 2012, +/+) that many older people felt that short time slots compromised the quality and scope of home care. A lack of travel time between slots was noted by users and carers as a contributory factor in a survey (OPCW, 2012, +). **(REC 1.1.1 & 1.1.2)**

1.12 Timing and reliability of appointments

There is good and moderate evidence from a UK qualitative study (Sykes and Groom, 2011, +); a less robust UK mixed methods study; (Quince, 2011, -/++) and two UK surveys; (CQC, 2013, +; OPCW, 2012, +) that care visits are not always made as arranged, causing distress to older people, and that the timing of visits, especially those designed to help with going to bed, could be at inappropriate times. **(REC 1.1.1, 1.1.2 & 1.1.3)**

2.1 Practitioners' views of the importance of person-centred care

There is good evidence from one UK qualitative study (Seddon and Harper, 2009, +) that care managers recognised the importance of effective support that is underpinned by a person-centred approach which takes into account individual preferences and priorities, and is organised locally to where older people live. **(REC 1.1.1)**

2.9 Time to care: Flexibility and reliability of visiting times

There is good evidence from one UK qualitative study (Francis and Netten, 2004, +) that some managers believed they had little control over the provision of a reliable service when visits overran due to ill or injured clients who required more care, as well as the impact of traffic on travelling to the next client. Some managers suggested that local authority commissioning arrangements should factor in travel time costs. **(REC 1.1.3)**

2.18 Response to service users' views by care providers

There is evidence from one good survey from Northern Ireland (DHSSPS, 2008, +) that 95% of service providers had, in the 12 months prior to the survey, sought the views of their service users or their representatives about the home care services they receive, with 72% stating that they had made changes in response to this information. **(REC 1.1.3)**

2.20 Practitioners' views on direct payments

There is good evidence from two UK qualitative studies (Clark et al, 2004, +; Manthorpe and Stevens, 2010, +) that care managers recognised the potential of IBs and DPs and believed

	they enabled people to purchase tailored, individual services which meet their personal needs, thus giving more independence, control and flexibility to service users. Managers felt that DPs were unsuitable for service users who have dementia. There is good evidence from one UK mixed methods study (Moran et al, 2013, +) which involved interviews with IB leads in sites where IBs had been piloted. IB leads suggested that care managers of older people may struggle the most with implementing IBs with their client groups due to concerns over whether older people would be capable of using them. **(REC 1.1.1)**
Other considerations	While the starting point for the recommendations on person-centred care was the evidence reviews in relation to questions 1.1 1.2, 2.1 and 2.2, this was an important cross-cutting theme which the GDG emphasised throughout the whole development process.
	The GDG noted that, as with other elements of the guideline, research lagged behind practice in this area, particularly in relation to the use of different funding mechanisms and their impact on perceived (and actual) choice, control and independence for different groups of older people using home care, and their carers.
	Additional relevant discussions points:
	• Focus on outcomes - The GDG felt that recommendations supporting personal 'aspirations, goals and priorities' was less jargonistic and clearer than referring to 'outcomes-focussed' home care.
	• Assets and aspirations - The need to ensure an 'asset based' approach to planning and delivering support underpinned 1.1.2 in particular, recognising that people have strengths and aspirations throughout their whole lives, irrespective of the health and social care needs they may also have. The need to help ensure people can live in a way that resembles, as closely as possible, the life they want was a recurring theme in GDG discussion. The principle of reablement might also be relevant to goals.
	• Person-centred care in practice - The need to ensure care is person-centred was seen as inextricably linked to the way that care is planned and delivered, particularly in terms of the extent to which support can be provided flexibly, to meet a wide range of needs (see also: Evidence to recommendations tables on 'Plan and review support' and 'Deliver home care'.)
	• The importance of involving people and their carers – while research data and GDG experience suggests this is happening, GDG members thought it important for this to be routine and throughout the process of planning and delivering support.

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Topic/section heading	Ensuring care is person centred
Recommendations	**Recommendations for home care providers and commissioners** 1.1.4 Prioritise continuity of care, using a core team of care workers, so that the person becomes familiar with them. 1.1.5 Ensure there is a transparent process for 'matching' care workers to people, taking into account: • the person's needs, and • the care workers' skills, and • if possible and appropriate, both parties' interests and preferences.
Research recommendations	The GDG considered there were no important gaps in the evidence to make research recommendations on.
Review questions	1.1 What are users' and carers' experiences of home care? 1.2 What do they think works well and what needs to change?
Quality of evidence	The quality of research evidence in respect of user and carers views of services is of moderate to good quality, predominantly qualitative with some surveys and mixed methods studies. Much of the evidence is recent. The reported methodology does not always make clear what data can be directly attributed to service user or carer opinion rather than researcher interpretation. However, there was consistency across studies in relation to the approaches to home care which users and carers valued, and consistency with practitioners' views on what constituted good home care. Surveys suggested that most users and carers had positive experience of home care, but that there was variation in experience, and shortcomings which could be addressed.
Relative value of different outcomes	These recommendations were informed predominantly by data on views and experience. However, the outcome of 'person-centred care', though not easily measured, underpins all the recommendations in this section.
Trade-off between benefits and harms	No effectiveness evidence was identified: it would be unlikely that a suitable and ethical comparator to person-centred care could be identified. Evidence and GDG experience indicated that harms associated with poorly coordinated, unreliable, unresponsive or rushed home care, and that which did not take into account the person's views and aspirations, may include increased anxiety and poor quality of life for both users and carers in need of home care support.
Economic considerations	The recommendations were based on data on views and experience of home care and not effectiveness or cost-effectiveness data.

| Evidence statements – numbered evidence statements from which the recommendation(s) were developed | **1.3 Users value kind and caring workers and developing relationships**

There is good evidence from a number of UK studies, for example, a survey (CQC, 2013, +) and a qualitative study (Walsh and Shutes, 2013, +), consistent over most studies, that users and carers acknowledge and value warm, kind and caring home care workers, and the ability to develop relationships by having continuity of workers. **(REC 1.1.4)**

1.5 Importance of having the same worker(s)

There is good evidence from a UK qualitative study (Sykes and Groom, 2011, +), one UK survey; (OPCW, 2012, +); and a UK mixed methods study (London Assembly, 2010, +/+) that older people value having the same familiar workers, but that they are not always made aware of a change in personnel, causing anxiety and raising the need for training in that person's particular needs. **(REC 1.1.4)**

1.6 Language as a barrier to good communication

There is good evidence from two UK qualitative studies (Walsh and Shutes, 2013, +; Sykes and Groom, 2011, +) that communication is hampered if the worker and the person they care for do not speak the same language. **(REC 1.1.5)**

1.8 Dignity, respect and ability to deliver culturally appropriate home care

There is good evidence from two UK surveys (DHSSPS, 2010, +; CQC, 2013, +), that, while most service users feel they are treated with dignity and respect, not everyone feels this way, and that there are particular shortcomings reported in a UK qualitative study (Cattan and Giuntoli, 2010, +), and in a UK mixed methods study; (London Assembly, 2010, +/+) in the delivery of culturally appropriate services, and matching care workers to users who speak the same language. **(REC 1.1.5)**

1.13 Impact of personal assistants on choice and flexibility

There is moderate evidence from a UK qualitative study (Ekosgen, 2013, +) and a UK mixed methods study; (Lakey and Saunders, 2011, -/+) that people arranging or funding their own care hope to benefit from greater continuity of care, better relationships and care tailored more precisely to their needs, but that many found the lack of support to employ carers caused them stress and anxiety, and might mean that their care was not good value. **(REC 1.1.4)**

2.10 Time to care: Continuity of care

There is good evidence from one UK qualitative study (Francis and Netten, 2004, +) that managers recognised the importance of continuity of care and made attempts to create teams of workers who worked regularly with individual service users, arranged introductory visits to enable service users to meet their |

	new home care worker in advance. Inadequate sick leave procedures and high staff turnover are concerns which could negatively impact on continuity of care. There is moderate evidence from one UK qualitative study (Devlin and McIlfatrick, 2010, +) that community nurses perceived continuity of home care staff as an integral feature of high quality palliative care. **(REC 1.1.4)** **2.11 Dementia care** There is good evidence from one UK qualitative study (Roberts, 2011, +) that it is important to provide timely support to people with dementia, with the need to build good relationships early between carers and the user before a person's decline into poorer health. **(REC 1.1.4 & 1.1.5)** **2.16 Migrant care workers: Language and cultural barriers** There is evidence from two good UK qualitative studies (Walsh and Shutes, 2013, +; Manthorpe et al, 2010, +) that managers had concerns regarding the language skills of migrant workers and felt that poor English could potentially cause difficulties when caring for older people, particularly those with hearing impairments. **(REC 1.1.5)**
Other considerations	The GDG discussed the following points, deemed to be of particular importance. • The importance of relationship building was widely evidenced. There was debate within the GDG about how to address the issue of providing time for the home care worker to get to know the person, rather than simply undertaking the designated tasks then leaving). The feeling of being rushed was a theme emerging from practitioner and user views evidence. The GDG agreed that there could not be specific time allocated to relationship-building, but that continuity of care and social interaction should be referenced in the recommendations. • There was extensive debate about the importance of matching workers with people using services, and some of the associated challenges. Although aspirational, there were opportunities here for cultural and language matches, and the possibility of supporting lasting and valued relationships. • Workforce surveys emphasised lack of time for relationship building and person centred care, and how this factor is associated with job satisfaction and performance. The GDG provided examples of where time spent building relationships with people using home care had resulted in increased satisfaction for workers and users.

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Topic/section heading	Providing information – information content
Recommendations	**Recommendations for local authorities** 1.2.1 In line with the requirements of the Care Act, local authorities must establish and maintain a service that gives people: information about how to access care and support, what support is available and who provides it; independent financial advice; and, details of how to raise concerns. Local authorities should give people who use or who are planning to use home care services and their carers details of: • Different funding mechanisms including the options available for people with personal budgets, for example having a managed budget, an individual service fund or direct payment, and ways to influence or manage them. • Where to find information about the range and quality of services available, the activities they offer and how much they cost. • What needs the home care services are expected to address, for example, personal care (help with tasks such as getting in and out of bed, washing and bathing, going to the toilet, dressing or eating and drinking) and help with housework and other services to help people remain safely at home and in their community. Other options such as: • saving allocated hours to be used at a later date (sometimes known as 'timebanking') • options such as a live-in carer or 'shared lives' (where the person stays in the community by living with another person or a family) • employing personal assistants. 1.2.2 Offer people and their carers information about local and national support groups and networks. **Recommendations for home care providers and commissioners** 1.2.3 Ensure people using services and their carers have information that supports them to make informed choices about their care, including: • what to expect from the home care service, and • their rights, and • what they should do if they are not happy with the service. Consider presenting this as part of a 'welcome pack' (or equivalent). 1.2.4 Offer the person a written summary of the information that has been provided to them (or provide this summary in another format that meets the person's needs). Be aware that the circumstances that lead people to need home care can be traumatic and people may find it difficult to take in a lot of information.

Research recommendations	Although the evidence on information was of moderate quality (see below), the GDG did not identify information as a key area to make research recommendations on within this guideline.
Review questions	Q 7.1 What information and support is helpful to people seeking access to home care services? Q 7.2 What information and support should be provided to people who use home care services to enable them to be aware of their options, and play a full role in reviewing their care and making decisions?
Quality of evidence	Overall, the evidence on information and support was of moderate quality, with some poor reporting of methodological detail. Qualitative papers and a mixed methods study detailed the needs of service users for information, although not all participants were recipients of home care (Cattan and Giuntoli, 2010). However, the evidence on information requirements was consistent across studies. The needs of service users and carers, and the Care Act requirements, underpin recommendations.
Relative value of different outcomes	The GDG agreed about the importance of making sure people using services and their carers have access to the information they need in an appropriate format for them in order to make informed choices and participate fully in care planning. Information is essential to person-centred care.
Trade-off between benefits and harms	Both the evidence statements and the GDG discussion identified that problems can occur when information is not provided (or not provided in a way that is appropriate for the person's needs), including, for example: people being concerned or confused about the options available, or not feeling in control of their support.
Economic considerations	Overall, there was a lack of cost-effectiveness evidence in this area. Findings from one national mixed methods evaluation (Windle et al, 2009 -) showed a relatively high probability that information and support was cost-effective and led to cost savings, but subsequent analysis found that cost savings were over-estimated. Interventions in this area were of relatively low cost.
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	**7.1 Local authorities' duty to provide information on home care** There is good evidence from two UK surveys (EHRC, 2013, +; DHSSPS, 2010, +) that some local authorities had not met minimum requirements to provide information for service users such as a register of personal assistants and a written guide to home care services in their area. Secondary data from a UK CSCI report (2006, +) found that only one-third of agencies had achieved the requirement of informing users about what service users can expect from a service, what they will have to pay, contact details which can be used in the event of a problem, and how to make a complaint. **(REC1.2.1 & 1.2.3)**

7.2 Service users' experience of information at the time of assessment

There is good evidence from a UK mixed methods study (London Assembly, 2010, +) that service users found the assessment process for social care eligibility was confusing, and that there were no adequate sources of information and advice to help them. **(REC 1.2.1 & 1.2.3)**

7.3 Information for people funding and/or arranging their own care

There and good evidence from a UK qualitative study (Ekosgen, 2013, +) that accurate information is especially important for self-funders and those wishing to employ personal assistants, to help them understand the complexities of individual budgets and employment law. A UK survey (EHRC, 2013, +) recommended that local authorities should provide advice, advocacy and brokerage services to ensure that older people can benefit, if they choose, from the 'greater autonomy inherent in personalised homecare.' **(REC 1.2.1)**

7.4 Information on home care roles

There is good evidence from a Northern Ireland survey (DHSSPS, 2010, +) and from a UK qualitative study (Ekosgen, 2013, +) that older people had not been provided with information about the role and tasks that their care workers would undertake. **(REC1.2.1, 1.2.3 & 1.2.4)**

7.5 Additional information requirements

There is good evidence from two UK qualitative studies (Cattan and Giuntoli, 2010, +; Ekosgen, 2013, +) that older people and their families require information on a variety of issues not directly related to home care such as eligibility for benefits and services (e.g. Carer's Allowance, television licences, etc) as well as the provision of medical devices or adaptations for the home. **(REC 1.2.1)**

7.6 Information on complaints procedures

There is good evidence from a UK mixed methods study (London Assembly, 2010, +) that service users found complaints procedures confusing. Evidence from a UK survey (EHRC, 2013, +) reported that some local authorities had produced a film and distributed comments and complaints forms more widely. **(REC 1.2.3)**

7.10 Information tailored to older people's needs

There is very good evidence from one UK qualitative study (Cattan and Giuntoli, 2010, +) that older people need more time to process information, and providing information only in the period immediately after a health crisis was often inappropriate. Some family carers of people with dementia preferred to be present when their relative was given new information to support the person in giving and recalling information. **(REC1.2.1 & 1.2.4)**

	7.11 Independent information
	There is good evidence from a UK mixed methods study (London Assembly, 2010, +) that older people are more likely to trust information provided by independent charities, as they think local authorities may have a vested interest in concealing entitlements.**(REC 1.2.2)**
	7.12 Home care worker's role in providing useful information
	There is evidence from a good UK survey (OPCW, 2012, +) that some older people 'often' received useful information from their care workers. **(REC 1.2.4)**
Other considerations	There was considerable discussion about who should provide which types of information, and how much frontline home care workers could reasonably be expected to know. The recommendations, therefore, reflect the different levels of knowledge different organisations and individuals might reasonably be expected to have, identifying where signposting to information sources is more appropriate.
	The GDG agreed on the potential helpfulness of ensuring people using services and carers have information in one place.
	The importance of making sure people not only have the information they need, but understand it and have a record of it, was emphasised by the GDG. This was emphasised because sometimes people are given information at times of acute stress or trauma, and it may be difficult to retain under these circumstances. It was thought that home care workers can play an important role in ensuring people have understood the information provided as well as in signposting. The particular importance of providing information - verbal, written and repeated at different times - to people who do not have an advocate or carer was also a recurring theme.
	The GDG also discussed the role of the local authority in information provision, providing more detail about the sorts of information that people may find useful in respect of home care services, and also emphasising the importance of ensuring people know about local networks. Related to this, the GDG discussed the need to ensure best use is made of the expertise and knowledge in the voluntary and community sector, recognising too that people may have existing relationships with different community-based organisations.

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Topic/section heading	Providing information – information format
Recommendations	**Recommendations for home care providers and commissioners** 1.2.5 Tailor all information for different audiences to ensure it is accessible and understandable. Ensure information is: • easy to read and in plain English • available in the person's language if needed • available in different formats and media (including information packs, telephone hotlines and electronic media) • made available in different venues, such as community centres or GP surgeries, as well as through face-to-face meetings with a social care practitioner • provided in formats that suit people with different communication or capacity needs, for example, large-print, braille or audio versions. 1.2.6 Ensure that information is updated regularly. Design information in a way that allows it to be updated easily.
Research recommendations	Although the evidence on information was of moderate quality (see below), the GDG did not identify information as a key area to make research recommendations on within this guideline.
Review questions	Q 7.1 What information and support is helpful to people seeking access to home care services? Q 7.2 What information and support should be provided to people who use home care services to enable them to be aware of their options, and play a full role in reviewing their care and making decisions?
Quality of evidence	The evidence on information and support was of moderate quality. Three surveys and a mixed methods study on the range and quality of information provided were not current, and only provided information on Local Authorities' provision at specific points in time. The needs of service users and carers, and the Care Act requirements, underpin recommendations for Local Authorities.
Relative value of different outcomes	The GDG recognised that providing information in a range of formats and ensuring it is up to date can be time-consuming and costly. The GDG noted that information providers need an understanding of the communication and information needs of the particular and diverse population of people who may be using or considering using services (rather than simply making all possible formats available to everyone). It was also thought that the ease of updating information needed to be considered in initial design to minimise costs. The impact of not providing appropriate information is difficult to measure as the likely impact on choice, control and quality of care is indirect.
Trade-off between benefits and harms	Both the evidence statements and the GDG discussion identified some of the problems that can occur for individuals and families when information is not provided (or not provided in a way that is appropriate for the person's needs: see LETR above).

Economic considerations	There was a lack of cost-effectiveness evidence in this area. Findings from one national mixed methods evaluation (Windle et al, 2009, -) showed a relatively high probability that information and support was cost-effective and led to cost savings, but subsequent analysis found cost savings were over-estimated.
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	**7.7 Sources of information** There is good evidence from two UK qualitative studies (Cattan and Giuntoli, 2010, +; Ekosgen, 2013, +) that users were most likely to access information on entitlements after being hospitalised or from a community recreation centre. Some users disliked having to use the internet to find information. Users preferred having an officer from adult services department to attend their GP practice to answer questions. There is good evidence from a UK mixed methods study (London Assembly, 2010, +) that some older people and their carers felt frustrated that one single organisation is not able to give them all the information they need to know and felt that information should be provided on a pan-London basis. **(REC 1.2.5)** **7.8 Need for information in a variety of languages** There is good evidence from one UK qualitative study (Cattan and Giuntoli, 2010, +) and one UK secondary data analysis (CSCI, 2006, +) that information should be provided in languages other than English, in particular for people from ethnic minority groups, as cultural or language barriers had led to 'people slipping through the net'. **(REC 1.2.5)** **7.9 Need for information to be concise and clear** There is good evidence from one UK qualitative study (Cooper and Urquhart, 2005, +) that information resources should be succinct and written in plain English. **(REC 1.2.5)** **7.11 Independent information** There is good evidence from a UK mixed methods study (London Assembly, 2010, +) that older people are more likely to trust information provided by independent charities, as they think local authorities may have a vested interest in concealing entitlements. **(REC 1.2.5)** **7.13 Dislike of phone menus** There is good evidence from two UK qualitative studies (Cattan and Giuntoli, 2010, +; Ekosgen, 2013, +) and a UK mixed methods study (London Assembly, 2010, +) that service users found voice message menus to be frustrating as the menus did not adequately signpost to the required services; and there were insufficient phone lines dedicated to answering social care queries. **(REC 1.2.5)**
Other considerations	The information recommendations draw on GDG discussion in relation to person-centred care (relevant to all research questions), and on statutory responsibilities to provide information within the Care Act 2014. The GDG agreed strongly with the evidence that indicated people want information in different ways and provided specific detail in recommendation 1.2.5 to describe what this looks like in practice, based on their experience. They also agreed that it is important for information to be up-to-date so people can be confident about using it.

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Topic/section heading	Planning and reviewing home care and support - multidisciplinary working
Recommendations	**Recommendations for commissioners** 1.3.1 Ensure integrated care and support is delivered to the person through a multidisciplinary team, where required. The team might include: • healthcare practitioners • social care practitioners, including home care workers • people from voluntary and community organisations, befriending and specialist services • advocates, including those appointed by the Court of Protection. 1.3.2 Ensure the person using services and their carers are involved in multidisciplinary team discussions about their care. **Recommendations for multidisciplinary teams** 1.3.3 Consider identifying a lead practitioner from among the people involved in delivering support to lead home care planning and coordinate care for each individual. Recommendations for home care and health service providers 1.3.4 Ensure that support is delivered in cooperation with a multidisciplinary team, recognising the expertise, knowledge and commitment of all practitioners.
Research recommendations	The GDG did not identify multi-disciplinary working as an area to make research recommendations on within this guideline.
Review questions	3.1 What approaches to home care planning and delivery are effective in improving outcomes for people who use services? 3.2 What are the significant features of an effective home care model? 3.3 Are there any undesirable/harmful effects from certain types of home care approaches? 3.4 What are the barriers to, and facilitators of, effective implementation of approaches shown (3.1) to deliver good outcomes?
Quality of evidence	Overall, studies reviewed lacked clarity and/or detail about the components of the models designed to facilitate shared care delivery involving home care workers and health practitioners.
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 multi-disciplinary care planning and support.
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 providing or failing to provide multidisciplinary support which includes home care workers. However, supplementary evidence from views and experiences data, especially from practitioners suggests that home care workers often feel unsupported and anxious about the people who they look after. Although likely to be the most frequent visitors to the home, they are not easily able to liaise

	with healthcare practitioners. The GDG noted that this could cause problems particularly when they identify a person's health conditions worsening, or have medications management concerns.
Economic considerations	The reviews found no cost-effectiveness evidence in relation to multidisciplinary team working.
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	**2.4 Job dissatisfaction: Relationships with other professionals**
	There is moderate evidence from two UK qualitative studies (Hek et al, 2004, +; Duff and Hurtley, 2012, -) that care workers experience difficulties in liaising and coordinating with healthcare services regarding home visits due to referral refusals and confidentiality issues. Care assistants working in collaboration with district nurses reported improved communication with nursing staff and felt valued by other professionals. **(REC 1.3.1, 1.3.3 and 1.3.4)**
	2.12 Roles and tasks of home care workers
	There is good evidence from one UK qualitative study (Cooper and Urquhart, 2005, +) that care workers were uncomfortable when they uncovered potentially serious health problems which they felt unqualified to deal with. Care workers also felt that their visits could lead to further isolation of the older person, because friends and family stopped visiting in the belief that the person's needs were now met. One moderate qualitative study (Patmore, 2004, +) suggested that there was variation in terms of what tasks home care workers are permitted to do, in addition to the normal 'personal care tasks'. In dealing with individual clients, respondents to the UK survey conducted by Hall and Wreford (2007, +) said they found it difficult to deal with issues such as cleaning up messes, challenging behaviours and the death of the clients. **(REC 1.3.2 and 1.3.4)**
Other considerations	While there was no effectiveness or cost-effectiveness evidence on multi-disciplinary team working, there was considerable evidence from views and experiences data, and from GDG members' experience that led them to make recommendations on this area. In particular, the GDG wanted recommendations to address the impact of fragmented care, particularly a lack of integration between health and social care professionals. Recommendations were informed by:
	• evidence from practitioners that home care workers can feel under-valued or insufficiently involved in planning and decision-making.
	• GDG consensus on the need for a coordinated approach to care planning, ideally led by a single practitioner who takes a coordinating role, working across health, social care, and the voluntary and community sector. There was extensive discussion about the terminology to be used to describe this role, with 'lead practitioner' agreed given that other potential terms (e.g. lead professional) already have specific meanings. The GDG recognised that this role could potentially be undertaken by a range of MDT practitioners

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Topic/section heading	Plan and review support - home care as part of a care package
Recommendations	**Recommendations for commissioners**
	1.3.5 Support home care as an important component of a care package for older people living in their own home, given that is likely to have a positive impact on psychological wellbeing at a relatively low cost, and that it can help people to feel more in control over their daily lives.
	1.3.6 Consider offering home care support to older people with low to moderate needs. This is because it may mean that they need less intensive support later on or may delay the time at which support is needed.
	1.3.7 Ensure home care packages address social care-related quality of life and the person's wider wellbeing in addition to practical support, (for example home cleanliness and comfort). Recognise that people who use home care services often need support that goes beyond their personal care needs.
Research recommendations	The following research questions are relevant to this issue: • What is the cost-effectiveness of different intensities of home care packages for older people with a range of care and support needs? • What is the most effective and cost-effective way to support people with dementia living at home? • What safeguarding practices are most effective in improving outcomes for people using services?
Review questions	3.1 What approaches to home care planning and delivery are effective in improving outcomes for people who use services? 3.2 What are the significant features of an effective home care model?
Quality of evidence	Overall, effectiveness studies lacked clarity and/or detail about the impact of home care within wider packages of social care. With the exception of the IBSEN study, there was a lack of moderate to high quality evidence on cost-effectiveness of different care planning approaches applicable to the UK home care context.
Relative value of different outcomes	The lack of effectiveness evidence relevant to these questions mean that it was not possible to ascertain and compare the relative value of outcomes associated with different models of care planning and support, including the impact of home care versus other social care support interventions.
	Supplementary evidence from views and experiences data, however, suggests there are significant positive outcomes in terms of people's satisfaction with, and experience of, the home care services they use, provided it: • is planned to help them live in the way they would like to, rather than focusing solely on their personal care needs. • allows them to be in control of their lives and their support, 'stepping up' their independence and autonomy

	as appropriate, in a graduated way.
	• is reliable, recognising that continuity is important.
	• recognises the importance of social interaction and relationship-building between the person using services and the worker.
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 of care planning and support.
Economic considerations	The review team carried out supplementary analysis (PSSRU, 2014) based on the IBSEN data to examine the cost-effectiveness of different home care packages and this provided additional economic evidence which was assessed as relatively robust. Full details are in Appendix C3. In summary this found that among the different components that were part of a wider home care package (such as personal assistant services, telecare, care management and meals on wheels) the home care variable appeared to have a significant impact on costs and outcomes for older people (controlling for all other factors). Early economic analyses (Netten and Forder, 2007, economic evidence rating -, Forder et al, 2013, economic evidence rating - ,suggests that home care might be more effectively allocated to include people with low to moderate needs for home care (possibly to prevent further deterioration).
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	**1.1 Value of home care to users in promoting independence** There is moderate and good evidence from two UK mixed methods studies (Quince, 2011, -/+; Lakey and Saunders, 2011, -/+), and one Northern Ireland survey (DHSSPS, 2010, +). that home care users, including those with dementia (Quince, 2011, -/++; Lakey and Saunders, 2011, -/+), value home care because it enables them to live at home independently. (DHSSPS, 2010, +), There is also good evidence from a UK survey (PCC, 2012, +/+) that some people feel that more practical support, such as help with household tasks, would help them achieve greater independence and control over their lives. **(REC 1.3.5 and 1.3.7)** **1.9 Home care provision is not holistic and does not cover the identified needs of users** There is good evidence from a UK qualitative study (Clough et al, 2007, +) and a UK survey (PCC, 2012, +/+) that older people feel that home care should incorporate a wider variety of tasks. Some older people felt that definitions of care should be more holistic and take into account non-health and social care related tasks, 'odd jobs', management of personal affairs, shopping, socialising, recreation and leisure. Similarly, a further UK qualitative study (Seddon and Harper, 2009, +) found that some older people felt that home care should be more flexible, for example by allowing staff to take older people shopping rather than collecting it for them. People contributing to the cost of care were particularly dissatisfied with this inflexibility, according to a UK secondary data study (CSCI, 2006, +). **(REC 1.3.7)**

	3.6 Intensity of home care for people with different levels of need Two economic studies (Netten and Forder, 2007, economic evidence rating -, Forder et al, 2013, economic evidence rating -) suggest that home care could be employed more cost-effectively if it was allocated more equally between different needs groups with a shift from people with severe towards people with low to moderate needs. **(REC 1.3.6)** **3.10 Social and emotional support within care planning** Evidence from one national mixed methods study that followed a case study approach (Windle et al, 2009, -) showed that emotional and social support for older people, such as emotional and social support can reduce depression and anxiety but did not confirm that it was likely to be cost-effective; interventions of this type could be provided at relatively small costs and there were likely to be wellbeing and wider outcomes that had not been captured in the cost-effectiveness findings. The study was broadly applicable and had only minor limitations so that findings could be used to inform recommendations. **(REC1.3.7)**
Other considerations	The recommendations here drew on economic evidence and expert witness testimony as well as GDG consensus. Specifically, the GDG agreed on the importance of: • emphasising, based on the additional economic analysis, the importance of home care as an intervention. This is on the basis that commissioners face difficult decisions in the context of budget pressures, and need to know that evidence supports home care as a valuable intervention for the population in question. • highlighting the need for home care to include support that is more than simply personal care, this was also highlighted through expert witness testimony. • emphasising the potential benefit of providing home care to people before their needs become critical, based on economic evidence from the literature, their own experience and expert witness testimony that need for home care hours could fall if people were encouraged to regain independence and confidence, and were introduced to other community services and support networks. The GDG noted that this was aligned with the emphasis on prevention in the Care Act 2014.

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Topic/section heading	Planning and reviewing home care and support – Supporting person-centred planning
Recommendations	**Recommendations for commissioners** 1.3.8 If a person chooses to take direct payments for home care, give them the support and information they need to manage the payments effectively. This should be regardless of whether they buy care through a regulated provider, directly employ a personal assistant or choose another way to meet the agreed need. 1.3.9 Consider asking people with experience of using a direct payment for home care to help provide training, support or advice to others thinking of doing so. 1.3.10 Aligned with the recommendations in Ensuring care is person-centred, ensure that lead practitioners and others involved in home care and support planning: • understand the principles and importance of involving the person using services, and their carers if relevant, as an equal partner in specifying the support and services they receive • know how to work in a way that maximises choice, control, dignity and respect for the person using services • have an awareness of common conditions affecting people using home care services, for example, sensory loss, dementia, physical and learning disabilities, and stroke • know about local organisations that provide specialist support • know about the funding options available for care and support • understand different funding mechanisms including the options available for people with personal budgets, for example having a managed budget, an individual service fund or direct payment. 1.3.11 Give lead practitioners relevant information about a person's circumstances before the home care planning process is started.
Research recommendations	The GDG did not identify care planning as a key area to make research recommendations on within this guideline.
Review questions	3.1 What approaches to home care planning and delivery are effective in improving outcomes for people who use services? 3.2 What are the significant features of an effective home care model? 3.3 Are there any undesirable/harmful effects from certain types of home care approaches? 3.4 What are the barriers to, and facilitators of, effective implementation of approaches shown (3.1) to deliver good outcomes?
Quality of evidence	Overall, there were no effectiveness studies which considered directly the process of informing and involving people in care planning, or the role of the lead practitioner in this. Most of the

	available evidence on effectiveness and acceptability of models concerned models of home care involving individual budgets and direct payments, and this is reflected in the evidence statements below. However, these evidence statements should be understood as relating to all home care planning.
Relative value of different outcomes	Although there were no effectiveness studies that demonstrated the outcomes of care planning led by a well-informed practitioner with good communication skills, the suggested outcomes are that the person needing home care and their carer(s) are well-informed about their options, and able to participate fully in the care planning process.
Trade-off between benefits and harms	The lack of effectiveness evidence topic meant that it was not possible to ascertain and compare the benefits and harms associated with different models of care planning and support.
	Supplementary evidence from views and experiences data, however, suggests there are significant benefits in terms of people's satisfaction with, and experience of the planning process, to have support that:
	• is planned to help them live in the way they would like to, taking into account their aspirations, needs and strengths;
	• allows them to be in control of their lives and their support, 'stepping up' their independence and autonomy as appropriate, in a graduated way;
	• supports person centred care, which requires that the people concerned are informed, encouraged and enabled to take a full part in the planning of care.
Economic considerations	No economic evidence directly applicable to these questions was identified. The GDG did, however, consider cost and resource use in making the recommendations.
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	Most of the available evidence on effectiveness and acceptability of models concerned models of home care involving individual budgets and direct payments, and this is reflected in the evidence statements below. However, these statements should be understood as relating to all home care planning.
	3.2 Older people's preference for personal assistants over traditional home care
	Good evidence from two studies - one UK randomised trial which evaluated IBs (Glendinning et al 2008a, +), one systematic review (Montgomery et al 2008, +) - suggested that older people might prefer employing a personal assistant (or someone who takes on a similar role) rather than traditional forms of home care when given the choice. **(REC 1.3.8, 1.3.9, 1.3.10 and 1.3.11**)
	3.17 Barriers to implementing individual budgets
	There is supplementary good evidence from one UK RCT (Glendinning et al, 2008a, +) and one UK mixed methods study (Baxter et al, 2008, +) to suggest that service providers' lack of knowledge and experience with IBs could be a barrier to implementation of this model. Some older people were reluctant

	to change. There were also concerns about the quality of home care provision with the employment of unqualified carers. **(REC 1.3.8, 1.3.9, 1.3.10 and 1.3.11)**
	3.18 Barriers to adopting individual budgets and direct payments
	There is good evidence from three UK mixed methods studies (Glendinning et al, 2008b, +; Moran et al, 2013, +; Lakey and Saunders, 2011, -) that receiving insufficient information about how to take up options for self-directed care can be stressful and limiting to older people. (REC 1.3.8, 1.3.9, 1.3.10 and 1.3.11)
Other considerations	The GDG agreed by consensus there is a need for a coordinated approach to care planning, ideally led by a single practitioner who takes a coordinating role, working across health, social care, and the voluntary and community sector. These recommendations related therefore to how the lead practitioner should work, the knowledge they should have and the sort of information they should be able to provide. GDG discussion built on the evidence about the importance of providing information on direct payments, extending this to ensure people knew about the range of mechanisms to manage available monies.
	The GDG emphasised the importance of spelling out the role and responsibilities of the lead practitioner in the recommendations. This was to ensure this person was equipped to involve service users and carers in planning, and to ensure equality of opportunity irrespective of how care is funded. GDG members noted - providing anecdotal examples from their experience – that self-funders could have more difficulty accessing information about support available but more flexibility in terms of building a package of support that suits their specific needs.

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Topic/section heading	Plan and review support - developing the care plan
Recommendations	**Recommendations for lead practitioners or other practitioner developing the care plan** 1.3.12 Before meetings to plan home care and support, give the person using services and their carer information about how the home care plan will be developed, negotiated and reviewed and the options available to them. Ensure people enough time to understand this information. 1.3.13 Ask people if they want carers or advocates involved in their home care planning and support, and respect their choice. 1.3.14 Consider planning support that enables the person to take more responsibility, including for the financial arrangements, to increase their independence over time. 1.3.15 Ask people about their aspirations, needs and priorities, as well as what gives them peace of mind, and makes them feel safe and unsafe. Ensure the home care plan: - empowers the person as much as possible, by recognising what they can and want to do - explicitly addresses safety, wellbeing, independence and any specialist needs - is informed by the experience, skills and insight of carers, as appropriate - addresses the range of practical support needed to help the person to live how they choose, as far as possible, rather than addressing only personal care needs (this could include, for example, support to help a person manage their own financial and personal affairs, do their own shopping and cooking, or socialise, or other help, depending on the person's needs and preferences) - describes how success and outcomes will be measured - is clear, concise and easy to navigate - has a summary at the start, with links to more detailed information.
Research recommendations	The GDG did not identify any research recommendations on developing care plans.
Review questions	3.1 What approaches to home care planning and delivery are effective in improving outcomes for people who use services? 3.2 What are the significant features of an effective home care model? 3.3 Are there any undesirable/harmful effects from certain types of home care approaches? 3.4 What are the barriers to, and facilitators of, effective implementation of approaches shown (3.1) to deliver good outcomes?
Quality of evidence	There were no effectiveness studies on the different models of developing and drawing up care plans. Recommendations drew upon studies which showed the importance of person centred care, the priorities identified (for RQ 1.1 and 1.2) by users and carers, the information needs of people using services and their

	carers, and the importance of knowing about care options (for example, to support direct payments).
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	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 of care planning and support.
	Supplementary evidence from service users' and carers' views and experiences data, however, suggests there are significant benefits in terms of people's satisfaction with, and experience of the services they use, to have support that:
	• is planned to help them live in the way they would like to, rather than focusing solely on their personal care needs.
	• allows them to be in control of their lives and their support, 'stepping up' their independence and autonomy as appropriate, in a graduated way.
	• recognises the importance of social interaction and relationship-building between the person using services and the worker.
	Conversely, these data also indicated negative outcomes were associated with:
	• rigid adherence to care plans.
	• delivering support based on time available rather than by the person's needs.
Economic considerations	There was no economic evidence which directly concerned the impact of care planning. The GDG did, however, consider cost and resource use in making the recommendations.
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	**1.1 Value of home care to users in promoting independence**
	There is moderate and good evidence from two UK mixed methods studies (Quince, 2011, -/+; Lakey and Saunders, 2011, -/+), and one Northern Ireland survey (DHSSPS, 2010, +). that home care users, including those with dementia (Quince, 2011, -/++; Lakey and Saunders, 2011, -/+), value home care because it enables them to live at home independently. There is also good evidence from a UK survey (PCC, 2012, +/+) that some people feel that more practical support, such as help with household tasks, would help them achieve greater independence and control over their lives. **(REC 1.1)**
	3.3 A stepped approach to introducing self-directed care to older people
	There is good evidence from one good quality comparison evaluation of self-directed care (Ottmann and Mohebbi, 2014, +) that a 'stepped' approach to providing support to manage self-directed care– i.e. one which enables the person to take increasing control, over time – is experienced positively by older people, and can contribute helpfully to delivering the outcomes they want to achieve. **(REC 1.3.14 and 1.3.15)**

	1.9 Home care provision is not holistic and does not cover the identified needs of users There is good evidence from a UK qualitative study (Clough et al, 2007, +) and a UK survey (PCC, 2012, +/+) that older people feel that home care should incorporate a wider variety of tasks. Some older people felt that definitions of care should be more holistic and take into account non-health and social care related tasks, 'odd jobs', management of personal affairs, shopping, socialising, recreation and leisure. Similarly, a further UK qualitative study (Seddon and Harper, 2009, +) found that some older people felt that home care should be more flexible, for example by allowing staff to take older people shopping rather than collecting it for them. People contributing to the cost of care were particularly dissatisfied with this inflexibility, according to a UK secondary data study (CSCI, 2006, +). **(REC 1.3.15)** **3.10 Social and emotional support within care planning** Evidence from one national mixed methods study that followed a case study approach (Windle et al, 2009, -) showed that emotional and social support for older people, such as emotional and social support can reduce depression and anxiety but did not confirm that it was likely to be cost-effective; interventions of this type could be provided at relatively small costs and there were likely to be wellbeing and wider outcomes that had not been captured in the cost-effectiveness findings. The study was broadly applicable and had only minor limitations so that findings could be used to inform recommendations. **(REC 1.3.15)** **7.10 Information tailored to older people's needs** There is very good evidence from one UK qualitative study (Cattan and Giuntoli, 2010, +) that older people need more time to process information, and providing information only in the period immediately after a health crisis was often inappropriate. Some family carers of people with dementia preferred to be present when their relative was given new information to support the person in giving and recalling information. **(REC 1.3.12)**
Other considerations	The GDG agreed by consensus there is a need for a coordinated approach to care planning, ideally led by a single practitioner who takes a coordinating role, working across health, social care, and the voluntary and community sector. These recommendations related therefore to what the lead practitioner should consider when completing the care plan with the person. Specifically, the GDG agreed these recommendations should: - emphasise care planning as a collaborative exercise in which people could express their views and aspirations - enable the person to take on more responsibility over time, in order to help promote their independence and increase their control. - promote equity of opportunity irrespective of how care is funded, or the person's needs.

	• make clear that the person should have the choice about whether their carer or advocate is involved
	• ensure the person and their carer should have a copy of their care plan as this does not happen routinely
	• promote a coproduced approach which, when people are considering direct payments, means ideally involving others who have had experience of this mechanism.

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Topic/section heading	Plan and review support – risk management
Recommendations	**Recommendations for lead practitioners (or other practitioners planning home care)** 1.3.16 When assessing risk, balance the risk of a particular behaviour or activity with how it is likely to benefit the person's wellbeing and help improve their quality of life. The lead practitioner should: • complete a risk plan with the person as part of the home care planning process and include this in the home care plan • ensure the risk plan includes strategies to minimise risk, for example specialist equipment; use of verbal prompts; use of support from others • ensure the risk plan includes the implications of taking the risk for the person and the home care worker • carry out risk assessments as part of home care planning and at relevant intervals, such as when significant factors change. 1.3.17 Liaise with healthcare practitioners and other professionals to ensure the home care plan promotes wellbeing, particularly for medicines management, pain management and pressure sore and moisture lesion prevention and care. 1.3.18 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.
Research recommendations	The GDG did not make any research recommendations in this area, and were mindful of a potential future NICE guideline on management of medication in the home.
Review questions	3.1 What approaches to home care planning and delivery are effective in improving outcomes for people who use services? 3.2 What are the significant features of an effective home care model? 3.3 Are there any undesirable/harmful effects from certain types of home care approaches? 3.4 What are the barriers to, and facilitators of, effective implementation of approaches shown (3.1) to deliver good outcomes?
Quality of evidence	Overall, there was no good evidence found on the consideration of risk within the data on care planning and delivery. The quality of evidence on safe care was of moderate quality, there was no evidence on effectiveness, and the evidence considered awareness of potential abuse and environmental hazards, which are not directly relevant to considering risk within (initial) care planning. Areas relevant to care planning did include medication management.

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 frameworks of risk management.
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 approaches to risk management in care planning and support. Supplementary evidence from views and experiences and the data presented for safe care suggests that planning to minimise risk should: • consider the trade-off between supporting people to do what they want, and allowing them to be in control of their lives • negotiate safeguards and interventions which might help minimise risk (see also the evidence in the LETR table on telecare) • put in place support for home care users, workers and unpaid carers to understand the importance and effects of treatments, including medication. This might include liaison with healthcare personnel.
Economic considerations	There was no economic evidence on this area. However, the economic plan and considerations of sub-groups did suggest that people living alone, and/or cognitive impairment, had poorer outcomes in health and wellbeing and that this could involve risk and should be carefully considered in care planning.
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	These recommendations were all derived from GDG consensus.
Other considerations	The GDG agreed that planning for risk management within care planning and review was a critical area for the guideline and that they could form recommendations based on their own knowledge and experience and informed by discussions about the evidence on safe care. Specific relevant discussions points are summarised below. • The GDG agreed the need for a 'risk positive' approach in order to promote better quality of life for people using services. There was considerable discussion about the issue of risk, particularly about how to ensure people can take the same informed risks they could choose to take were they not in need of care and support. The GDG support a risk-benefit approach to risk assessment which requires the lead professional to balance risks against benefits and 'contract' with the person and their carer, where appropriate, so that they can take risks that are expected to bring significant benefits, and so that they understand consequences if something goes wrong.

| | They discussed and agreed by consensus what 'risk positive' means in terms of the way that a risk plan (which should be part of the home care plan) should be completed. |
| | • GDG members also talked about the need for health care professionals, particularly those responsible for medications management to be involved in care planning. Medication is a concern for home care workers, and the care plan should record appropriate details (see also the LETR table on Safe care where there is a complementary recommendation aimed at healthcare professionals, to promote their involvement in this respect.) |

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Topic/section heading	Planning telecare
Recommendations	**Recommendations for lead practitioners (or other practitioners planning care):** 1.3.19 Always discuss with the person and their carer whether telecare could complement their home care package (and any other services they are using). 1.3.20 Discuss the potential benefits of telecare, such as how it can provide reassurance to the person and their carer, while bearing in mind the rights of a person, particularly in relation to privacy, choice and control. 1.3.21 Consider addressing the potential negative effect of social isolation on people's health and consider including voluntary sector and community organisations to maintain family and local community links, working with the carer as appropriate. 1.3.27 If the person wishes to use telecare, work with them to identify their preferred telecare options that maximise dignity and help them live in the way that they choose. 1.3.28 Ensure telecare does not replace personal contact, unless the person using services wants it to. 1.3.29 Record in the home care plan how the telecare equipment meets the person's needs and will help them achieve their desired outcomes. 1.3.30 Offer people using home care services information about options for telecare that could help them. Include information on potential risks and benefits, so they can make an informed decision.
Research recommendations	The following research question is relevant to this topic: What types of telecare are most effective and cost-effective, when provided to older people as part of a package of home care?
Review questions	6.1 What elements of telecare that could be used in planning and delivering home care are effective in improving outcomes for people who use services and their carers? 6.2 What are the views of users and family carers on the use of telecare as part of a home care package?
Quality of evidence	Overall, the evidence on telecare was of mixed quality and findings failed to demonstrate significant benefits. There was often a lack of detail about the specifics of the intervention – the type or types of telecare delivered - and definitions of telecare varied between studies. Studies, which included 2 systematic reviews, failed to demonstrate significant benefits for users and carers. Qualitative research of moderate quality involving both users and carers found that some people felt reassured by alarms and sensors, but carers did not find that less informal care was needed.

Relative value of different outcomes	While telecare evaluation has focused on specific outcomes, such as decreased hospital admissions and reduced falls, these are difficult to demonstrate in the short term. Whether people who use telecare feel safer and more independent may be more important. Whether carers feel less anxiety about the person when telecare monitoring is in place is a consideration, but this may depend on whether there are rapid and responsive services when telecare equipment identifies cause for concern.
Trade-off between benefits and harms	GDG members were concerned that telecare should never be used as a substitute for home care, as this could lead to neglect and social isolation. People receiving home care support consistently said they valued contact and conversation with home care workers. The cost of telecare, which may be borne by the user, is a potential 'harm' if the benefits are uncertain.
Economic considerations	Based on existing cost-effectiveness evidence, there was a low probability that second-generation telecare was cost-effective. However, this evidence came from only one trial and a replication of the trial might be required to confirm findings.
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	**6.10 Reasons for not wanting telecare: lack of confidence** There is moderate evidence from three UK qualitative studies (Sanders et al, 2012, +; Jarrold and Yeandle, 2011, +; Clark and McGee-Lennon, 2011, -) that some older people had a general distrust of modern technologies or lacked confidence in their abilities to use telecare devices. Carers had concerns about the capacity of the person they cared for and their ability to operate telecare equipment. In particular, carers of people with cognitive impairments such as dementia feared that telecare would not be of benefit and could be potentially harmful for very ill older people by further confusing an individual with cognitive impairment. **(REC1.3.19, 1.3.20, 1.3.30)** **6.11 Information about, and preparation for, telecare** There is good evidence from one UK qualitative study (Sanders et al, 2012, +) that older people felt that the introduction to telecare which they had received did not encourage or enable them to use the equipment and they were worried by the discussion of cost of telecare. Another good qualitative UK study (Jarrold and Yeandle, 2011, +) found that carers felt that the equipment had been adequately explained to them at installation, although some carers felt that they lacked access to information about new or recent developments in telecare services. **(REC 1.3.19 and 1.3.20 and 1.3.30)**
Other considerations	The GDG spent considerable time discussing telecare, based on their experience. They discussed telecare in a wider sense than simply second generation equipment referenced in the economic studies and agreed that this should be included in the guideline on the basis that there were many devices which could provide useful support to people using home care and their carers. In discussing the views evidence and, again, bringing their own experience to bear, they developed specific recommendations about how the use of telecare should be

	planned, specifically highlighting:
	- The pace of change in telecare, and the relative shortfall of evaluative research on specific types of telecare interventions. - The issue of acceptability including consent, capacity and wider ethical issues about specific aspects of telecare, e.g. remote monitoring and support. Use of telecare may be part of the wider issue of risk assessment, and may have an impact on an individual's freedoms and rights. - Concern that telecare devices should be carefully matched to individual need and potential benefit: that is to say, the outcomes it was meant to achieve for that specific individual, using a person-centred perspective. An important part of the process was information, discussion and negotiation of different options with the person who is to use telecare, plus close attention to feedback. Aligned with the principles of person-centred care, the GDG included consensus recommendations about ensuring telecare (if used) is part of a package of support designed to delivers the outcomes the person wants, and the way it will contribute to intended outcomes should be recorded in the home care plan and reviewed. - The importance of not replacing human contact with technology, recognising the risk of social isolation among this group of older people. They built on the evidence to emphasise the benefits of helping older people living at home to link to networks within their local community as a way of complementing any telecare support in place. The GDG also drew on evidence from the expert witness (TB), noting that, while the majority of home care users do not need 24-hour care, they may benefit from devices which can provide 24-hour support of some type, citing, for example: monitors linked to kettles; finger print recognition systems to enable people to get in their house if they lose keys; medication alerts etc.). GDG members thought it unlikely that telecare was currently discussed with people at the stage of planning their home care, but thought it important to recommend it is considered – and options discussed with people – at this stage.

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Topic/section heading	Plan and review support – prioritising and reviewing aspects of the care plan
Recommendations	**Recommendations for home care providers** 1.3.22 Ask people: • which elements of their home care service are a priority for them, and • whether some home care time may be used flexibly (that is, used for a variety of jobs according to what is needed). 1.3.23 Give people and their carers if appropriate, a copy of their home care plan in a format that meets their needs. 1.3.24 Ensure all practitioners providing support complete the home care plan, and deliver support in an integrated way according to the plan. 1.3.25 Undertake an initial review of the home care plan after about 6 weeks, then review regularly at least annually. This should involve the person and their carers (if appropriate) in a meaningful way. 1.3.26 Consider working with other agencies to ensure that people who use home care services have a single home care and support plan rather than separate plans from each service or provider.
Research recommendations	The GDG did not make any research recommendations on care planning.
Review questions	3.1 What approaches to home care planning and delivery are effective in improving outcomes for people who use services? 3.2 What are the significant features of an effective home care model? 3.3 Are there any undesirable/harmful effects from certain types of home care approaches? 3.4 What are the barriers to, and facilitators of, effective implementation of approaches shown (3.1) to deliver good outcomes?
Quality of evidence	Overall, the quality of the evidence on priorities for service users and carers was qualitative, detailing the importance of including measures to reduce social isolation and increase participation, prioritising aspects other than personal care that mattered to service users, and allowing flexibilities. Much of this information was included in the evidence on service user views.
Relative value of different outcomes	The lack of effectiveness studies relevant to these questions meant that it was not possible to ascertain and compare the relative value of outcomes associated with applying different user-led priorities within care planning and support. However, user satisfaction and quality of life are clearly important outcomes.
Trade-off between benefits and harms	The lack of effectiveness studies relevant to these questions meant that it was not possible to ascertain and compare the benefits and harms associated with different models of care planning and support. Supplementary evidence from views and experiences data,

	however, suggests there are significant benefits in terms of people's satisfaction with, and experience of the services they use, to have support that:
	- is planned to help them live in the way they would like to, rather than focusing solely on their personal care needs. - allows them to be in control of their lives and their support, 'stepping up' their independence and autonomy as appropriate, in a graduated way. - is reliable, recognising that continuity is important. - recognises the importance of social interaction and relationship-building between the person using services and the worker. There was evidence from studies of self-directed care that people hoped and believed that taking control over budgets and recruitment of carers would facilitate these features.
Economic considerations	There was insufficient data available to ascertain the cost-effectiveness of home care packages or to understand in-depth the economic impact of different components of home care packages.
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	**3.3 A stepped approach to introducing self-directed care to older people** There is good evidence from one good quality comparison evaluation of self-directed care (Ottman and Mohebbi, 2014, +) that a 'stepped' approach to providing support to manage self-directed care– i.e. one which enables the person to take increasing control, over time – is experienced positively by older people, and can contribute helpfully to delivering the outcomes they want to achieve. **(REC 1.3.22)** **3.11 Flexibility of home care support** There is moderate evidence from one UK mixed methods study (Gethin-Jones, 2012b, +), one UK survey (Netten et al, 2007, +) and one UK qualitative study (Duff and Hurtley, 2012,-) that service users and care managers associate high quality care to be related to flexibility with providers able to: vary the hours given and how the time is spent, and ensure workers have sufficient travel time between visits. Good evidence from one UK mixed methods study (Moran et al, 2013, +) and one UK qualitative study (Manthorpe and Stevens, 2010, +) highlighted the opportunity IBs provide for increased flexibility of support. **(REC 1.3.22 and 1.3.26)** **3.14 Volunteer support in the home** There is poor evidence from one UK mixed methods study (Bowers et al, 2006, -) that service users found the service provided by volunteers can be particularly outcome-focused as they start with the tasks that need completing rather than the time available. **(REC 1.3.22)**

	3.16 Barriers to good home care: need for reliable care that addresses outcomes such as social participation
	There is good evidence from two UK mixed methods studies (Gethin-Jones, 2012b, +; PCC, 2012, +) to suggest that older people can feel disengaged and socially isolated where services were not commissioned for outcomes. **(REC 1.3.22)**
	3.15 Unreliable home care services (visits missed or late)
	Unreliable home care services left older people alone and without the required support. There is evidence from two UK qualitative studies (Duff and Hurtley, 2012, -; Roberts, 2011, +) that fragmented and uncoordinated inter-agency working resulted in delays and difficulties addressing health care needs or poor handovers between health and social care staff. **(REC 1.3.24 and 1.3.26)**
Other considerations	The recommendations relevant to planning and reviewing care draw on GDG discussion in relation to person-centred care (relevant to all research questions) as well as considerable evidence on views and experiences.
	As well as evidence specific to different models, the GDG focused on what providers and commissioners needed to do and developed recommendations based on the evidence on specific aspects of home care planning and review (that is, as opposed to recommending a particular model), expert witness testimonies and their own experience.
	The GDG agreed that the recommendations should address:
	- the need to ensure people and their carers if appropriate have a copy of their home care plan- in a format that meets their needs - that they can keep in their home and refer to - the value service users placed upon social interaction and participation. - the demand for flexible use of home care workers' time, and preferences for being supported to leave the house, and having the flexibility to save up time for activities that could not be undertaken within limited time slots - the importance of having a home care plan as an agreement of what was to be done, but also the need for it to build in flexibility, and be regularly reviewed if the person or carer felt that change in circumstances warranted review - the importance of integrated working with other services and agencies, including the voluntary sector, to deliver and support priorities (such as transport to venues).

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Topic/section heading	Delivering home care – Time to care
Recommendations	**Recommendations for commissioners** 1.4.1 Ensure contracts allow home care workers enough time to provide a good quality service including having enough time to talk to the person and their carer. They should ensure that workers have time to do their job without being rushed or compromising the dignity of the person who uses services. 1.4.2 Home care visits shorter than half an hour should be made only if: • the home care worker is known to the person, and • the visit is part of a wider package of support, and • it allows enough time to complete specific, time limited task or to check if someone is safe and well, for example. 1.4.3 Consider contracting and monitoring in a way that allows services to be delivered flexibly to ensure the person can identify what is a priority for them. This might include, for example, allowing providers (with the person's agreement or at their request) to use time flexibly. Recommendations for home care managers and providers 1.4.4 Ensure home care visits are long enough for home care workers to complete their work without compromising the quality of their work or the dignity of the person, including scheduling sufficient travel time between visits. Take into account that people with cognitive impairments, communication difficulties or sensory loss may need workers to spend more time with them to ensure they have the support they need.
Research recommendations	The following recommended research questions are relevant to this section: • What is the cost-effectiveness of different intensities of home care packages for older people with a range of care and support needs? • What is the most effective and cost-effective way to support people with dementia living at home?
Review questions	3.1 What approaches to home care planning and delivery are effective in improving outcomes for people who use services? 3.2 What are the significant features of an effective home care model? 3.3 Are there any undesirable/harmful effects from certain types of home care approaches? 3.4 What are the barriers to, and facilitators of, effective implementation of approaches shown (3.1) to deliver good outcomes?
Quality of evidence	The evidence to support recommendations on the time allotted to home care visits was of moderate quality, using predominantly qualitative and survey methodology and there were no effectiveness studies . The evidence relating to views and experiences of users and carers and of practitioners (see Person-centred care) also addressed this topic.

Relative value of different outcomes	The absence of effectiveness studies relevant to this topic meant that it was not possible to ascertain and compare the relative value of outcomes associated with different ways of delivering home care. Relevant outcomes of different time allocations would reflect user and carer satisfaction, safety and wellbeing, and effect on social isolation of older people living at home.
Trade-off between benefits and harms	The absence of effectiveness studies relevant to this question meant that it was not possible to compare measurable benefits and harms associated with different time allocations in the delivery of home care. Evidence from other reviews questions, and qualitative evidence, suggests that: • workers who spend short periods may not have time to complete the allotted tasks • older people, and particularly those with cognitive or sensory impairment, need more time to be helped to wash, dress and eat, and short slots may not cater for their basic needs, including nutrition • service users and carers are often isolated and value the time spent in simple conversation with home care workers • workers and clients who are from different language and cultural backgrounds may require more time to communicate and comply with particular needs.
Economic considerations	The overwhelming economic consideration is the cost of additional time. Time spent with clients is effectively governed by the hourly rates that commissioners are willing to pay.
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	**1.4 Importance of communication and 'being listened to'** There is very good evidence from a UK qualitative study (Cattan and Giuntoli, 2010, ++); and two UK surveys (CQC, 2013, +; OPCW, 2012, +) that good communication, 'being listened to' and encouraged to express their views is important to service users and carers. **(REC 1.4.1 and 1.4.3)** **1.11 Users' and carers' views on allotted time slots** There is good evidence from several UK studies, a secondary data study (CSCI, 2006, +), a mixed methods study; (London Assembly, 2010 +/+); and two surveys (Netten, 2007, +; PCC, 2012, +/+) that many older people felt that short time slots compromised the quality and scope of home care. A lack of travel time between slots was noted by users and carers as a contributory factor in a survey (OPCW, 2012, +). **(REC1.4.1, 1.4.2 and 1.4.4)** **2.8 Time to care: duration of visit and impact on care** There is good evidence from a range of UK studies that care workers thought that time allowed for visits was insufficient. Moderately good evidence from one qualitative study (Duff and Hurtley, 2012, -) and one survey (Unison, 2012, +) suggests that care workers believed that the use of 15 minute visits was not enough time to provide good quality care. There is good

evidence from one qualitative study (Walsh and Shutes, 2013, +) to suggest that time constraints acted as a barrier to the development of good relations between service users and care workers. Good evidence from a survey (Angel, 2012, +) found that 34% of providers expressed concern that undertaking personal care in such short timeframes was putting the dignity of service users at risk. There is good evidence from one qualitative study (Wibberley et al, 2013, +) that due to time pressures, care workers often endure unclean workplaces (users' homes) as they are not able to help their elderly clients with cleaning. **(REC 1.4.1, 1.4.2 and 1.4.4)**

2.9 Time to care: flexibility and reliability of visiting times

There is good evidence from one UK qualitative study (Francis and Netten, 2004, +) that some managers believed they had little control over the provision of a reliable service when visits overran due to ill or injured clients who required more care, as well as the impact of traffic on travelling to the next client. Some managers suggested that local authority commissioning arrangements should factor in travel time costs. **(REC 1.4.1, 1.4.2 & 1.4.4)**

3.8 Time to spend conversing with service users

There is moderate evidence from one secondary data analysis (Henderson 2006 + citing Patmore 2005) that good quality practice allows time for the workers to complete the required tasks as well as having time to chat or help with household task (such as washing up or pet care). Moderate evidence from one UK mixed methods study (Gethin-Jones, 2012b, +) showed that service users reported benefits as a result of being able to form a relationship with their care workers. In a UK qualitative study (Ekosgen, 2013, +), self- funders highlighted the importance of building trust, a positive relationship with their care workers, thus ensuring continuity of care. **(REC 1.4.1, 1.4.2 & 1.4.4)**

3.11 Flexibility of home care support

There is moderate evidence from one UK mixed methods study (Gethin-Jones, 2012b, +), one UK survey (Netten et al, 2007, +) and one UK qualitative study (Duff and Hurtley, 2012,-) that service users and care managers associate high quality care to be related to flexibility with providers able to: vary the hours given and how the time is spent, and ensure workers have sufficient travel time between visits. Good evidence from one UK mixed methods study (Moran et al, 2013, +) and one UK qualitative study (Manthorpe and Stevens, 2010, +) highlighted the opportunity IBs provide for increased flexibility of support. **(REC 1.4.3)**

	3.20 Barriers to good home care: rushed care slots
	There is good evidence from two UK surveys (Angel, 2012, +; UNISON, 2012, +) and two UK mixed methods studies (Gethin-Jones, 2012b, +; PCC, 2012, +) and one secondary analysis study (Henderson, 2006, +) to suggest that care workers felt the service they offered was compromised due to 15-minute and 30-minute appointment, or appointments being booked too closely together. Users reported feeling 'rushed'. **(REC 1.4.1, 1.4.2 and 1.4.4)**
Other considerations	There was extensive GDG discussion about the evidence to suggest short timeslots can compromise care with a wide range of examples provided by GDG members from their own experience. In addition to the evidence summarised under 'Plan and review support' in relation to time-task (vs outcomes-focussed) commissioning, expert witness (TB) testimony identified that it can sometimes be appropriate for workers to make short visits (e.g. less than half an hour) but this should only be the case under certain circumstances, where the worker is known to the person.

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Topic/section heading	Delivering home care - complaints
Recommendations	**Recommendations for home care managers and providers** 1.4.5 Ensure there is a complaints procedure in place. Tell people about how they can make a complaint either in writing or in person. 1.4.6 Make the complaints procedure available on your website and in other ways appropriate to people using the service and their carers. Give information about escalating complaints if necessary (to the commissioning body and Ombudsman) or ensure that this information is readily available.
Research recommendations	The GDG did not make any recommendations in this area.
Review questions	3.1 What approaches to home care planning and delivery are effective in improving outcomes for people who use services? 3.2 What are the significant features of an effective home care model? 3.3 Are there any undesirable/harmful effects from certain types of home care approaches? 3.4 What are the barriers to, and facilitators of, effective implementation of approaches shown (3.1) to deliver good outcomes?
Quality of evidence	Ability to complain was considered in RQ 1 (user and carer views and experiences), and RQ 7 (on information needs). Both the London Assembly (2010) and the PCC (2012) reported that some older people feared that lodging a complaint would negatively affect their service provision. Overviews from regulatory bodies, for example, Care Quality Commission (2013) and CSCI (2006), were said to be informed by complaints among other evidence.
Relative value of different outcomes	The absence of effectiveness studies relevant to this topic meant that it was not possible to ascertain and compare the relative value of outcomes associated with different ways of supporting people to make complaints.
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 ways of supporting people to make complaints. Complaints provide an important route to address a legitimate grievance, and are an important source of feedback to commissioners and providers about the quality of services.
Economic considerations	There was no economic evidence on making, or responding to, complaints.
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	**7.6 Information on complaints procedures** There is good evidence from a UK mixed methods study (London Assembly, 2010, +) that service users found complaints procedures confusing. Evidence from a UK survey (EHRC, 2013, +) reported that some local authorities had produced a film and distributed comments and complaints forms more widely. **(REC 1.4.5 & 1.4.6)**

Other considerations	GDG members agreed strongly that all elements of the guideline should be informed by what users, carers and practitioners think about works well and what needed improvement. This required a complaints process that was easily accessible, and that was a routine aspect of service user feedback. While the GDG acknowledged that providers will usually have complaints policies and procedures in place, both evidence and GDG experience indicated people sometimes do not know how to complain, or do not feel able to do so. This may be the case particularly if they do not have someone to advocate for them, or a carer. Recommendations seek to emphasise the importance of ensuring people know how to complain and are supported to do so without fearing reprisal.

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Topic/section heading	Delivering home care – continuity of care
Recommendations	**Recommendations for home care managers and providers** 1.4.7 Prioritise continuity of care (so that the person knows the home care practitioners and they are familiar with how that person likes support to be given) – particularly given that this can ensure any risks or concerns are identified early – by: • introducing people to new care workers, and • building teams of workers around a person and their carer, and • informing people in advance if staff will be changed and explaining why, and • working with people to negotiate any changes to their care plan, for examples when visits will be made, and • recognising that major changes (for example moving from home care to use of personal assistants) can make people feel unsafe. 1.4.8 Ensure home care workers are able to deliver home care in a way that meets the person's cultural and language needs. 1.4.9 Consider the need for independent advocacy if a person lives alone, has difficulty expressing their views and aspirations or routinely lacks capacity. 1.4.10 Closely monitor risks associated with missed or late visits and take prompt remedial action. Recognise that people living alone (without carers or advocates) or those who lack capacity may be particularly vulnerable if visits are missed or late.
Research recommendations	The GDG considered that there were no important gaps in the evidence to make recommendations on.
Review questions	3.1 What approaches to home care planning and delivery are effective in improving outcomes for people who use services? 3.2 What are the significant features of an effective home care model? 3.3 Are there any undesirable/harmful effects from certain types of home care approaches? 3.4 What are the barriers to, and facilitators of, effective implementation of approaches shown (3.1) to deliver good outcomes?
Quality of evidence	The evidence for this topic was relatively good, including a range of qualitative and survey material from users and carers, and from practitioners as well as material from surveys from providers and the social care workforce. There was no effectiveness or economic studies which addressed this issue.
Relative value of different outcomes	Outcomes associated with good continuity of care include close and trusting relationships between users, their families and paid carers, and job satisfaction for workers. Such relationships are of great importance to people who are socially isolated and maybe homebound. Being familiar with a person's needs is important to person-centred and quality of care and reduces the need to spend time 'training' new workers (a role that users and

	carers have sometimes said falls to them, and may be particularly difficult if there is a cultural or language mismatch between service user and provider). Having a known, familiar and trusted carer is important to dignity and control for service users, particularly in relation to personal and bodily care.
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 continuity of care. However, being able to send the same workers to service users, and to rely on their commitment and punctuality, is likely to benefit providers. However, sickness and other leave, the need for carers in work to cover for those absent, staff turnover and static labour markets may all serve to frustrate these goals.
	When people have cognitive or sensory impairment and/or live alone, missed visits can represent a real risk of harm (for example, falls, dehydration and confusion) to people.
Economic considerations	There was no economic evidence identified on continuity of care, or on the cost of missed calls. The GDG did, however, consider cost and resource use in making the recommendations.
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	**1.5 Importance of having the same worker(s)**
	There is good evidence from a UK qualitative study (Sykes and Groom, 2011, +), one UK survey (OPCW, 2012, +) and a UK mixed methods study (London Assembly, 2010, +/+) that older people value having the same familiar workers, but that they are not always made aware of a change in personnel, causing anxiety and raising the need for training in that person's particular needs. **(REC 1.4.7 and 1.4.10)**
	2.10 Time to care: continuity of care
	There is good evidence from one UK qualitative study (Francis and Netten, 2004, +) that managers recognised the importance of continuity of care and made attempts to create teams of workers who worked regularly with individual service users, arranged introductory visits to enable service users to meet their new home care worker in advance. Inadequate sick leave procedures and high staff turnover are concerns which could negatively impact on continuity of care. There is moderate evidence from one UK qualitative study (Devlin and McIlfatrick, 2010, +) that community nurses perceived continuity of home care staff as an integral feature of high quality palliative care. . **(REC 1.4.7, 1.4.8, 1.4.9 and 1.4.10)**
	3.15 Unreliable home care services (visits missed or late)
	Unreliable home care services left older people alone and without the required support. There is evidence from two UK qualitative studies (Duff and Hurtley, 2012, -; Roberts, 2011, +) that fragmented and uncoordinated inter-agency working resulted in delays and difficulties addressing health care needs or poor handovers between health and social care staff. **(REC 1.4.7 and 1.4.10)**

Other considerations	GDG members agreed strongly that all elements of the guideline should be informed by what users, carers and practitioners think about works well. The recommendations relevant to delivery of continuity of home care therefore, draw on GDG discussion in relation to person-centred care (relevant to all research questions) as well as considerable evidence on views and experiences.
	Other points raised:
	There was discussion in GDG about the importance of continuity of care, and very serious, potentially life-threatening implications of missed or late visits for some people. There was discussion about how for others, missed or late visits would not be so problematic. The GDG described how those living alone may be particularly vulnerable, particularly as, in many cases, the home care worker is the only person they see regularly.
	There is ample evidence that users and carers prefer continuity of care. Understanding that this is not always deliverable, the recommendations consider how people can be introduced to new workers, so that they feel prepared, and informed where workers are late or have to miss a call.
	The GDG agreed the focus should be on ensuring that there is sufficient flexibility for people using services to be able to change appointment times with the worker or provider where it suits them, quickly and easily, while also ensuring there are alerts when visits are missed or late, to ensure vulnerable people are not at risk of harm.
	however, the GDG highlighted that sometimes it is appropriate for visit times to be changed - e.g. if the person using services has requested it - and for the person expecting the visit to be informed through a simple and agreed process. The recommendations about visit timing therefore aim to place responsibility on providers to monitor missed calls and respond appropriately.

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Topic/section heading	Delivering home care – Visiting people at home
Recommendations	**Recommendations for home care workers** 1.4.11 Ensure the person who uses services (or their carer) is contacted if you will be late or unable to visit, as well as informing your manager, if appropriate. 1.4.12 Make every effort to avoid missed calls because these can cause major concern or have serious implications for people's health or wellbeing. 1.4.13 Ensure the record you complete routinely on each visit is detailed enough to keep people, their carers and practitioners fully informed about what has been provided. Record any incidents or changes. The record could form an additional part of the home care plan or could be a separate 'care diary'.
Research recommendations	The GDG did not make any research recommendations on this area.
Review questions	3.1 What approaches to home care planning and delivery are effective in improving outcomes for people who use services? 3.2 What are the significant features of an effective home care model? 3.3 Are there any undesirable/harmful effects from certain types of home care approaches? 3.4 What are the barriers to, and facilitators of, effective implementation of approaches shown (3.1) to deliver good outcomes?
Quality of evidence	The evidence in this area was limited, and the recommendations drew largely on the expertise of the GDG, and the need for home care workers to support the recommendations on ensuring continuity of care.
Relative value of different outcomes	The lack of effectiveness studies relevant to these questions meant that it was not possible to ascertain and compare the relative value of outcomes associated with continuity of care. A fuller discussion is provided in the previous LETR table.
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 ways of delivering continuity of care. There is ample evidence (see relative value of different outcomes above) that users and carers prefer continuity of care. Understanding that this is not always deliverable, the recommendations consider how people can be introduced to new workers, so that they feel prepared, and informed where workers are late or have to miss a call.
Economic considerations	There was no economic evidence identified on continuity of care, or on the cost of missed calls. The GDG did, however, consider cost and resource use in making the recommendations.

Evidence statements – numbered evidence statements from which the recommendation(s) were developed	Evidence statements are consistent with those included in recommendations for providers in relation to continuity of care, most notably: **1.5 Importance of having the same worker(s)** There is good evidence from a UK qualitative study (Sykes and Groom, 2011, +), one UK survey (OPCW, 2012, +) and a UK mixed methods study (London Assembly, 2010, +/+) that older people value having the same familiar workers, but that they are not always made aware of a change in personnel, causing anxiety and raising the need for training in that person's particular needs. **(REC 1.4.11 & 1.4.13)** **3.15 Unreliable home care services (visits missed or late)** Unreliable home care services left older people alone and without the required support. There is evidence from two UK qualitative studies (Duff and Hurtley, 2012, -; Roberts, 2011, +) that fragmented and uncoordinated inter-agency working resulted in delays and difficulties addressing health care needs or poor handovers between health and social care staff. **(REC 1.4.11, 1.4.12 & 1.4.13)**
Other considerations	GDG members agreed strongly that all elements of the guideline should be informed by what users, carers and practitioners think about works well. The recommendations relevant to delivery of home care, therefore, draw on GDG discussion in relation to person-centred care (relevant to all research questions) as well as considerable evidence on views and experiences. Specific relevant discussions points include: • Reliability of service, also related to timing of visits- there was considerable discussion about the potentially serious implications of workers missing or being late for appointments, for example, if a person needed to take medication at a certain time, or had sustained an injury. • Communication - The GDG highlighted how it can be difficult, both for people using services and different groups of professionals, to have enough information, on a day-to-day basis about the support being provided by different people. While there is a requirement for workers to record information, this can often be very brief. The GDG suggested that a 'care diary' (or equivalent), owned by the person using services and completed by everyone involved in providing support was suggested by service user and carer members as being particularly helpful. This may be particularly useful if one worker has to substitute for another who is unable to work.

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Topic/section heading	Delivering telecare
Recommendations	**Recommendations for the lead practitioner** 1.4.14 Ensure that the telecare provider gives the person and their carer information about how to use the equipment, and confirm that the person can confidently use it. 1.4.15 Regularly review a person's use of telecare to ensure they find it useful. Involve the person in the review and seek feedback from others, such as carers or call centres. During the review, tell the person about any new telecare options available. 1.4.16 Provide telecare call centres with all relevant information about a person's circumstances (if the person agrees). 1.4.17 If providing alarm-based telecare, ensure response systems are in place. For example, the alarm can be linked to a warden, live-in carer, family member or contact centre. 1.4.18 If the alarm is set to alert a carer who does not live near the person, consider ensuring there is a 24-hour, 7-days-a-week contact close by who is able to provide assistance.
Research recommendations	The following research question is relevant to this topic: What types of telecare are most effective and cost-effective, when provided to older people as part of a package of home care?
Review questions	6.1 What elements of telecare that could be used in planning and delivering home care are effective in improving outcomes for people who use services and their carers? 6.2 What are the views of users and family carers on the use of telecare as part of a home care package?
Quality of evidence	Overall, the evidence on telecare was of mixed quality and findings failed to demonstrate significant benefits. There was often a lack of detail about the specifics of the intervention – the type or types of telecare - delivered, and definitions of telecare often varied between studies. Studies, which included 2 systematic reviews, tended to concern different but important outcomes and did not demonstrate benefit. Qualitative research of moderate quality involving both users and carers found that some people felt reassured by alarms and sensors, but carers did not generally find that less informal care was needed because of the technology in use.
Relative value of different outcomes	While telecare evaluation has focused on specific outcomes, such as decreased hospital admissions and reduced falls, these are difficult to demonstrate in the short term. Whether people who use telecare feel safer and more independent may be more important. Whether carers feel less anxiety about the person when telecare monitoring is in place is a consideration, but this may depend on whether there are rapid and responsive services when telecare equipment identifies cause for concern.
Trade-off between benefits and harms	GDG members were concerned that telecare should never be used as a substitute for home care, as this could lead to neglect and social isolation. People receiving home care were consistently said they valued contact and conversation with

	home care workers.
	There was concern from carers of people with cognitive impairment that older people might find the devices confusing and worrying, and concern from users that their autonomy would be undermined by the installation of telecare equipment within their home. The cost of telecare, which may be borne by the user, is a potential 'harm' if the benefits are uncertain.
Economic considerations	Based on existing cost-effectiveness evidence there was a low probability that second-generation telecare was cost-effective. However, this evidence came from only one trial and a replication of the trial might be required to confirm findings. In the absence of further evidence the GDG might decide to recommend the use of first-generation telecare.
	GDG members also noted that a significant aspect of the cost of telecare concerns maintaining a service or call centre which responds to alarms or other warnings.
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	**6.1 Impact of telecare support on wellbeing of older people**
	There is good evidence from one UK cluster RCT (Hirani et al, 2014, ++/+) to suggest that older people who received home-based telecare support were significantly more likely to achieve a small improvement in mental health-related quality of life and psychological wellbeing than those who received usual health and social care at 12 months. **(REC1.4.15)**
	6.3 Impact of telecare on independence and perception of safety
	There is good evidence from one UK controlled study (Brownsell et al, 2008, +/+) that older people offered telecare were more likely to report going outdoors and spending more hours out of the home. They were also more likely to feel safe during the day and night and to be less fearful of crime. Two poorly described UK surveys (Beale et al, 2009, -) (Rainbow, 2008, -) reported that older people in the National Telecare Development Program felt safer, and more independent, and perceived that their families now worried about them less. There is poor evidence from one UK survey (Beale et al, 2009, -) that older people felt that telecare equipment had reduced the amount of paid help they needed but that the equipment had not affected the amount of help which they needed from their family. **(REC 1.4.14 and 1.4.15)**
	6.7 Perceived impact of telecare on carers and caring
	There is poor evidence from two UK qualitative studies (Jarrold and Yeandle, 2011, +; Rainbow, 2008, -) that carers agreed that telecare had led to a reduction in stress and anxiety for them as carers, and perceived that the people they cared for had increased feelings of security, confidence and independence. Telecare had enabled some carers to engage in paid work alongside their caring role and that their relationship with the person they cared for had improved as a result of telecare. **(REC 1.4.14 and 1.4.15)**

	6.8 Acceptability of telecare devices to older people There is poor evidence from one UK qualitative study (Clark and McGee-Lennon, 2011, -) that some older people had concerns regarding the type of telecare which was installed in their homes, with a number suggesting that sensors were more appropriate than video surveillance. One poor quality survey (Beale et al, 2009, -) reported that older people found telecare devices worn on the person such as pendant alarms and fall detectors to be uncomfortable, and were concerned about activating them unintentionally. **(REC 1.4.14, 1.4.15 and 1.4.17)** **6.13 Cost-effectiveness of telecare** There is one robust UK study on cost-effectiveness and cost-utility, which is an economic evaluation carried out alongside a RCT by Hirani and colleagues (Henderson et al, 2014) which did not confirm that second-generation telecare was likely to be cost-effective, if only health outcomes and government costs were considered. It showed that second-generation telecare might slightly increase the costs of home care. This study was not designed to provide cost-effectiveness evidence for first-generation telecare. Studies that reported positive cost-effectiveness findings or cost savings of telecare (Beale et al, 2009; Clifford et al, 2012) used inappropriate designs which did not allow attribution of effects and associated cost savings to telecare in a robust manner so that findings could not be used to inform recommendations.
Other considerations	GDG discussion about planning telecare overlapped with that on delivering telecare. GDG members thought that it was difficult for providers, users and carers to be well-informed about the different devices available – and their potential usefulness- and that they should have recourse to an advisory or procurement service (perhaps within the NHS). In the absence of proven cost-effectiveness in terms of reducing need for care, it is uncertain whether or not the cost of telecare to may be justified. Having information about telecare options, and a comprehensive introduction to the devices, was thought to be important as was the need to review use and benefits. The GDG also agreed by consensus that the recommendations should specify the systems that need to be in place should be choose to use alarm-based telecare. Specifically, they emphasised the importance of ensuring that 24-hour responses are available, and that people responding to any alarms understand the person's needs.

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Topic/section heading	Ensuring safety and safeguarding people using home care services – medicines management & hazards in the home
Recommendations	**Recommendation for health care practitioners** 1.5.1 Consider regularly liaising with home care workers about the person's medication. 1.5.2 Write information and guidance for home care workers about medicines in the home care plan. **Recommendations for home care managers** 1.5.3 Ensure there is a written process to follow in the event of a safeguarding concern and ensure that the process is aligned with local authority procedures. The process should include key contacts such as: • emergency services • the registered manager of the home care provider • the local authority vulnerable adults or safeguarding helpline • other sources of support, for example, the Care Quality Commission, Action on Elder Abuse, the local Healthwatch. 1.5.4 Ensure home care workers are aware of the process. **Recommendations for home care providers** 1.5.8 Home care providers must have a medicines management policy. **Recommendations for home care providers and home care workers** 1.5.9 Ensure the person using the service, and their carers (if the person has involved them in their care) can direct the way home care is delivered. This is so that the person's safety, comfort, independence and sense of security are always promoted.
Research recommendations	The following research question is relevant to this topic: What safeguarding practices are most effective for improving outcomes?
Review questions	4.1 What are the effects of approaches to promote safe care?
Quality of evidence	Overall, the evidence found on safe care was of moderate quality, and there was no evidence on effectiveness. Both of the controlled quantitative studies which were included had relatively short follow-up periods, had been conducted in the US (i.e. Ganong et al, 2013; Gershon et al, 2012), and concerned awareness training on home hazards which was not directed at home care staff. A survey established the inconsistencies in awareness of possible abuse among workers. Four qualitative studies outlined the impact of environmental hazards in the home as a safe place (for workers and care users) to deliver care.

Relative value of different outcomes	There were no studies found which directly measured outcomes of approaches on the safety of people using services and their carers, but there were indications that workforce training to recognise hazards could raise awareness (Gershon, 2012). No studies measured outcomes for users and carers – for example, personal safety, and accommodation cleanliness and comfort.
Trade-off between benefits and harms	The GDG discussed how issues of safe care form a large part of the day-to-day work of providers and can be particularly challenging given the need to balance: • the rights of the person using services to live in a way that they choose, with the rights of the worker to fulfil their duties in a safe and sanitary working environment; • the rights and preferences of the person using services, with the need to safeguard them, which can be complex, for example, if their chosen carer is suspected of abuse. The GDG reiterated the concern that funding and commissioning practice was increasingly focussing only on personal care, with no service provided for housework and laundry, as this could contribute to unhealthy home environments.
Economic considerations	Overall, there was a lack of cost-effectiveness evidence in this area. However, 'feeling safe' was considered as an outcome in the review of care planning approaches; the additional analysis of primary data of the IBSEN study (PSSRU 2014, evidence level +, N=381) measured this outcome as part of the Adult Social Care Outcomes Tool (ASCOT).
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	**4.4 Home care workers could help improve environmental safety in service users' homes** There is moderate evidence from two US studies (an RCT, Ganong et al, 2013, +/-; a quantitative before and after evaluation, Gershon et al, 2012, +/-) that safety in service users' homes could be improved by training paid and unpaid carers to recognise hazards in the home (chemical, fall, fire, security and health), and to respond to them (e.g. through installing fire alarms, making pre-arranged calls, fixing rugs, teaching older people to use mobile phones). **(REC1.5.9)** **4.5 Evidence of hazardous and dirty homes** There is evidence of moderate quality from two UK qualitative studies (Taylor and Donnelly, 2006, on Northern Ireland, +; Wibberley 2013, +) that home care workers face a number of hazards and deficiencies in the workplace, many of which can impact negatively on service users and carers. In rural settings especially (Taylor and Donnelly, 2006 on Northern Ireland), these may include lack of running water, heating and functioning toilets. Both studies reported general squalor and filth, and rotting food. Comments from home care workers and managers reiterate the difficulty of balancing the client's preferences and privacy with their view of what is acceptable and healthy; and the problem that home care commissioners concentrate on personal care, although many older people cannot manage housework and laundry tasks. **(REC 1.5.3, 1.5.4 and 1.5.9)**

	4.6 The home as a hazardous workplace There is qualitative evidence of moderate quality from Northern Ireland (Taylor and Donnelly, 2006, +) that home care workers are themselves vulnerable to infection while working in insanitary conditions, as well as to risk of injury through manual handling, aggression or harassment from users and family members, and hazardous environmental conditions and equipment (e.g. electrical). It is not clear that home care workers have knowledge and strategies to deal with these difficulties (which may include refusal to continue the service).(1.5.3 , 1.5.4 and 1.5.9) **4.7 Medication management** There is UK qualitative evidence of poor quality (McGraw et al, 2008, -) in which no raw data was reported) that home care workers are increasingly involved in medication management, and that they encountered difficulties when users or carers refused the medication; did not know what they were for or how vital they were; and had no support from primary care clinicians to enable them to promote adherence. (1.5.1, 1.5.2 and 1.5.8)
Other considerations	The GDG discussed the various perspectives on safety in the home (user, carer, worker), recognising that this is multi-faceted issue. They thought that developing a culture of awareness of all types of risk and hazard in the home, and encouraging and supporting workers to communicate concerns, could be more effective than detailed protocols. They also consistently emphasised the importance of understanding what makes the person using services feel safe, comfortable and in control. Understand the person's perspective could help workers negotiate with the person when aspects of the home environment are considered hazardous. While there was only very limited evidence on medication management – and there is a forthcoming NICE guideline on this topic – the GDG agreed consensus recommendations on this issue, aimed at improving communication between health and social care practitioners.

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Topic/section heading	**Ensuring safety and safeguarding people using home care services**
Recommendations	**Recommendations for home care managers**
	1.5.5 Build a culture in which reporting of safety and abuse concerns is understood as a marker of good care, not just as a negative outcome of poor care. Build such a culture by, for example:
	• stating explicitly, as part of induction training, that safeguarding alerts are part of delivering a responsible home care service and that home care workers play a vital role in helping to safeguard a person using services, and
	• providing case study examples that demonstrate the far-reaching effects of not acting on safeguarding concerns.
	Recommendations for commissioners
	1.5.6 Recognise that safeguarding alerts can be a responsible element of providing home care, given that the home care worker may be the first person to spot abuse and should respond proportionately.
	Recommendations for home care providers
	1.5.7 Home care providers should have policies in place that ensure home care workers are supported through any safeguarding process.
Research recommendations	The following research question is relevant to this topic:
	What safeguarding practices are most effective for improving outcomes?
Review questions	4.1 What are the effects of approaches to promote safe care?
Quality of evidence	Overall, the evidence found on safe care was of moderate quality, and did not provide any material on effectiveness of different approaches. Four qualitative studies highlighted the difficulties of giving safe care in hazardous environments. A survey suggested that recognition of possible abuse was inconsistent, and the IPC (2013) rapid review outlined disincentives to report concerns, as well as a lack of research and evaluation on training programmes and a poor understanding of safeguarding practice in the private sector and in the employment of unvetted personal assistants.
Relative value of different outcomes	There were no studies found which directly measured outcomes of approaches on the safety of people using services and their carers, but there were indications that workforce training to recognise hazards could be helpful (Gershon, 2012).
Trade-off between benefits and harms	The GDG discussed how issues of safe care form a large part of the day-to-day work of providers and can be particularly challenging given the need to balance the rights and preferences of the person using services, with the need to safeguard them, which can be complex, for example, if their chosen carer is suspected of abuse.

Economic considerations	There was a lack of cost-effectiveness evidence in this area. However, ''Feeling safe' was considered as an outcome in the review of care planning approaches; the additional analysis of primary data of the IBSEN study (PSSRU 2014, evidence level +, N=381) measured this outcome as part of the Adult Social Care Outcomes Tool (ASCOT).
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	**4.1 Abuse concerns reported by home care services** There is moderate evidence from a UK evidence review (Institute of Public Care or IPC, 2013, evidence level +/+) that home care services are less likely to report abuse and safeguarding concerns than are staff working in care home settings. Financial abuse (by whom is not stated) is thought to be the most common type of abuse reported in home care. **(REC1.5.5, 1.5.6 and 1.5.7)** **4.2 Training and awareness of abuse among home care workers** There is moderate to good evidence from a UK evidence review (IPC, 2013, evidence level +/+); from a UK qualitative study (Simic et al, 2012, +) and from a UK survey (Bell et al, 2004, +) that understanding, awareness and training concerning abuse among home care staff is uncertain in scope and quality, and may be reported by staff as not satisfactory. Staff who had been involved in abuse inquiries were particularly dissatisfied with the training and support given. **(REC1.5.5 and 1.5.7)** **4.3 Reasons for not reporting concerns about abuse** There is moderate to good evidence from a UK evidence review (IPC, 2013, evidence level +/+) and a UK qualitative study (Simic et al, 2012, +) that home care and other social care staff may be discouraged from reporting concerns because: • There is poor support for staff involved in abuse allegations, which may be very protracted, and may affect present and future employment even if they are exonerated • Home care staff may have no access to an independent source of advice if they have concerns, and therefore fear that any concern may quickly accelerate into a heavy-handed enquiry by the local authority • Local authorities enquiries are thought to be aggressive in their handling of concerns, and inclined to attribute blame • CQC and local authorities regard reporting as a negative measure of bad care, rather than a positive commitment to tackle bad care and neglect. **(REC1.5.5, 1.5.6 and 1.5.7)**
Other considerations	There was extensive discussion about how safeguarding incidents are perceived by different stakeholder groups and the challenges this can pose in respect of reporting and responding to them. Building on the evidence statements, the GDG agreed detailed recommendations based on their concerns about potential under-reporting of safeguarding issues. They discussed the importance of both providers and commissioners taking a balanced view of safeguarding reporting, recognising

	that alerts are only one piece of evidence among a range of information about a service. They emphasised the opportunity provided by the guideline to help build a culture in which safety and abuse concerns (and safeguarding alerts) can be dealt with constructively.

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Topic/section heading	Recruiting, training and supporting home care workers: improving organisational approaches to recruitment, induction, training and support
Recommendations	**Recommendations for home care providers** 1.6.1. Have a transparent and fair recruitment and selection process that: • uses values-based interviews and approaches to identify the personal attributes and attitudes essential for a caring and compassionate workforce, and • ensures workers have the necessary literacy and numeracy skills to do the job. 1.6.2 Consider involving people who use home care and their carers in recruiting and training home care workers. 1.6.3 Ensure that new home care workers are observed at work more than once during their probationary period. 1.6.7 Use feedback from people using the service and their carers to assess training needs for the workforce. 1.6.8 Ensure home care workers have opportunities to refresh and develop their knowledge and skills. **Recommendations for home care managers** 1.6.9 Managers should : • respond promptly to workers when they request support to deal with difficult situations • supervise workers in a timely, accessible and flexible way, at least every 3 months and ensure an agreed written record of supervision is given to the worker • observe workers' practice regularly, at least every 3 months and identify their strengths and development needs • appraise workers' performance regularly and at least annually. The annual appraisal should include a review of workers' learning and development needs, and feedback from people who use the service and their carers. **Recommendations for local authorities** 1.6.10 Develop workforce plans for the home care sector, in collaboration with providers, identifying current and future workforce needs. Include training and how such needs might be met by prioritising available local authority resources in the plans.

Research recommendations	The following research question is relevant to this topic: What are the effects of different approaches to home care training on outcomes for people who use home care services?
Review questions	5.1 What are the effects of workforce training, supervision and support on outcomes for people who use home care services and their family carers?
Quality of evidence	Overall, the evidence on training, supervision and support was poor, because there was no material that directly addressed the review question, and no experimental studies or data on cost-effectiveness. Five of the eight studies considered by the GDG relied on survey material, with two mixed methods studies reporting practitioner views.
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 outcomes associated with different approaches to workforce training, supervision and support. The impact on users and carers was the most important outcome, but no studies were found to demonstrate this.
Trade-off between benefits and harms	The GDG discussion which informed the recommendations identified that there are potentially trade-offs between the level of general versus specialist skills that home care workers have, but a lack of evidence about the most appropriate skill-mix, or impact of different models. The GDG members recognised the potential pitfalls of home care staff acquiring, by default, responsibilities for medical care tasks which they were not adequately trained and supervised to deliver.
Economic considerations	No studies were identified on the cost-effectiveness of workforce training, and the lack of effectiveness studies that used standardised measures on health and wellbeing meant it was not possible to derive any conclusions about likely cost-effectiveness of different training programs.
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	**1.2 Users' views of quality of care** There is good evidence from one UK qualitative (Sykes and Groom, 2011, +) and two UK survey studies; (OPCW, 2012,+; Netten et al 2007, +) that users recognise and value the competence of home care workers, and but some good evidence from the first survey that poor training may compromise the quality of care (OPCW, 2012, +). **(REC1.6.3, 1.6.7, 1.6.8, 1.6.9 and 1.6.10)** **1.3 Users value kind and caring workers and developing relationships** There is good evidence from a number of UK studies, for example, a survey (CQC, 2013, +) and a qualitative study (Walsh and Shutes, 2013, +), consistent over most studies, (e.g. CQC, 2013, +; Walsh and Groom, 2013, +) that users and carers acknowledge and value warm, kind and caring home care workers, and the ability to develop relationships by having continuity of workers. **(REC 1.6.1 and 1.6.2)**

	2.7 Ability to care There is good evidence from one qualitative study (Francis and Netten, 2004, +) that some managers believed that whilst caring skills are 'instinctive', they could be instilled, maintained and assessed through induction and training. **(REC 1.6.1, 1.6.2, 1.6.3, 1.6.7 and 1.6.8)** **5.1 Impact of workforce characteristics on users' perceptions of service quality** There is moderate evidence from one UK survey study (Netten et al, 2007, +) which suggests that older people's perception of good quality home care is positively associated with an older and more highly trained workforce (but the negative association between workers with NVQ2 qualification was an exception to this rule). **(REC1.6.7)** **5.2 Decline in training opportunities for home care workers** There is moderate evidence from two UK survey studies (Rubery et al 2011, +; Hall and Wreford, 2009, +) that the shift of provision from local authority in-house home care services to a mixed economy of providers is associated with difficulties in providing and resourcing training to the home care workforce. Social care workers delivering home care are less likely than those in residential settings to receive adequate induction and additional training (possibly because it is more difficult to organise and release staff time for training). **(REC 1.6.8 and 1.6.10)** **5.4 Training for migrant care workers** There is good evidence from one UK mixed methods study (Cangiano et al, 2009, ++/+) that migrant workers need more support from employers to improve language skills and cultural awareness, delivered in ways which do not compromise their ability to work.**(REC1.6.8 and 1.6.10)** **5.6 Lack of cost-effectiveness studies on training of home care workforce** No studies were identified on the cost-effectiveness of workforce training, and the lack of effectiveness studies that used standardised measures on health and wellbeing meant it was not possible to derive any conclusions about likely cost-effectiveness of different training programs.
Other considerations	The GDG identified that, while there was only limited research evidence from the review on training, there was some relevant evidence from the views and experience data – particularly about the characteristics valued in workers, by people using services - which they used to inform the recommendations. They also agreed on the importance of making wider recommendations about workforce skills and competence, not least because there is no clear agreement on the core skills set needed for home care workers at present. They had extensive discussion about 'good practice' in recruitment, induction and supervisory support based on their experience, which informed consensus recommendations.

	Particularly notable points were: • Workers' induction and ongoing supervision should involve feedback from people who use services and their carers. • Supervision, ongoing support and opportunities for development are critical for ensuring a high-quality service and providers could potentially benefit from a more collaborative relationship with local authorities to think about what could be done at a locality level.

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Topic/section heading	Recruiting, training and supporting home care workers: specific training needs identified by and for the workforce
Recommendations	**Recommendations for home care providers** 1.6.4 Ensure home care workers 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. 1.6.5 Make provision for more specialist support to be available to people who need it – for example, in response to complex health conditions – either by training your own home care workers or through partnerships with specialist organisations. 1.6.6 Ensure home care workers have the knowledge and skills needed to perform their duties safely by providing, as part of the full induction and ongoing training package, specific training on : • what constitutes 'safe' care • identifying and responding to possible or actual abuse or neglect • identifying and responding to environmental risks • safe care policies and procedures. **Recommendations for healthcare professionals working in primary and secondary care** 1.6.11 Liaise with home care workers to provide integrated, person-centred support that promotes wellbeing, particularly for medication management, pain management and tissue viability care. **Recommendations for commissioners** 1.6.12 Consider commissioning training to ensure health and social care practitioners understand how they should collaborate to provide integrated planning and delivery of home care and support.
Research recommendations	The following research question is relevant to this topic: What are the effects of different approaches to home care training on outcomes for people who use home care services?
Review questions	5.1 What are the effects of workforce training, supervision and support on outcomes for people who use home care services and their family carers?
Quality of evidence	Overall, the evidence on training, supervision and support and identified needs of the workforce was of moderate quality, but there was no material that directly addressed the review question. Five workforce surveys and two mixed methods studies considered training and support needs identified by the workforce.

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 outcomes associated with different approaches to workforce training, supervision and support. Qualitative commentary from practitioners does, however, provide persuasive insight into where workers feel they could improve services with adequate training and supervision (e.g. caring for people with dementia and at the end of life).
Trade-off between benefits and harms	GDG discussion which informed the recommendations identified that there are potentially trade-offs between the level of general versus specialist skills that home care workers have, but a lack of evidence about the most appropriate skill-mix, or impact of different models (see Research recommendations). However, GDG members recognised the potential pitfalls of home care staff acquiring by default, responsibilities for medical care tasks in which they were not adequately trained and supervised.
Economic considerations	No studies were identified on the cost-effectiveness of workforce training, and the lack of effectiveness studies that used standardised measures on health and wellbeing meant it was not possible to derive any conclusions about likely cost-effectiveness of different training programs.
Evidence statements – numbered evidence statements from which the recommendation(s) were developed	**2.6 Standards of training, especially in and specialist care** There is moderate evidence from one UK survey (Unison, 2012, +) to suggest that care workers were critical of the standard and amount of training provided and that 41% of care workers had not been given specialist training to deal with their clients' specific medical needs, such as dementia and stroke care. A further UK qualitative study (Duff and Hurtley, 2012, -) found that both staff and managers felt that training in communication with people with dementia, and in responding to anxiety and distress, was needed. **(REC 1.6.4, 1.6.5, 1.6.11 and 1.6.12)** **2.12 Roles and tasks of home care workers** There is good evidence from one UK qualitative study (Cooper and Urquhart, 2005, +) that care workers were uncomfortable when they uncovered potentially serious health problems which they felt unqualified to deal with. Care workers also felt that their visits could lead to further isolation of the older person, because friends and family stopped visiting in the belief that the person's needs were now met. One moderate qualitative study (Patmore, 2004, +) suggested that there was variation in terms of what tasks home care workers are permitted to do, in addition to the normal 'personal care tasks'. In dealing with individual clients, respondents to the UK survey conducted by Hall and Wreford (2007, +) said they found it difficult to deal with issues such as cleaning up messes, challenging behaviours and the death of the clients. **(REC1.6.4 and 1.6.6)**

	5.3 Home care workers' perception of need for training in particular areas
	There is good quality evidence from three UK studies, a survey (Hall and Wreford, 2009, +), a mixed methods study (Cangiano et al,2009, ++/+) and a qualitative study (Devlin and McIlfatrick, 2010, +) that home care staff feel they would benefit from more training in specific topics, such as dementia care and working with families facing death and bereavement.**(REC 1.6.4 and 1.6.6)**
	5.5 Need for some training in health-related areas
	There is moderate to good evidence from three UK studies, a scoping review (Manthorpe and Martineau, 2008, +/+);, a survey (Nancarrow et al, 2005, -); and a mixed methods study (Devlin and McIlfatrick, 2010, +) that social care practitioners working in such services as intermediate care and home-based palliative care often do not receive training and supervision that supports their delivery of basic healthcare for older people living at home with complex needs. There is a need for strategic solutions at all levels to ensure that social care staff and qualified clinical (mainly nursing) practitioners collaborate and complement each other's work. **(REC 1.6.4, 1.6.5, 1.6.6, 1.6.11 and 1.6.12)**
Other considerations	The GDG identified that, while there was only limited research evidence, this was an important area about which to make recommendations, noting particularly that people using home care are increasingly frail and have support needs that often extend beyond 'traditional' personal care tasks. In particular, they thought the guideline should help workers understand when to intervene (and ensure they have the skills and support to do so) and when to signpost or refer to specialist support.
	Consensus recommendations were developed following extensive discussion about the types of common and specialist support needs that affect people using home care; and, the need to ensure people are supported in an integrated way, to address the current problem of workers feeling isolated or insufficiently equipped to deal with the person's needs, and incoherent care provision.

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4 Implementation: getting started

The Guideline Development Group has identified areas in this draft guideline that they think may have a big impact on practice, or which could be difficult to implement. The 3 areas identified as the biggest implementation challenges were:

- Delivering services that support the aspirations, goals and priorities of the person using them (recommendation 1.1.1).
- Working effectively in multidisciplinary teams coordinated by a lead practitioner (recommendations 1.3.1, 1.3.3 and 1.3.4).
- Helping people to determine which care options will best meet their needs and preferences (related to recommendation 1.3.10).

Further details on each of these areas are provided below.

How stakeholders can help us with implementation

During consultation we want you to let us know whether you agree with the 3 areas identified. If not, which other aspects of the guideline will have a bigger impact, or be more of a challenge to implement?

Please also send us suggestions about how implementation challenges could be addressed. You could, for example, share examples of good practice, or provide educational materials or other resources that you have found useful. This information will be used to write an implementation section for the final guideline.

Please use the comments form to send us your feedback.

Challenges for implementation

Delivering services that support the aspirations, goals and priorities of the person using them

Home care providers will need to review how they deliver services to see whether improvements are needed to ensure that they meet individual needs. Many services are built on a 'one size fits all' model and changing this will

1   take time. It is likely to be a complex process because services will need to

2   work across boundaries and be flexible. (Related to recommendation 1.1.1.

3   ***Working effectively in multidisciplinary teams coordinated by a named***

4   ***lead***

5   Multidisciplinary working can be complex and challenging particularly if it

6   involves working across traditional boundaries and professional specialisms.

7   In the case of people receiving home care, a number of people are usually

8   involved in their care and wellbeing (for example, carers, health and social

9   care practitioners with diverse roles and volunteers). Recognising each of

10   these people as members of a multidisciplinary team, each with expertise to

11   draw on when required, and identifying a single lead practitioner for the team

12   needs commissioners and home care providers to change the way they work

13   together. (Related to recommendations 1.3.1 and 1.3.3.)

14   ***Helping people to determine which care options will best meet their***

15   ***needs and preferences***

16   Lead practitioners will need to be confident of their knowledge and

17   understanding of the different care, support and funding options. They should

18   have the necessary skills to help people make informed and appropriate

19   choices. This may involve a significant change in practice for some

20   organisations where people often perceive that the role of the lead practitioner

21   is limited to processing them through a system. Home care managers and

22   commissioners may need to work together to explore how this can be

23   achieved locally. (Related to recommendation 1.3.10.)

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6 Related NICE guidance

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

Published

- Managing medicines in care homes. NICE social care guideline 1 (2014)
- Osteoarthritis. NICE clinical guideline 177 (2014)
- Stroke rehabilitation. NICE clinical guideline 162 (2013).
- Falls. NICE clinical guideline 161 (2013).
- Medicines adherence NICE guideline CG136 (2011).
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- Chronic fatigue syndrome/myalgic encephalomyelitis. NICE clinical guideline 53 (2007).
- Dementia. NICE clinical guideline 42 (2006).
- Parkinson's disease. NICE clinical guideline 35 (2006).
- Nutrition support in adults. NICE clinical guideline 32 (2006).
- Type 1 diabetes. NICE clinical guideline 15 (2004).
- Multiple sclerosis. NICE clinical guideline 8 (2003).
- Multiple sclerosis. NICE clinical guideline. Publication expected October 2014.

In development

NICE is developing the following guidance:

- [Older people with long-term conditions](). NICE social care guidance. Publication expected September 2015.

- [Transition between inpatient hospital settings and community or care home settings for adults with social care needs]() NICE social care guidance. Publication expected November 2015

- [Transition between inpatient mental health settings and community or care home settings]() NICE social care guidance. Publication expected August 2016

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9 A technical team at the NICE Collaborating Centre for Social Care was

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7 *Declarations of interests*

8 The following members of the Guideline Development Group made

9 declarations of interest. All other members of the Group stated that they had

10 no interests to declare.

Committee member	Interest declared	Type of interest	Decision taken
Ajibola Awogboro	Director: Rembola Social Enterprises	Personal pecuniary interest	None
Ajibola Awogboro	Assistant Director Business Support and Commissioning - Royal Borough of Greenwich	Non-personal pecuniary interest	None
Bobbie Mama	Inspector at the Care Quality Commission	Non-personal pecuniary interest	None
Nicola Venus-Balgobin	Project Manager; Older People with Dual Sensory Loss Awareness program, Sense, the leading national charity for people who are deafblind. This post is funded by the Department of Health	Non-personal pecuniary interest	None
Bridget Warr	CEO of the United Kingdom Home Care Association (UKHCA), the professional association for home care providers from all sectors, (employed	Non-personal pecuniary interest	None

	for four days per week). Chair of two boards/committees at Sense and Chair of NHS England Continuing Health Care IRPs (SouthWest)		
Miranda Wixon	Director: The Home care Partnership Ltd. Chair: Ceretas (Voluntary). Chair: Brent Healthwatch (voluntary). Trustee: Action on elder abuse (Voluntary	Personal pecuniary interest	None
Max Wurr	Employer of City and County Healthcare Group. As of December 2013, I also hold an equity stake in the company.	Personal pecuniary interest	None
Max Wurr	Senior manager of City and County Healthcare Group, a group of domiciliary care providers that collectively constitutes one of the largest providers of domiciliary care services in the UK	Non-personal pecuniary interest	None
Max Wurr	I am a Board member of the United Kingdom Homecare Association	Personal non-pecuniary interest	None

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8   Glossary and abbreviations

Abbreviations

Abbreviation	Term
ADL	Activities of daily living
ANOVA	Analysis of variance
ASCOT	Adult Social Care Outcomes Toolkit
CG	Comparison Group
DP	Direct payment
EQ-5D	EuroQol: a standard health measure that allows the calculation of quality-adjusted life years (QALYs)
FACE	Functional Analysis of Care Environments which is a range of commercial assessment tools including a tool to assess the needs for telecare; the tools produced by 'FACE Recoding & Measurement Systems'
GHQ	General Health Questionnaire
GLM	Generalised linear model
GP	General practitioner
Hrs	Hours
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
IG	Intervention group
lb	Lower bound
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)
Q	Quarter
RCT	Randomised controlled trial
SCRQOL	Social care-related quality of life
SD	Standard deviation
SE	Standard error
up	Upper bound
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.

1 About this guideline

2 What does this guideline cover?

3 The Department of Health (DH) asked the National Institute for Health and
4 Care Excellence (NICE) to produce this guideline on Home care (see the
5 scope).

6 The recommendations are based on the best available evidence. They were
7 developed by the Guideline Development Group (GDG) – for membership see
8 section 6.

9 For information on how NICE social care guidelines are developed, see The
10 social care manual.

11 Other information

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

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