

**Personal care and practical support at home: a systematic review of older people's views and experiences**

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## **Abstract**

### **Purpose**

Considering the views of service users is important to identify their needs as this helps providers to develop appropriate and responsive services. For older people receiving home care, recognising their needs is the first step towards supporting them to maintain independence and promote wellbeing.

### **Design/methodology/approach**

A systematic review was conducted in 2014 to explore the personal experiences of older people in England about the care and support they received at home. Studies published between 2004 and 2013 were identified from bibliographic databases and websites.

Seventeen studies satisfied the inclusion criteria. Data were extracted using a standardised coding tool and narratively synthesised. Study quality was evaluated.

### **Findings**

Nine themes were identified. Older people valued an approach that was person-centred, flexible, and proactive to respond to their changing needs and priorities, focusing on what they can or would like to do to maintain their independence. Allowing time to build trust between older people and their care workers helped to realise older peoples' aspirations and goals. Practical help to promote choice and reduce social isolation was perceived to be as important as personal care.

### **Practical implications**

Evidence from this review contributed to the development of a social care guideline on home care, and informed key practice recommendations for care providers in England.

### **Originality/value**

This review highlighted the value older people place in person-centred care incorporating practical help both inside and outside the realm of personal care.

**Keywords**

Older people, personal care, practical support, views and experiences

**Paper type**

Systematic review

## **Introduction**

Several reports have raised concerns about the quality of home care services for older people in the United Kingdom (UK) (Equality and Human Rights Commission, 2011, Care Quality Commission [CQC], 2011). Cited examples included disregard for old people's privacy, dignity and choice; limited access to information; poor care coordination; frequent staff changes and poor staff understanding of user preferences and issues related to safeguarding including abuse and neglect (CQC, 2011).

The Care Act (2014) was introduced amid a complex and rapidly evolving landscape of demographic shift to an ageing population that is putting pressure on public services. This Act set mandatory guidance relating to new national eligibility criteria for access to adults care and support. Despite the rising demand in care needs, there have been year-on-year reductions in local authority-funded care and fewer hours of care being provided (UK Homecare Association [UKHCA] 2012, 2016). It has been argued that publicly funded home care has been limited to only those with the highest care needs rather than to all who need or would benefit from such a service (CQC, 2011; UKHCA, 2012, 2016).

In the UK, home care (also known domiciliary care) refers to a range of services that can be offered to people who require health and social care support, so they can continue living in their own homes. Depending on the person's circumstances, Local Authorities (LA) or health services can fund either all or part of a person's home care package. It can also be paid for by the person using the service in part or full. Support can be delivered on a short or long-term basis and may vary from brief visits to provide help with specific tasks, or comprehensive 24-hour support. It usually involves assistance with activities of daily living,

personal care (such as help with washing or toileting), and may include help with domestic tasks like cooking, cleaning and shopping (NHS Choices, 2015). Those who live alone are likely to be particularly dependent on their home care support and many are also supported by unpaid family carers (Carerstrust, 2015). People aged 65 or older accounted for 79% of users of home care service funded by LA in 2014-15 (UKHCA, 2016, NHS Digital, 2015).

The cost of care is subject to regional variation depending on the quality of the accommodation and facilities offered. In England, the weekly average cost of care per adult for long-term residential care in London was estimated to be around £628, rising to £881 if nursing care was included (NHS digital 2016; Laing and Buisson, 2017). The weekly average cost of home care varied from £430 as provided by local authority to £200 as provided by the independent sector, with a weighted average of £17 per hour (NHS Digital, 2016). In 2014-15, 96% of all home care funded by LA in England was delivered by the independent and voluntary sector (UKHCA, 2016) and £5.09 billion was spent on residential care and £2.03 billion on home care in 2015-16 (NHS Digital, 2016). Comparison of expenditure between residential care and home care costs illustrates the potential value of enabling people to stay in the community rather than in residential settings. Other funding options include a personal budget in the form of a direct payment from LA to the individual to purchase care instead of using council-arranged services (NHS Choices, 2018), and self-funders who choose to pay for all their care and support from their own private resources. Changes in social care funding reforms following the introduction of the Care Act are now postponed till 2020 (Department of Health and Social Care, 2016) and this will have considerable resource implications for LA as home care providers and for people accessing home care services.

Under the 2014 Care Act, LA has a duty to help people meet needs to achieve the outcomes that matter to them in their lives and which in turn promote/maintain their wellbeing and independence. These outcomes will vary from one person to another because each individual will have different interests, relationships, demands and circumstances within their own life. To help people to achieve these outcomes, consideration of their views, based on personal experiences of care and support as service users, and the extent to which they feel supported to live their life as they want to, is therefore of key importance. To date, there has been no published systematic review of evidence regarding views and experiences from older people about the care they received at home. This review was conducted in 2014 as part of a series of systematic reviews to inform the development of a national guideline on home care, published in 2015 (NICE, 2015a). It aims to explore what older people and their family carers think about current practice in England, to assess how their diverse needs can be met and to identify key areas for improvement in the service.

## **Methods**

We conducted a systematic review drawing on primary research literature.

### *Inclusion and exclusion criteria*

- Population: People aged 65 years and older, receiving home care services, and their family carers.
- Context: within the broader context of social care - personal care and practical support at home provided by social care practitioners;
- Intervention/Setting: home care delivered in the older person's home.  
Studies involving residential care home residents or related to home care

reablement services and the medical management of health conditions at home were excluded.

- Outcomes: data-driven, including service user satisfaction; quality of care; choice and control; involvement in decision-making; dignity and independence; quality of life;
- Language: English only;
- Country: UK only;
- Search date: 2004 to 2013;
- Type of evidence: empirical studies with qualitative and quantitative data reporting views of older people and their family carers about home care service they received.

### *Search strategy*

A broad literature search was undertaken on 16 bibliographic databases to identify empirical studies from research-active organisations spanning social care, health and social science research, until November 2014, including: the Applied Social Sciences Index and Abstracts, Cochrane Library databases, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Econlit, EMBASE, Health Management Information Consortium (HMIC), International Bibliography of the Social Sciences, Library and Information Science Abstracts, Medline, PsycINFO, Sociological Abstracts, Social Policy and Practice (which includes AgeInfo and Social Care Online), Social Services Abstracts, Social Work Abstracts, Social Science Citation Index, and Worldwide Political Science Abstracts. The database searches were supplemented by searching over 30 online sources, including websites of research-active organisations, specialist registers and databases during January 2013, including AgeUK,

GeroLit, Evidence Database on Aging Care, Joseph Rowntree Foundation, NHS Evidence, and the Nuffield Trust.

The literature search was designed and conducted by the information specialist (CS) in collaboration with the other members of the review team. The searches were based upon retrieving research citations that contained the following two concepts: 1) the setting or intervention of "home care" and 2) one or more of the population groups of "older people, 65 years and over", "carers", "workforce" and "social care organisation". Examples of search strategies are available (NICE, 2015a). Screening of records was undertaken by one reviewer, following double-screening of 10% of the samples, to ensure consistency of screening between reviewers. Each study was critically appraised for quality and relevance to the review question, and relevant data was extracted by two reviewers (either IK or DR). These steps were quality assured by double-coding (by both IK and DR) of a random sample of papers. In addition, a further random sample of 10% of included studies was quality assured by counter-checking by a senior reviewer. Where independent decisions were inconsistent, agreement was reached by discussion and consensus among the review team.

#### *Data extraction and study quality assessment*

Screening, data extraction and analysis of the included studies was undertaken within EPPI-Reviewer 4.0, a systematic review management tool (Thomas and Brunton *et al.*, 2010). All studies were appraised using NICE Quality Appraisal Checklists outlined in the NICE social care guideline manual (NICE, 2014b). Included studies were rated ('++', '+' or '-') individually to indicate their quality, based on assessment of risk of bias, appropriate to the study

design. The rating was based on the number of criteria fulfilled, and how likely unfulfilled criteria could alter the study's conclusions. These criteria considered internal validity such as methods of data collection, analysis and reporting; and external validity, based on whether the findings can be applied to similar contexts such as the home care setting, and similarity of the population in the UK. A '++' rating indicates that all or most of the checklist criteria have been fulfilled, where they have not been fulfilled the conclusions are very unlikely to alter; '+' indicates that some of the checklist criteria have been fulfilled, where they have not been fulfilled, or not adequately described, the conclusions are unlikely to alter. A '-' indicates that few or no checklist criteria have been fulfilled and the conclusions are likely or very likely to alter (NICE, 2014b).

### *Data synthesis*

We adopted a narrative synthesis approach and sought to explore patterns in the data and identify related concepts within the studies. As there was corroboration and considerable agreement across studies about what mattered to older people and their families, findings were grouped together under similar themes.

## **Results**

### *Study selection*

After removal of duplicate records, our initial search identified 21,402 records. These records were screened against our eligibility criteria and 17 studies were included in this review (see Figure 1).

< Insert Figure 1 about here >

### *Study characteristics*

All of the included studies were conducted in the UK and published between 2007 and 2013, involving over 16,000 older people aged between 60 and 90 years and their family carers. Of the 17 studies, six were journal articles and eleven were reports from various organisations. There were six qualitative studies, five quantitative survey studies, and six mixed methods studies. Two papers reported different aspects of care involving the same population of older people with dementia. Three studies specifically related to experiences of older people receiving home care which they wholly or partly managed or funded, on a direct/personal budget for older people with dementia, or individual budget scheme. One study targeted older people from black and minority ethnic backgrounds. The evidence was generally of medium to low quality. The characteristics and quality of the studies are shown in Table 1.

< Insert Table 1 about here >

### *Views and experiences of older people and their family carers*

The nine themes identified shared some degree of overlap between them and they reflected older people's wish for personalised care and practical help.

Theme 1- Characteristics/competency of home care workers

Professionalism of home care workers was a characteristic deemed important by older people (Sykes and Groom, 2011), including having the right knowledge and skills. A survey found that 77% of service users said that this was 'always' or 'often' the case with their care workers, noting that where workers were poorly trained, this had compromised the quality of support they received (OPCW, 2012). Care workers having good knowledge and understanding of older people's routines was appreciated both by the people who received care and their families. They valued care workers who demonstrated certain qualities such as kindness friendliness and gentleness (CQC, 2013). Another survey found that some older people associated both an older (aged over 40 years) and a more trained workforce with better care provision (Netten *et al.*, 2007). This study also showed an association between poor service quality and staff trained to National Vocational Qualification (NVQ) level 2 ( $p < 0.001$ ), which may reflect the fact that younger, less experienced workers are more likely to have taken NVQ courses at entry.

## Theme 2- Principles of 'good' home care: promoting independence

Older people and their family carers felt that having control over their lives was necessary in order to maintain independence. The potential benefit of home care services in terms of reducing isolation and loneliness was important to them. Some older people commented positively when they felt that staff supported their choice and independence by helping them to do as much as they could for themselves (*"Although I am not well I still feel am in control as they ask me what I would like them to do"* CQC, 2013: p. 19). One survey found that 85% of service users said that they could not manage at all without the help from their care workers, and 29% said that the help they received made them 'a lot more independent' than they had been (DHSSPS, 2010). Home care service was much valued by people with

dementia and their family carers as it helped them to become less dependent, be active in the community, and remain living in their own homes (Quince, 2011).

### Theme 3- Person-centred care: need to being listened to and respected

There were conflicting experiences on whether older people felt they were listened to and respected, and whether they felt that their choices and decisions were taken into consideration in planning their care. Older people from minority ethnic backgrounds said that good communication and 'being listened to' was central to good care, as was being treated with dignity and respect (Cattan and Giuntoli, 2010). One survey found that 72% of older people receiving home care felt that they were 'always' or 'often' listened to but that their choice had not been incorporated into the care plan (*'My opinion counts for nothing'*) (OPCW, 2012: p. 9). In another study, 89% of older people reported that they had always been treated with dignity and respect but 16% also reported that they were not involved in the decision-making process about their care plans (DHSSPS, 2010). In the same study, 56% felt they were only sometimes or never told in advance about changes in their care service. Older people said that lack of interest in, or respect for, their views left them feeling that their care was not designed to meet their personal needs: they felt *'like a number'* (Sykes and Groom, 2011: p. 30). A national report found that older people's changing needs were not often recognised (*'My needs varied, some care workers saw it, some didn't'*) (CQC, 2013: p. 27). Conversely, the same report also found that older people's needs and abilities were reviewed regularly to ensure they received the right level of assistance and care (*'I always know what's going on, because they say what they are doing'*) (CQC, 2013: p. 18).

### Theme 4 - Person-centred care: practical support and flexibility of care

Older people would like their care be more holistic and take into consideration social and non-health related tasks. For example, 30% of respondents said that there was something they would like their care workers to do for them which they did not currently do, such as household 'odd jobs', management of personal affairs, outings and activities enabling socialising, recreation and leisure (Clough *et al.*, 2007; PCC 2012). Older people also felt that practical support from care workers, such as taking on minor household chores, would help them to become more independent; as 30% of them paid for additional help and relied on family carers, mostly with practical tasks (PCC, 2012). Flexibility in providing care was much appreciated, for example by allowing staff to take older people shopping rather than doing the shopping for them (Seddon and Harper, 2009). Another study found that 80% of older people said that the availability of a handyperson service was an important factor that enabled them to live at home (Brannelly and Matthews, 2010).

#### Theme 5 - Person-centred care: barrier to communication

There were concerns about use of different languages being a barrier to communication.

In one study, older people and their family carers from 10 ethnic communities said that they were worried about language barriers hindering their ability to communicate their needs and preferences to English speaking care staff (Cattan and Giuntoli, 2010; London Assembly, 2010). Similarly, care provided by non-English speaking workers was also a concern and some older people felt uncomfortable when care workers spoke amongst themselves in a language other than English (Sykes and Groom, 2011).

#### Theme 6 - Person-centred care: time to care and build working relationship

The potential benefit of home care services in terms of reducing isolation and loneliness was well-acknowledged. One survey found that 77% of older people said that their care workers made them feel less lonely (DHSSPS, 2010). Most family carers also viewed home care staff positively and felt reassured by their presence (PCC, 2012). However, despite positive comments from 72% of older people that the number of hours of care allocated to them was satisfactory (DHSSPS, 2010), there were concerns regarding short visiting slots. In one study, 16% of older people did not feel that their needs had been met, and they most commonly attributed this to a lack of time (PCC, 2012; CQC, 2013). There were reports of care workers rushing through their practical tasks leaving little time for conversation, the latter deemed central to building trust and rapport between the carers and the people they cared for (Sykes and Groom, 2011). Some older people felt that short time slots undermined the concept of person-centred care (London Assembly, 2010).

Support packages that incorporated 10 or more minutes of travel time between appointments into the care workers' paid hours was associated with significantly higher quality care ( $p < 0.001$ ) (Netten *et al.*, 2007). Similarly, older people felt that their care had been compromised when workers' travel time had to be taken from their contact time together (OPCW, 2012). About 74% of old people reported having been asked what visiting times would be convenient for them (DHSSPS, 2010), but that often their preference could not be accommodated because the times available for visits often varied from day to day, according to family carers of older people with dementia (Quince, 2011). Some evening visits, for example, took place very early in the late afternoon or evening, meaning that the older person had to go to bed before they wished to (Sykes and Groom, 2011).

## Theme 7 - Person-centred care: continuity and consistency

Older people preferred their care to be delivered by care workers familiar to them and in whom they could trust (Sykes and Groom, 2011). Only 35% of older people said that their care workers were always familiar to them (OPCW, 2012), whilst another report found that 39% of older people said that they always saw the same care workers (DHSSPS, 2010). Older people were generally positive about their regular care workers but many felt they have limited choice with regard to new and unfamiliar workers arriving at their home (*'... we have had over 25-30 [care workers] since they started coming'*) (CQC, 2013: p. 21). Some older people had received no warning when their care worker was changed (Sykes and Groom, 2011). Having to explain care needs to each new member of staff was frustrating and could be particularly upsetting for older people with communication difficulties, for example, stroke survivors (London Assembly, 2010). Reliability of care workers was a concern. A report found that 69% of older people said that their care worker arrived punctually (DHSSPS, 2010), but some were left in distress when changes to visiting times were not communicated in advance (OPCW, 2012).

## Theme 8 - Person-centred care: outcome-focused approach

Outcome-focused care aims to achieve the aspirations, goals and priorities identified by the service users (Glendinning, 2006), whereas task-focused care is the division of care needs into time allocated components, measured by the completion of the tasks rather than the outcomes. A pilot study found positive effects on psychological wellbeing, as well as a significant reduction in levels of personal concern scores (e.g., loneliness, loss of independence, feeling a burden) among older people who received outcome-focused care when compared with those who received the task-focused care irrespective of their physical

health status (Gethin-Jones, 2012a). A follow-up study, based on 20 older people, was conducted to collect their views on these two models of home care (Gethin-Jones, 2012b). Appropriate outcomes were initially identified by agreement between older people and the care workers, allowing the former flexibility, as a means of exchange, to save allocated hours (sometimes known as 'timebanking') to be used at a later date to achieve the desired outcomes. Examples included older people being supported to go to places they wanted to outside the home, seeing football matches, meeting friends/hosting visitors at home, or just sitting in the garden. One lady was able to bank enough time to be taken to visit her husband's grave and to tidy up the nearby ground which had become overgrown. This study suggested that the option of timebanking had a positive impact on older people's quality of life because it had the potential of reducing loneliness, social isolation, and a lack of purpose in the world, which were common concerns among older people, especially those with little support from their immediate family (Gethin-Jones, 2012b). Care in which workers were governed by task lists to be completed within allocated time slots lacked the flexibility to respond to people's changing circumstances, needs or preferences, also likely to miss the opportunity for engagement between the care workers and the older person to establish a good working relationship (Gethin-Jones, 2012b). In another study, older people found their care plans to be too rigid in the context of their changing circumstances and priorities. They felt that, when the needs arise, shifting the focus away from care plans and record-keeping to helping them achieve desired outcomes should be considered to ensure that home care remained responsive to their fluctuating needs and aspirations (Sykes and Groom, 2011).

Theme 9 - Person-centred care: Managing own budget to organise care

One of the ways of exerting choice and control is the use of personal budget to manage and fund a person's own care as these schemes enabled them to organise varied and flexible support. A personal budget is the amount of money the local authority allocates for the individual's care, based on its assessment of his/her needs. Older people were able, for example, to use allocated funds to purchase equipment, or fund hobbies, respite and leisure activities, thus promoting wellbeing and independence (Glendinning *et al.*, 2008). To explore older people's experiences of using their individual budget (IB) for home care, Moran *et al.* (2013) interviewed 40 older people and their proxies and reported that some older people and their families found it stressful to deal with the administrative responsibilities of employing staff, doing tax returns, and were anxious about overspending. Subsequent analyses, based on a sample of 263 older people, found no significant difference in ASCOT outcomes (Adult Social Care Outcomes Toolkit) (Netten *et al.*, 2011) between the IB and non-IB group at 6 months, albeit a relatively short period of follow-up (Moran *et al.*, 2013).

Self-funders, who pay for all their care and social support themselves, have most control to 'buy in' care and support services they want. However, one study showed that though self-funders were able to ensure a more consistent and flexible service by organising it themselves, they found the administrative responsibilities burdensome (Ekosgen, 2013).

Direct employment of personal carers/assistants could benefit people with dementia who needed social activity, flexible approaches and assistance with practical issues.

Nevertheless, one study found a general lack of information and support for people with dementia and their family carers to arrange and manage direct payment schemes (Lahey and Saunders, 2011).

## **Discussion**

This review on older peoples' views and experiences as recipients of home care services found both positive and negative comments, highlighting areas where existing support worked well and where improvement would be needed. Their perspectives had a unique value 'in its own right', giving a voice to older people who value an approach with greater focus on practical help and flexibility to support their changing needs and priorities.

Our findings showed that being treated with respect and dignity, having consistency and flexibility of care were perceived as the principal aspects of 'good' home care. While older people often expressed appreciation of the warmth, knowledge, kindness and professionalism of their care workers, there was also evidence that some did not feel adequately 'listened to', did not have sufficient access to information and choices and did not feel involved in the decision-making process about their care plan. Short visiting slots to carry out essential tasks which only recognised basic physical needs such as washing and dressing and feeding were perceived by older people to be insufficient, and an undignified and impersonal way of delivering care. Scheduling sufficient travel time between visits for care workers would help to alleviate this time deficit. Missed and delayed visits, or a change of care personnel, which was not communicated to the older person before the visit, caused anxiety and distress to older people, especially those who lived alone. It is understandable that older people in vulnerable circumstances prefer their care provided by someone they know and not be faced with a series of strangers in their own home to carry out intimate personal tasks. Options for older people 'banking' their time in exchange for activities such as outings and visits was found to have a positive effect on their psychological wellbeing (Gethin-Jones, 2012a; 2012b). The wider use of an approach which permits care workers to

carry out activities outside physical personal care, according to the wishes of the older person, could deliver valuable benefits in combatting social isolation, establishing more human contact time and connection with the wider world.

Under the personalisation agenda, the UK government policy is giving older people (aged 65+) more control over the provision of social care and support services to help them live independently in their own homes. As this 'self-directed' support policy progresses nationally, the uptake of direct payments is likely to increase (UKHCA 2016). There is some evidence that the number of people self-funding their own home care has increased (Baxter and Glendinning, 2014). Older people, in purchasing services directly – irrespective of whether funds are their own or from statutory services – said they found the administrative responsibilities of organising their own support and managing their budget stressful. Evidence from this review showed that the lack of access to information, advice and support in planning and managing budget were perceived to be barriers for older people and their families wishing to exercise more choice and control over the services they preferred.

Older people are especially vulnerable to loneliness and social isolation which are associated with reduced quality of their lives, and this can have a serious impact on their health (Nicholson, 2012; Tomaka *et al.*, 2006). It is important for practitioners to recognise that people who use home care services often need support that goes beyond their personal care needs. To be supported to do 'ordinary things' (such as taking a walk, visiting friends, eating out) promote the feeling of connectedness to the outside world and a sense of wider wellbeing. This review suggests that the key features of an approach which works well are

those which focus on advancing the outcomes that matters to the person concerned. Such approaches could usefully include:

- Mechanisms to facilitate choice and control to ensure that older people to become active, rather than passive recipient of their care;
- Support that is professional, dignified and culturally sensitive, where care workers are ready to listen and have a respect for the older person's wishes, recognising that there are changing priorities in what people want or need;
- Sufficient time for care workers and older people to develop a working relationship built on trust and rapport;
- Coordination of a reliable and consistent service to minimise the anxiety and distress caused, such as when visits are late, delayed or missed;
- A greater focus on practical help and flexibility to support old people's changing needs and priorities, such as 'banking' time to be used in different ways, according to people's wishes and preferences;
- Access to information, help and advice to maximise care choice and ongoing support with budget planning

### *Limitations*

Quality of the evidence was generally low (see Table). The studies were often poorly reported with insufficient contextual and methodological details provided to be certain of the strength of the evidence. Response rate to surveys was low and unclear. It was not always possible to distinguish if the views expressed were from the older persons themselves or from their family members. In the two studies involving older people with dementia, family carers' views dominated as they spoke as the older person's proxies whose

views may not accurately reflect those of the older person they looked after. In addition, there was a high likelihood of recall bias inherent in self-reported data, especially from respondents who were self-selected, as was the case with the participants in our included studies.

There were potential biases in the review process. We did not explicitly examine the different health status, living conditions and unpaid family support networks available to the older people as these factors are likely to affect their care need profile, and would directly or indirectly influence their views and perceptions. Some bias in the review process may also have arisen from inclusion of studies with insufficient information. We included only studies conducted in a 10-year period to reflect recent care practices in England, and to ensure the number of outputs was manageable. Although this review aimed to examine views on home care services in England, we included four studies from Wales and Northern Ireland to broaden our perspectives within the UK, aware that the social care system in these two regions works slightly differently from those in England. The inclusion of views and experiences from non-UK studies would have given this review a universal picture of the values and aspirations older people cherish as the essence of their care. However, the context differences and variations in what constitutes home care across different countries may limit the applicability of the findings.

### *Implications for practice*

Person-centred care is now central to the health and social care policy in the UK, enshrined in the Health and Social Care Act (2012). It has been projected that the population aged over 65 years will grow over the coming years, both in real terms and as a percentage of the

total population (The Office for National Statistics, 2018). The rising eligibility thresholds for local authority-funded social care combined with a growing ageing population means that the number of older people being cared for in their own homes is set to increase well into the future. As individual needs and priorities vary with advancing age, the intensity and range of their care and support needs would vary. Older people's wish for more control and independence can cause tension with the need for security, care and support. There is unlikely to be a 'one size fits all' solution. The incorporation of practical support and help to promote choice is much appreciated by older people and can be complementary to personal care. If homecare is to be person-centred and proactive to correspond with older people's priorities and preferences, it would have a considerable bearing on how the services will be purchased, provided and regulated. Accommodating the diverse needs of older people will necessitate a new way of organising their care. The challenges lie in setting targets for what is achievable within the constraints of funding for social care now and in the future. The reconsideration and delay in social care funding reforms until 2020 will further exacerbate these challenges in the UK. Similar situations are likely to be experienced in other European countries where the dominant model for care and support for older people is 'ageing in place', helping older people to stay in their own homes for as long as possible (Centre for Policy on Ageing 2014). Finding viable options to secure a long-term future in adequately funding the care and support needs of the current generation of older people remains a formidable policy issue.

Evidence from this review contributed to a series of systematic reviews conducted to inform the development of the NICE social care guideline on *Home care: delivering personal care and practical support to older people living in their own homes*, published in 2015 (NICE,

2015a). This guideline focuses on ‘what works’ and considers how home care in England should be planned and delivered; and addresses how those responsible for managing and providing home care should work together to deliver safe, high-quality services that promote independence and support older people to do the things that are important to them. It provides good practice recommendations aimed at social care practitioners and providers on key areas in the planning and delivering of home care, and they reflected strongly a person-centred approach to foster independence and wellbeing, a shift to finding solutions rather than providing services (NICE, 2015a). Implementation to encourage and promote the uptake of this guidance in practice in England is in continuous progress.

#### *Implications for research*

There is a need for further research of robust design to gather good quality views data from older people as recipients of home care, in particular from diverse populations such as older people from ethnic minority backgrounds, and those with intellectual or physical disabilities. This would expand the current evidence base and inform the development of future studies to investigate the impact of different intensities of home care packages on outcomes for older people with a broad range of care and support needs. To address these gaps and uncertainties identified in the evidence, key research recommendations were proposed in the NICE social care guideline on *Home care* that would benefit from future research (NICE, 2015a).

#### **Conclusions**

A home care service which works to meet the diverse needs and aspirations of older people needs to be considered in the wider context in which many service components and

professional values come together to enable and support older people to maintain control of their lives, to stay living in their own homes and maximise independence. This systematic review highlighted the value older people place in person-centred care incorporating practical help both inside and outside the realm of personal care. This approach will need to be designed, delivered and reviewed in a way that puts older people, as recipients of support, in the centre and in control of the process by which they receive their care.

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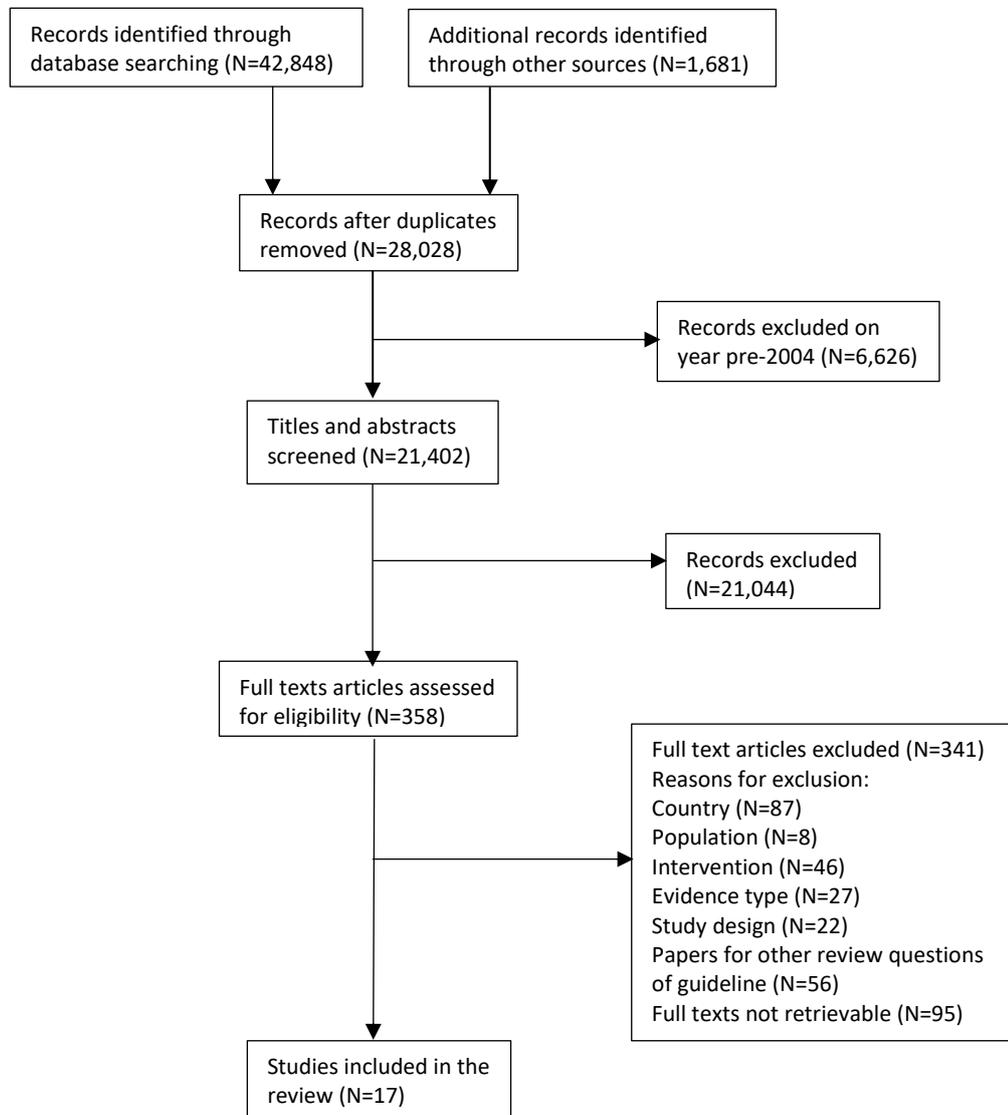
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\* Studies included in this review

Figure 1. Study flow diagram



**Table 1. Views and experiences of older people: characteristics of included studies**

	Author/ country/ study design	Aims of study	Participants	Method of data collection/analysis	Main findings	*Overall quality assessment
1.	Brannelly and Matthews 2010  England  Survey	To evaluate users' perceptions of the Handyperson Service	Population: Older people receiving home care  Sample size: • Survey= 75/131 (57% response rate) • Interview= 19 ( no findings reported)  Sample characteristics: • Age= mostly aged over 76 • Gender= 79% female • Ethnicity=93% white	• Survey	Nearly 80% credited the service as being an important factor enabling them to remain living at home.	Internal validity: –  External validity: +  Overall quality assessment: –
2.	Cattan and Giuntoli 2010	To identify views and support needs perceived to be important by older people, their families	Population: Older people receiving home care and their	• Focus groups and in-depth interviews • Development of key themes.	<i>What needs to change?</i> Concerns about unmet needs: • Support from providers not well co- ordinated	Internal validity: +  External

Author/ country/ study design	Aims of study	Participants	Method of data collection/analysis	Main findings	*Overall quality assessment
England  Qualitative study	and carers	<p>family carers.</p> <p>Sample size:</p> <ul style="list-style-type: none"> <li>• Focus groups=older people (N=137); family carers (N=33);</li> <li>• In depth interviews= older people (N=38); family carers (N=15).</li> </ul> <p>Sample characteristics:</p> <ul style="list-style-type: none"> <li>• Age=69% aged 65 to 90 years;</li> <li>• Gender=74% female;</li> <li>• Ethnicity: from 10 ethnic communities (African Caribbean, n=7, Bangladeshi n=19, Hungarian n=9, Indian n=13, Irish n=3, Italian n=21, Pakistani n=34, Polish n=15, Ukrainian n=12 and</li> </ul>		<ul style="list-style-type: none"> <li>• Emotional needs not always considered, and non-English speakers found staff did not ask family carers about their personal preferences and support needs</li> <li>• Some felt they received less service support because their family carers were expected to provide it</li> <li>• Culturally appropriate meals not always available</li> <li>• Being able to trust workers, and have some relief from loneliness</li> <li>• Carers came at the wrong times, e.g. earlier than the older person preferred to go to bed</li> <li>• inflexible and unreliable services.</li> <li>• Communication: information should be available for non-English speakers</li> <li>• Not respecting the dignity of the individual.</li> </ul> <p><i>Poor care standard:</i></p> <ul style="list-style-type: none"> <li>• Poor adherence to hygiene routines</li> <li>• Not tidying up after completion of care tasks</li> </ul>	<p>validity: +</p> <p>Overall quality assessment: +</p>

Author/ country/ study design	Aims of study	Participants	Method of data collection/analysis	Main findings	*Overall quality assessment
		White British n=37).			
3. Clough et al. 2007  England  Qualitative study	To identify barriers to achieving person centred support for older people	Population: Older people receiving home care  Sample size: 7 focus groups with older people (N=79)  Sample characteristics: • Age, gender, ethnicity: not reported	<ul style="list-style-type: none"> <li>• Focus groups</li> <li>• Development of key themes.</li> </ul>	<i>Tasks old people would like home care to include in addition to personal care:</i> <ul style="list-style-type: none"> <li>• Household odd jobs such as cleaning, laundry, basic security (installing smoke alarms, grab rails, etc.), garden maintenance</li> <li>• Management of personal affairs such as managing utilities and correspondence, seeking advice, reading and writing (especially if the person's sight is failing)</li> <li>• Assistance with shopping, collecting prescriptions, and going to hairdresser</li> <li>• Socialising, recreation and leisure - getting out and meeting friends.</li> </ul>	Internal validity: +  External validity: +  Overall quality assessment: +
4. Care Quality Commission (CQC) 2013  England  Mixed	To inspect standards of care by gathering the views of home care service users	Population: Older people receiving home care  Sample size: • Survey and web questionnaires (N=1140);	<ul style="list-style-type: none"> <li>• Survey and web questionnaires</li> <li>• Data analysis method not described</li> </ul>	<i>Main concerns:</i> <ul style="list-style-type: none"> <li>• Late and missed visits</li> <li>• Lack of consistency of care workers</li> <li>• Lack of support for staff to carry out their work</li> <li>• Lack of respect and involvement of users</li> <li>• Failure to address issues around travel time</li> </ul>	Internal validity: –  External validity: +  Overall quality assessment: –

Author/ country/ study design	Aims of study	Participants	Method of data collection/analysis	Main findings	*Overall quality assessment
methods		<ul style="list-style-type: none"> <li>• Telephone interviews (N=2742)</li> </ul> <p>Sample characteristics:</p> <ul style="list-style-type: none"> <li>• Age=75% aged over 65 years</li> <li>• Gender, ethnicity not reported</li> </ul>		<ul style="list-style-type: none"> <li>• Failure to keep people informed about changes to their visits</li> <li>• Poor care planning and documentation of care needs and routines</li> <li>• Lack of regular care review</li> <li>• Limited information provided to people about the choices available</li> <li>• Lack of staff understanding regarding their safeguarding.</li> </ul>	
5. Department of Health, Social Services and Public Safety (DHSSPS) 2010  Northern Ireland  Survey	To describe older people's experiences of home care and its quality, their involvement with care planning and information received	<p>Population: Older people receiving home care</p> <p>Sample size: N=4,321 (out of 9,999 originally surveyed, response rate of 48%)</p> <p>Sample characteristics:</p> <ul style="list-style-type: none"> <li>• Age=83% aged 65-85 years; 17% under 64 years</li> <li>• Gender=69% female</li> </ul>	<ul style="list-style-type: none"> <li>• Survey by postal questionnaires</li> <li>• Descriptive statistical analysis</li> </ul>	<p><i>Information about changes to care plan:</i></p> <ul style="list-style-type: none"> <li>• 44% reported that they had always been told in advance about changes to their home care services</li> <li>• 21% reported that they had never been told in advance about changes to their home care services</li> </ul> <p><i>Involvement in decisions about care plan:</i></p> <ul style="list-style-type: none"> <li>• 84% reported that they were involved in decisions about their home care services</li> <li>• Involvement in the decision making increased with decreasing ability – 'Not able' users (92%) more likely to say they had been involved than 'not</li> </ul>	<p>Internal validity: +</p> <p>External validity: +</p> <p>Overall quality assessment: +</p>

Author/ country/ study design	Aims of study	Participants	Method of data collection/analysis	Main findings	*Overall quality assessment
		<ul style="list-style-type: none"> <li>• Disability=91% have a disability</li> <li>• Ethnicity: not reported.</li> </ul>		<p>really able' (87%) users.</p> <p><i>Information on role of care worker:</i></p> <ul style="list-style-type: none"> <li>• 81% stated that their provider had explained the role of their care worker(s) to them.</li> </ul> <p><i>Written guide to home care services:</i></p> <ul style="list-style-type: none"> <li>• 62% reported that they had been provided with a written guide to the home care services</li> <li>• 'Not able' users (72%) were more likely to say they had been given a written guide than 'not really able' (63%) users</li> <li>• 96% reported that they understood the details the written guide provided about their home care services.</li> </ul>	
6. Ekosgen 2013  England  Qualitative study	To determine the support needs of self-funders	<p>Population: Older people who self-funded their home care</p> <p>Sample size: N=108 older people</p> <p>Sample characteristics: • Age ≥ 65 years</p>	<ul style="list-style-type: none"> <li>• Focus groups, face-to-face and telephone interviews</li> <li>• Content analysis</li> </ul>	<p><i>Needs for information/support:</i></p> <ul style="list-style-type: none"> <li>• Information regarding the recruitment of care and support workers difficult to navigate. <i>"I feel very lost....I want to recruit a personal assistant but I don't know how to go about it properly. (Self-funder).</i></li> </ul>	<p>Internal validity: +</p> <p>External validity: +</p> <p>Overall quality assessment: +</p>

Author/ country/ study design	Aims of study	Participants	Method of data collection/analysis	Main findings	*Overall quality assessment
		<ul style="list-style-type: none"> <li>• Gender= 75% female</li> </ul>			
7. Gethin-Jones 2012a	To examine whether an outcome-focused model for homecare Improves subjective wellbeing	<p>Population: Older people receiving home care</p> <p>Sample size: N=40 (20 received outcome-based home care; 20 receiving time- tasked home care)</p> <p>Sample characteristics:  <ul style="list-style-type: none"> <li>• Age: over 76 years</li> <li>• Sex: 58% females</li> <li>• Ethnicity: not reported</li> </ul> </p>	<ul style="list-style-type: none"> <li>• Questionnaire survey</li> <li>• ANOVA statistical analysis</li> </ul>	<p><i>*Personal concerns scores:</i> Significant improvement in the outcome-focused group when compared with the time/task group (<math>p&gt;0.00</math>)</p> <p><i>Self-rated subjective wellbeing:</i> Those receiving outcome-focused care showed the most significant improvement (no data reported)</p> <p><i>Human contact time:</i> Outcomes-focused care participants received considerably more time spent with home care staff than the time/task group.</p> <p><i>*Examples of personal concerns:</i></p> <ul style="list-style-type: none"> <li>• Not having family support</li> <li>• Constantly different staff</li> <li>• Loneliness; not being able to meet friends.</li> <li>• Being dependent on others or being a 'burden' to their family</li> <li>• Inability to have help to do unremarkable but 'ordinary' things,</li> </ul>	<p>Internal validity: +</p> <p>External validity: +</p> <p>Overall quality assessment: +</p>
England					
Survey					
Linked study to Gethin- Jones 2012b					

Author/ country/ study design	Aims of study	Participants	Method of data collection/analysis	Main findings	*Overall quality assessment
				such as to go into the garden; to hold my grandchild	
8. Gethin-Jones 2012b  England  Qualitative study  Linked study to Gethin- Jones 2012a	To examine self-identified concerns of older people who received outcome-focused and time-focussed models of home care (a follow-up study to Gethin-Jones 2012b)	Population: Older people receiving home care  Sample size: N=20 (10 received outcome-based home care; 10 receiving time-tasked home care)  Sample characteristics: • Age: over 76 years • Sex: 65% females • Ethnicity: not reported	• Semi-structured interviews • Development of key themes.	<p><i>Outcome-focused home care:</i></p> <ul style="list-style-type: none"> <li>• Reduce isolation by ‘banking-up’ time for outings, meeting friends/ receive visits</li> </ul> <p><i>"I feel I have my life back. John [home care worker] has arranged that when I bank up enough hours he comes round and watches some games with me [football matches] ...."</i></p> <ul style="list-style-type: none"> <li>• Better social interaction- <i>"..she (care worker) said it's OK with Doris [wheelchair bound]...I could bring her to see you. I haven't seen Doris since her stroke....it took a bit of sorting out but I see Doris every week, so I don't feel so isolated"</i></li> <li>• Flexibility in care delivery <i>"Do you know it upset me to see the state of my husband's grave it was all overgrown....but Andy (carer) said next time he would bring my gardening tools and tidy it....."</i></li> </ul> <ul style="list-style-type: none"> <li>• Consistency of staff</li> </ul>	Internal validity: +  External validity: +  Overall quality assessment: +

Author/ country/ study design	Aims of study	Participants	Method of data collection/analysis	Main findings	*Overall quality assessment
9. Lakey and Saunders 2011  England  Mixed methods  (Study linked to Quince <i>et</i>	To describe the views of people with dementia and their carers on their use of direct payments and personal budgets	Population: Older people with dementia receiving home care, and their family carers  Sample size: N=40 people with dementia  Sample characteristics: • Age=91% ≥65	<ul style="list-style-type: none"> <li>• Survey and interviews and focus groups.</li> <li>• Data analysis method not described</li> </ul>	<p><i>“ Good.... you get the same people and you feel you can trust them”</i></p> <p><i>Time-tasked home care:</i></p> <ul style="list-style-type: none"> <li>• Lack of flexibility in care delivery <i>“I ask...it’s nice could they just help me to sit out for 10 min, but they just say it’s not on their schedule (care plan) they can’t do it.”</i></li> <li>• Lack of engagement with care workers <i>“They rush in rush out ..... They never ask me how I am or even give me eye contact”.</i></li> </ul> <p><i>Views and experiences on direct payment:</i></p> <ul style="list-style-type: none"> <li>• Direct payment users were more likely than non-direct payment users to report that they had <i>“... received enough information; that the person with dementia is getting all the support they need; and that services made life easier.”</i></li> <li>• Satisfaction with getting specific services such as assistance with domestic work (cleaning and shopping)</li> <li>• Stressful processes in applying for</li> </ul>	Internal validity: –  External validity: +  Overall quality assessment: –

Author/ country/ study design	Aims of study	Participants	Method of data collection/analysis	Main findings	*Overall quality assessment
al. 2011)		years • Gender=not reported • Ethnicity: not reported.		<p>and using direct payments on which there was little information:  <i>“I would need a lot of information and help, especially with accounting and employment.”</i> (Person with dementia)</p> <p><i>“There’s lots of information on the internet, but it’s hard to know what is most relevant. So you’d need support with this.”</i> (Family carer)</p> <p><i>Concerns:</i></p> <ul style="list-style-type: none"> <li>• Social services can use personal budgets to abdicate responsibility</li> <li>• Personal budget not promoted by councils and people don’t know what it is</li> <li>• Information and ongoing support needed to manage personal budgets:  <i>“It is an extra responsibility... it was very upsetting... I did feel very abandoned.”</i> (Family carer)</li> </ul> <p><i>Barriers to take-up:</i></p> <ul style="list-style-type: none"> <li>• Lack of confidence and a perception that they would be ‘too difficult’.</li> </ul>	

Author/ country/ study design	Aims of study	Participants	Method of data collection/analysis	Main findings	*Overall quality assessment
10. London Assembly 2010  England  Mixed methods	To review access to home care for older Londoners	<p>Population:</p> <ul style="list-style-type: none"> <li>• Older people receiving home care and their family carers</li> <li>• Charities and organisations representing older people and care providers</li> </ul> <p>Sample size: N=73 older people and carers participated via: - a 'listening event' and 2 focus groups</p> <p>Sample characteristics:</p> <ul style="list-style-type: none"> <li>• Age=≥ &gt;65 years</li> <li>• Gender= not reported</li> <li>• Ethnicity=33 users and carers were recruited through BME or Irish community</li> </ul>	<ul style="list-style-type: none"> <li>• Included a 'listening event', two focus groups, a 'call for written views'.</li> <li>• Data analysis method not clearly described</li> </ul>	<p><i>Challenges identified:</i></p> <ul style="list-style-type: none"> <li>• The assessment process slow, complicated and poorly managed</li> <li>• Services not responsive to cultural needs, nor an individual's situation or changing needs</li> <li>• Frequent staffing changes leading to lack of continuity of care and older people had to explain their support needs to each new carer</li> <li>• One participant said that 45 different care workers had supported his wife over two years</li> <li>• Information and advice about services available difficult to access.</li> </ul>	<p>Internal validity: –</p> <p>External validity: +</p> <p>Overall quality assessment: –</p>

Author/ country/ study design	Aims of study	Participants	Method of data collection/analysis	Main findings	*Overall quality assessment
11. Moran, Glendinning and Wilberforce 2013  England  Mixed methods	To explore older people's experiences of planning to use their Individual budget (IB) for home care (The IBSEN Study)	Population: Older people using their IB for home care, and their proxies  Sample size: Quantitative analysis (N=263)  Qualitative analysis (N= 40; 9 old people; 19 old people with their proxies; 12 with proxies only)  Sample characteristics: • Age: 60 ->75 years • Sex: 63% females • Ethnicity: 15% Black and minority ethnic (BME)	• Face-to-face and telephone interviews • Framework analysis approach	At 6 months No significant difference between the IB and no IB group in Adult Social Care Outcomes Toolkit (ASCOT) measures: 1. Personal care/comfort 2. Social participation and involvement 3. Control over daily life 4. Meals and nutrition 5. Safety 6. Accommodation cleanliness and comfort 7. Occupation and employment.  <i>Plans for using IB:</i> • To purchase equipments to aid mobility, respite, maintain hobbies, on outings or leisure activities <i>"...either go swimming or museum or an art gallery....'cause I need to get out, you know...."</i>  Advantages of IB • Opportunities for choice and control <i>"..being able to go to church, having someone come in to make the bed and prepare vegetables for me."</i> • Using IB flexibly to 'other things' such as shopping and housework.  Concerns about IB	Internal validity: +  External validity: +  Overall quality assessment: +

Author/ country/ study design	Aims of study	Participants	Method of data collection/analysis	Main findings	*Overall quality assessment
				<ul style="list-style-type: none"> <li>• Anxious about administrative responsibilities with managing the budget, employing staff and over-spending <i>"...will be difficult for, I mean I'm no paperwork person at all."</i></li> <li>• Did not wish to have such worry at their time of life <i>" .....at the moment I haven't got the time and the brain to work out financial details .... I'm quite happy with the arrangement I've got."</i></li> <li>• Support needed with choosing options, recruiting staff, administrative tasks <i>" The paperwork, it was beginning to addle my brain...."</i></li> </ul>	
12. Netten, Jones and Sandhu 2007	To investigate provider level influence on service user perceptions of home care service quality	Population: Older people receiving home care	<ul style="list-style-type: none"> <li>• Questionnaire survey</li> <li>• Multivariate analyses</li> </ul>	<p><i>Older people's perception of quality:</i></p> <ul style="list-style-type: none"> <li>• Higher service quality associated with users younger than 85 years (<math>p &lt; 0.01</math>), and with older people in receipt of at least 10 hours per week of home care (<math>p &lt; 0.001</math>)</li> <li>• In-house providers were perceived as higher quality when compared with independent sector providers (<math>p &lt; 0.001</math>).</li> </ul>	Internal validity: +  External validity: +  Overall quality assessment: +
England		Sample size: N=7935 older people receiving home care			
Survey					

Author/ country/ study design	Aims of study	Participants	Method of data collection/analysis	Main findings	*Overall quality assessment
		<p>Sample characteristics:</p> <ul style="list-style-type: none"> <li>• Age=86% aged ≥75 years</li> <li>• Gender=75% female</li> <li>• Ethnicity=1% BME.</li> </ul>		<p><i>Workforce characteristics associated with higher quality of home care:</i></p> <ul style="list-style-type: none"> <li>• An older workforce (workers over 40 years) was associated with higher quality care, (p&lt;0.001)</li> <li>• A more highly trained workforce (hours of training) was associated with high service quality (p&lt;0.01)</li> <li>• The NVQ2 qualification was negatively associated with service quality (p&lt;0.001)</li> <li>• A higher proportion of care workers employed with the provider for over 5 years was also associated with higher quality (p&lt; 0.001)</li> <li>• Level of turnover in the past year was negatively associated with service quality (p&lt; 0.001)</li> <li>• Higher proportion of workers having guaranteed working hours and higher female wage rate relative to local rates were associated with higher service quality (p&lt;0.001)</li> <li>• Part-time working (less than 10 hours a week) was associated with lower service quality (p&lt;0.01)</li> <li>• 10 or more minutes for travel allowed between visits was associated with higher service quality (p&lt;0.001)</li> </ul>	

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13. Older People's Commissioner for Wales (OPCW) 2012	To describe issues important to older people in receipt of home care in Wales	Population: Older people receiving home care, and their family carers	<ul style="list-style-type: none"> <li>• Survey</li> <li>• Content analysis</li> </ul>	<p>• Provider flexibility to vary hours given and the way hours were used within agreed limits was associated with higher service quality (p&lt;0.001)</p> <p><i>What works- Listening to clients:</i> 72% said that they often felt listened to</p> <p><i>Users' appreciation for the care they received:</i> "The quality of the care my husband receives is 'second to none' and we are very grateful for their help"</p> <p><i>Enabling the person to live at home:</i> 50% of older people said they always had good quality of care, and 30% often</p> <p>"I could not remain in my own home without them."</p> <p><i>What needs to change:</i> Choices not being incorporated into care plans</p> <p>"My opinion counts for nothing....because they only want their own way ... and the clients' view really doesn't matter at all."</p> <p><i>Having the right knowledge and skills,</i></p>	<p>Internal validity: +</p> <p>External validity: +</p> <p>Overall quality assessment: +</p>
Wales		Sample Size: N=1029			
Survey		Sample Characteristics: <ul style="list-style-type: none"> <li>• Age=<math>\geq</math> aged 65</li> <li>• Gender=not reported</li> <li>• Ethnicity=not reported.</li> </ul>			

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				<p><i>including induction:</i> Over 75% felt that paid carers often had the right skills, but problems were identified around induction <i>"I feel that the care workers need more training they are left to fend for themselves after only a week's 'shadowing'"</i></p> <p><i>Time pressures:</i> Less than 50% of older people felt that their care workers give them as much time as they need <i>"...15 minute calls during which they are meant to get the person up, wash and dress them and provide breakfast. The 15 minutes also includes travel time to the next call. Many older people forgo the washing and ask the staff to prepare their breakfast."</i></p> <p><i>Use of unfamiliar staff:</i> 35% of respondents said they were always familiar with the carer sent, and lack of communication about changes of staff a cause of distress, but recognised that retention of staff was a problem. <i>"It seems that girls leave quickly because of the pay, hours and job expectations."</i></p>	

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14. Patient and Client Council (PCC) 2012  Northern Ireland  Mixed methods	To explore the experiences of older people receiving home service in Northern Ireland	<p>Population: Older people receiving social care and home care and their family carers</p> <p>Sample size: N=700 completed questionnaires; 38 interviewed and 170 took part in discussion groups</p> <p>Sample characteristics: • Age=<math>\geq</math>65 years • Gender=70% female • Ethnicity=not reported.</p>	<ul style="list-style-type: none"> <li>• Questionnaire survey, interviews and discussion groups</li> <li>• Descriptive statistical analysis</li> </ul>	<p><i>Older peoples' views:</i></p> <ul style="list-style-type: none"> <li>• 87% of people using services rated them positively</li> <li>• 16% did not feel their needs were met, most commonly attributed to lack of time available</li> <li>• Typical concerns included: short visits and/or inconvenient visit times; lack of continuity or quality in care staff inflexibility of service; and, poor staff training</li> <li>• Care should be more joined-up and take into account non-health and social care-related tasks</li> <li>• 30% people paid for additional help, mostly with practical tasks, while many also relied on family carers</li> <li>• Some felt that more practical support from care workers would help them be more in-dependent</li> </ul> <p><i>Family carers' views:</i></p> <ul style="list-style-type: none"> <li>• Families felt reassured by home care staff's visit</li> <li>• Similar concerns as older people - brevity of visits, poor care continuity, inflexibility and poor administration</li> <li>• Particular concerns (in terms of quality, health, safety and hygiene</li> </ul>	<p>Internal validity: –</p> <p>External validity: +</p> <p>Overall quality assessment: –</p>

Author/ country/ study design	Aims of study	Participants	Method of data collection/analysis	Main findings	*Overall quality assessment
15. Quince 2011  England  (Study linked to Lakey and Saunders 2011)  Mixed methods	To describe the experiences and aspirations of people with dementia and their family carers about the home care they received	Population: Older people with dementia receiving home care and their family carers  Sample size: N=48 people with dementia  Sample characteristics: • Age=91% ≥65 years • Gender=not reported • Ethnicity: not reported.	• Questionnaires and interviews • Data analysis method not described	standards) about staff in some private agencies.  <i>Service users' views:</i> • 83% stated that the person with dementia wanted to live in their own home • 59% considered links to the community to be important for the person with dementia • 70% reported they were satisfied with the quality of service received • People with dementia and family carers highlighted independence, being active and engaged, and socialising as of key importance to people with dementia <i>"Lots of going out; helps you remain independent and gets things circling" – person with dementia.</i>  <i>Issues in timing of care:</i> <i>"I have carers coming in morning and night. But it's difficult to set any times. In the afternoons it's any time between four and half past seven. In the mornings it might be half past seven or ten o'clock" –person with dementia.</i>  <i>Information and access to other</i>	Internal validity: –  External validity: +  Overall quality assessment: –

Author/ country/ study design	Aims of study	Participants	Method of data collection/analysis	Main findings	*Overall quality assessment
				<p><i>services:</i></p> <ul style="list-style-type: none"> <li>• 41% said that they had been given enough information on free information and support</li> <li>“I have all the information I need.... but sometimes you just need to phone somebody” – carer of person with dementia</li> </ul> <p><i>Co-ordination of dementia care:</i></p> <ul style="list-style-type: none"> <li>• 51% said services were mostly satisfactory on staff understanding of dementia</li> <li>• Services unsatisfactory for their availability soon after a diagnosis (47%); in terms of the amount of time staff can spend with people with dementia (43%); flexibility (41%); continuity of staff (42%) and focus on needs (39%)</li> <li>• 52% of family carers felt they had inadequate support to them in their caring role.</li> </ul>	
16. Seddon and Harper 2009  Wales	To explore what works well to support older people live in their own homes and participate in their local	Population: • Older people receiving home care. • Family carers	• Focus groups • Development of themes	<p><i>What older people feels needs to change:</i></p> <ul style="list-style-type: none"> <li>• More person-centred approach, with greater sensitivity to older people’s needs and preferences</li> </ul>	Internal validity: +  External validity: +

Author/ country/ study design	Aims of study	Participants	Method of data collection/analysis	Main findings	*Overall quality assessment
Qualitative study	communities	<p>Sample size: N=35 older people, 18 family carers</p> <p>Sample characteristics: • Age= 68 to 94 years. • Gender=2 males • Ethnicity: not reported</p>		<ul style="list-style-type: none"> <li>• Greater flexibility in the tasks undertaken as part of a home care service to ensure that older people are not isolated from the community</li> <li>• Lack of continuity of carers prevents a more personalised service (which relies on familiarity), but recognised that retention and the low status of staff was a sector-wide difficulty in this regard.</li> </ul>	Overall quality assessment: +
17. Sykes and Groom 2011  England  Qualitative study	To explore older people's experiences of home care	<p>Population: Older people receiving home care, and their family carers Sample size: N=40 (12 self- funders)</p> <p>Sample characteristics: • Age= 66 to 69 years • Gender: 13 males • Ethnicity: 35 White British; 5</p>	<ul style="list-style-type: none"> <li>• In-depth interviews</li> <li>• Content analysis</li> </ul>	<p><i>What is valued:</i></p> <ul style="list-style-type: none"> <li>• Skill and professionalism of care workers</li> <li>• Seeing the same workers and being able to build 'warm' relationships</li> <li>• Self-funded care more flexible and responsive to their needs.</li> </ul> <p><i>What needs to change:</i></p> <ul style="list-style-type: none"> <li>• 'Slapdash' approaches to preparing food, tidying, etc.</li> <li>• Workers who look 'scruffy' and unkempt</li> <li>• Workers rushing through their work, with no time for conversation</li> <li>• Workers who 'speak over' the older</li> </ul>	<p>Internal validity: +</p> <p>External validity: +</p> <p>Overall quality assessment: +</p>

Author/ country/ study design	Aims of study	Participants	Method of data collection/analysis	Main findings	*Overall quality assessment
		Black African/Caribbean		person in a language other than English <ul style="list-style-type: none"> <li>• Lack of respect for service users who felt they were treated 'as a number'</li> <li>• The assignment of different carers without warning</li> <li>• Poor timing of visits and time keeping practices</li> <li>• Unreliable services with workers who don't turn up for scheduled visits.</li> <li>• Minimal flexibility to carry out non-personal tasks.</li> </ul>	

\*Overall quality assessment

++ All or most of the checklist criteria have been fulfilled, where they have not been fulfilled the conclusions are very unlikely to alter

+ Some of the checklist criteria have been fulfilled, where they have not been fulfilled, or not adequately described, the conclusions are unlikely to alter

- Few or no checklist criteria have been fulfilled and the conclusions are likely or very likely to alter

<https://www.nice.org.uk/process/pmg10/chapter/appendix-g-methodology-checklist-qualitative-studies>