National Institute for Health and Care Excellence

Home care
Scope Consultation Table

27th August 2013 – 24th September 2013

Stakeholder	Section No	Comments	Developer's Response
Association of Directors of Adult Social Services	3.3	List of relevant policies / guidance needs to be updated	Thank you for your comment. Please be reassured that the list is intended to be illustrative rather than comprehensive. We will update this and provide additional references, as required, as part of the main phase of guidance development.
Association of Directors of Adult Social Services	4.1	Clarity of groups covered – i.e. only those aged 65+	Thank you for your comment. Following debate at the stakeholder workshop along with comments received at consultation, it was decided not to specify a lower age limit to allow a degree of flexibility.
Association of Directors of Adult Social Services	4.3.1	Clarity that scope will include private home care providers	Thank you for your comment. All home care providers are in scope: section 3.2.1 has been amended to add this detail.
Allied Healthcare	3.1.4	Although the figure for numbers receiving funding for social care is stated given that the numbers of self funders appear to be growing (TLAP- People paying for care)the estimates and growth projections for self funders is not referenced. The expansion of self-funding market may have significant influence within the sector on how services are delivered and operate as well as service user choice.	Thank you for this useful perspective. The guidance will cover those funding their own care.
Allied Healthcare	3.2.2	It's questionable whether moving and handling is a basic nursing task as this is now regarded as fundamental	Thank you for this informative commentary. Guidance development will require us to understand the range of

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		social care activity. Health related tasks that are delegated nursing activities (Nursing and Midwifery Council define delegated activity) such as peg feeding or medication via routes other than oral are increasingly become part of care worker responsibilities often without clinical oversight i.e. they are part of a social care contract and specification . This type of health related activity is where there are unclear boundaries and standards of what is acceptable and safe is not consistent. Providers have different approaches to training and competency assessments and local health providers are often reluctant to support with this. There are multiple benefits to multidisciplinary working with nurses supervising care workers to deliver a broad range of activities traditionally limited to nurses. It is essential that the broad range of innovative care models delivered by multi-disciplinary teams is recognised. Constraining thinking could inhibit innovation, impede integration of care, and reduce cost effectiveness.	activities undertaken by home care providers, and the skills, competencies and supervision required for these roles. We also intend to explicitly review models of integrated and partnership working to deliver home care services
Allied Healthcare	3.2.6	Task and time approach is not just limited to personal care; it often involves health related activities such as medication management. Further exploration by NICE of the data used to measure task and time activities is required to ensure the data is robust and can be benchmarked against other sources.	Thank you for your comment. Medicines support is within scope, as we understand it to be a major concern, about which the Guidance Development Group will consider evidence.
Allied Healthcare	3.2.7	Clear guidance on how health and social care should work together should also refer to shared documentation and improving communication. Terminology is important. The use of social care staff and healthcare professionals creates an unsatisfactory distinction and might be construed as suggesting care workers are not	Thank you for raising this. Integration is central to the scope of this topic as most home care users will have health and social care needs. We have amended the scope by using the term 'practitioner' to relate to professionals in both health and social care sectors.

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		'professional'. NICE should not use 'professionals' and if a distinction is needed NICE should consider 'care workers' and 'healthcare practitioners'. However, where possible NICE should only make the distinction where an activity cannot be done one group.	
Allied Healthcare	4.2.1	The scope needs to also refer to supported living	Thank you for your comment. This will also be within scope: for brevity, we have referred to care delivered in the older person's home.
Allied Healthcare	4.3.1	Medication Management poses significant risks for social care with each LA and Health commissioner having their own policies and procedures which it expects providers to comply with. The definitions within each of these policies are varied and the activities care workers are permitted to undertaken is diverse. Given the complexity of the subject, limiting it to 'medication prompts' is not going to be sufficient and covering this topic in its entirety should be dealt with as a separate topic by NICE specifically focussing on social care but cross referenced in these standards. There is lack of up to date consistent specific guidance for social care providers which needs to be properly addressed.	Thank you for your comment. We have changed the reference to 'medication support' which can be interpreted in a way that does not assume a particular role. Feedback from a number of consultees has identified this as an issue of concern for home care providers, and the Guidance Development Group will consider how best to address this.
Allied Healthcare	4.3.1b	Workforce issues: this should include continuity and consistency of care and how this is measured and maintained	Thank you for your comment. We expect to encounter these markers within review questions on the experience of service users and carers, and in reviewing joint working, training and support of staff.
Allied Healthcare	4.3.2	Although Health and clinical services provided by health staff. is excluded this creates an artificial distinction that is less and less relevant in an era of integrated delivery. Specifically Health and clinical services provided by care workers (under supervision if necessary) should be	Thank you, this has been noted. We will include clinical/nursing functions provided by home care workers who are not healthcare workers, and home care tasks provided by integrated teams;

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		included	
Carers Trust	3.2.3	We are not convinced that a distinction between older peoples care and that for younger adults is meaningful or justified	Thank you for your comment. As 80% of recipients of home care are 65+, it was decided that this could justify the focus on older people. This is outlined in the equality impact assessment. There is also evidence that older people may receive poorer services than younger adults. We have not set a specific age limit to allow some flexibility. We will ask the Guidance Development Group to consider how more generic recommendations can be identified and used to promote better care across a wider age group, if applicable.
Carers Trust	3.2.7	Should include communication and relationships between staff and carers, including involving carers in decision making, recognising them as experts in that context, and their needs as individuals	Thank you. We agree and do intend to include these aspects in scope. We have slightly expanded the point to make this clearer. We will also be reviewing the evidence in this area with one or more review questions on views of carers on what makes a good home care service.
Carers Trust	4.3.1	Liaison and joint working between home care and healthcare staff **and liaison with carers.** The scope needs to include the issue of relationship building and time to learn: carers tell us the relationship with care workers is crucial. Time is needed to build up relationships with the service user and carers, and to learn what works and does not work, and the service user's and carer's preferences for how care should be provided. This needs to be built into packages of care provided and the necessary skills development built into	Thank you for your comment. We have amended the reference in 4.3.1 to show slightly more detail. We will also have one or more review questions on views of carers about what works and does not work.

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		training programmes.	
Carers UK	3.2.3 & 4.1.2	The guidance should cover all adults in receipt of home care. It is important that there is guidance for all adults and where guidance needs to be specific about different aged user groups, this should be made clear within this guidance. Excluding younger adult's risks creating fragmented practice.	Thank you for your comment. There is evidence that older people may receive poorer services than younger adults. Also, as 80% of recipients of home care are 65+, it was decided that this could justify the focus on older people. Population sub-groups have been identified in the Equality Impact Assessment, e.g. the very old. We do acknowledge the point that aspects of the guidance will apply to home care generally and we will ask the Guidance Development Group to consider how more generic recommendations can be identified and used to promote better care.
Carers UK	3.2.8	The inclusion of the impact on family and friends is welcome but as well as the impact of respite services for the carer, a greater emphasis is needed on the impact that reliable and high quality domiciliary care for the cared for person has on carers. In particular this should include the impact on carer health and need to address carer health inequality as well as their ability to work or pursue leisure activities.	Thank you for your comment. We have expanded the reference in the scope (4.3.1) to home carers working with family and friends.
Carers UK	4.3.1a	The guidance should pay particular attention to the communication routes for carers and families to contact home care staff. It is really important that families are able to get assurances that home care visits have taken place, keep up to date about the condition of the cared for person and also to have someone to give feedback to and if necessary to complain to.	Thank you for your comment. We agree this is important, and have explicitly referenced the need to build relationships and share information and decisions with carers.

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		Particularly for those providing care at a distance or working alongside caring, difficulty in keeping in touch with a care worker to find out about a visit or check a visit has taken place can be a major source of stress and contribute the carer feeling unable to cope or to take time away from the cared for person. Those in receipt of care and particularly older service users can be reluctant to complain. Families often have an important role in feeding back information and working with the home care worker or agency to drive up standards. Home care workers must therefore make a huge effort to involve family and facilitate communication by providing a named contact and back up contact.	
Carers UK	4.5	The focus on the economic impact of unpaid care is welcome but this must include the economic contribution of unpaid care, the lost opportunity to the economy of carers leaving work to care full time and the economic impact on families of the inability to work alongside caring.	Thank you for your comment, this has been noted. We will pay attention to available evidence on the costs and impact of unpaid care in developing our economic plan.
Community Equipment Code of Practice Scheme CIC	General	There needs to be reference made to the training requirements and availability in the use of (i.e. not assessment) disability equipment e.g. electric beds, hoists and pressure mattresses, for home care staff, as a great percentage of older people will be using this equipment. As an example CECOPS have developed a Code of Practice which outlines responsibilities. This is supported by HSE, CQC, RCN, ADASS etc. CECOPS also offer training at all levels. Perhaps home care agencies should be required to access this or similar training and/or LAs should include in tenders. Maybe a one day awareness	Thank you for your comment. Training for home care staff is within scope.

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		session.	
College of Occupational Therapists	General	The College welcomes the development of this new social care guidance and agrees with the scope of the topic.	Thank you.
Durham County Council	General	Whilst it is recognised that there is a need for guidance, we would encourage engagement with both the providers and the commissioners to ensure that what is included in the guidance is useful for all parties. The guidance will need to recognise the considerable pressure on social care budgets. The standards must not cause the overall cost of home care to increase.	Thank you, we agree. To help achieve this, we are building dissemination and adoption into our guidance development process. Specifically, we: have established an Adoption Issues Log, where we can capture any evidence that helps us understand what the sector needs from this guidance; are developing strategies for dissemination and communication with the sector; have held a stakeholder workshop on t he topic;, are currently recruiting for Guidance Development Group (GDG) members including providers, users and commissioners. There is also scope for us to involve expert testimony in the guidance development process, if required, and there will be further consultation as the guidance is developed. Guidance development includes work on both effectiveness and cost effectiveness.
East & South East England Specialist Pharmacy Services	3.2.2 and 3.2.7	There is an urgent need to clarify the roles and responsibilities of home care and healthcare with respect to medicines support. Is medicines support a health or social care task? The Medicines Act 1968 is not detailed enough in this respect and guidance available (old CSCI) is subject to professional/organisational interpretations, leading to inconsistencies and clients are left unsupported	Thank you for your comment. Medicines support is within scope, as we understand it to be a major concern, about which the Guidance Development Group will consider evidence. There is also likely to be a guidance topic referred to NICE focussing on managing medicines in community settings in the near future.
East & South East England Specialist Pharmacy Services	3.2.5 and 3.2.6	"Time and task" approach is not always flexible to allow medicines taking to be supported in a way that is safe as per instructions or for clients to get maximum benefits.	Thank you for your comment. Medicines support is within scope, as we understand it to

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		Commonly, medicines to be taken before or after food or at specific times present a challenge e.g. Alendronate which is a drug to prevent fractures which need to be taken 30minutes before breakfast is impossible to give safely in a 15minute slot. Also pain killers that require 6 hours interval are sometimes given before to fit with the carer visits rather than client's needs.	be a major concern, about which the Guidance Development Group will consider evidence.
East & South East England Specialist Pharmacy Services	3.3	Add Guidance relating to managing medicines in social care settings "The handling of medicines in social care" by Royal Pharmaceutical Society. (mentioned in the CQC essential standards document in the Schedule of Applicable Publications)	Thank you for this suggestion. As the guidance referenced in the scope is limited to NICE guidance, we will draw this to the attention of the Guidance Development Group.
East & South East England Specialist Pharmacy Services	4.3.1a bullet 3, point 3	Basic nursing care – the example "medication prompt" usually refers specifically to the occasional reminder to take medicines. "Medication support" is more appropriate to avoid misinterpretation as it encompasses all types of medication support provided by home care including prompting, administration. I suggest that " medicines support" should be a point in its own right because of the high risks associated with poor use in this client group	Thank you. We have amended the scope to refer to medication support.
East & South East England Specialist Pharmacy Services	4.3.1b bullet 1	Workforce is a big issue with medicines support, particularly, poorly trained/ incompetent care workers who have a negative impact on safe handling of medicines and ensuring that clients get the best outcomes from taking medicines	Thank you for your comment. We agree that medicines support is a big issue: please see response to previous comment above.
East & South East England Specialist Pharmacy Services	4.4	Appropriate use of medicines is important when assessing evidence around health related outcomes, safety and adverse events, QoL, ability to carry out ADLs	Thank you for your comment, this has been noted.
East & South East	5.1.1	Add NICE medicines adherence. Clinical guidance 76	Thank you for your comment. The NICE guideline on

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England Specialist Pharmacy Services		Add SCIE Research briefing 15: Helping older people to take prescribed medication in their own home: what works?	Medicines Adherence is focussed on involving patients more in order to improve adherence, and is not specific to the home or home care practitioner's role. NICE scopes do not include SCIE Research Briefings. However, we will be searching for relevant evidence and literature, which should identify these and other relevant resources.
East & South East England Specialist Pharmacy Services	General	Frail older people and those with dementia take more medicines, are more reliant on home care for support with medicines and suffer more from the consequences of adverse medicines events including hospital admission, non-adherence and waste. The management of medicines CQC standard is the 2nd highest area of non-compliance by home care agencies and yet is not given due attention/weight in the document (CQC Care Update March 2013) I have attempted to highlight in the various sections why medicines support is a priority	Thank you for your comment. Concern about medication support, particularly for frail older people who may not be managing has been highlighted by consultees. This is included in the scope. The Guidance Development Group will need to consider how best to address this, within the guidance development activity.
East Riding of Yorkshire Council	3.2.2	Previously, specifications would detail the relevant tasks required of a domiciliary care worker; however, specifications are now outcome based and the detail of task has been lost. Whilst this can be seen as positive in terms of meeting outcomes, it can lead to uncertainty as to specific role.	Thank you. The guidance development group will consider evidence about how care is planned and what is delivered. We will pay attention to any available evidence that describes the comparative benefits of task versus outcomes-based planning.
East Riding of Yorkshire Council	3.2.5	Satisfaction surveys are undertaken at review to gather service user views on their care and support however, it is acknowledged that many people who are in receipt of care will not wish to pass negative feedback for fear of consequences.	Thank you for this point. There will be specific review questions on user/carer views on and experience of home care.
East Riding of Yorkshire Council	3.2.6	Where domiciliary care is tendered with focus on quality as well as price, then this should support in realistic bids from providers	Thank you for this point. The guidance will focus on quality and outcomes of services using the best available evidence.

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East Riding of Yorkshire Council	3.2.7	The focus on integrated services will support improved communication and practice.	Thank you for your comment. We recognise that most home care users will have both health and social care needs.
East Riding of Yorkshire Council	3.4.3	This issue supports the need for registration of home care workers.	Thank you for your comment. The potential role of personal registration in improving outcomes for service users and carers may be considered during guidance development.
East Riding of Yorkshire Council	4.3	Activities and exclusions appear comprehensive.	Thank you.
East Riding of Yorkshire Council	4.4	Comprehensive	Thank you.
East Riding of Yorkshire Council	5.3	Links to the relevant NICE Pathways and guidance would be very useful and underlines the increasingly complex care required in the Home setting.	Thank you. As well as the building on and signposting to existing NICE publications, we aim to ensure the different pieces of social care guidance complement each other.
East Riding of Yorkshire Council	General	Guidance for the delivery of personal care and practical support to older people living in their own homes would be welcomed for this increasing area of provision.	Thank you.
Housing Learning and Improvement Network	4.2.1	We would like to reinforce the importance of the inclusion of sheltered and extra care housing within the scope of the Guidance as settings within which home care takes place, albeit those specific commissioning models have been excluded.	Thank you for your comment, this has been noted.
Housing Learning and Improvement Network	4.3.1	"Care and support planning" needs to include the issues arising from time and task rather than outcome-based care planning, and the narrowness of focus of many assessments and care plans	Thank you. We anticipate that guidance development will consider the best available evidence regarding the comparative benefits of different types of planning.
Housing Learning and Improvement Network	General	The scope appears to cover most of the relevant areas.	Thank you.
Leeds City Council	3.1.1	The assumption that it is cheaper to support people within	Thank you for making this important point, which will be

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		home care assumes that the average cost would remain the same if some people currently going into res care stayed at home with home care. There are increasingly numerous examples of very high cost care packages where individuals are living in the community with complex needs, requiring multiple extended visits by 2 or more staff. Such large packages are often considerably more costly than residential care packages providing similar support.	flagged with the Guidance Development Group. We agree that intensive home care may not be cheaper than residential care. We hope that, where data permit, guidance will demonstrate relationships between costs and outcomes such as choice and control for service users.
Leeds City Council	3.2.1	We agree that the term domiciliary care may be misunderstood, especially by service users, carers and other non-professionals and an alternative should be considered. Clarifying that it is care provided in an individual's home that is being considered would improve understanding and clarity.	Thank you for your comment. There was considerable debate at both Scoping Group meetings and the stakeholder workshop on this issue, which concluded that home care was the preferred term, as reflected in the title. We have focussed on the activities home care may deliver, but also expanded section 3.2.1 to show that we do intend to include a range of models and services.
Leeds City Council	3.2.2	**Re-ablement should be considered as being in scope.** We believe that a central aspect of care is the promotion of independence and the active reduction of dependence with the enhancement and maintenance of functional skills, especially around the activities of daily living. **Any set of standards must clearly define which are social care and which are health based tasks. Clarity is required especially around the prompting of medication** and what are termed "basic" health related tasks, what are these and who should they be supervised by. This is especially important for groups such as individuals	Thank you for your comment. We have included the ethos of reablement in the scope, and this is reflected in outcomes (4.4), where we have strengthened the point by referring to maximising and prolonging independence at home. Reablement services as a defined intervention are not in scope but may form part of a future social care guidance topic. A number of consultation comments, and comments made at the stakeholder workshop also highlight these, or similar points .The Guidance Development Group will determine how this issue is to be handled during the

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		over 85, those who lack capacity or who have communication difficulties. Prompting medication for someone who has a mental health condition can introduce a number of complications that require specialist competencies to address appropriately a one size fits all approach must be avoided if we are to provide individualised solutions and maximise outcomes. A detailed picture of the requirements for each service users will promote clarity in the competencies required for home care staff against both the care being provided and the needs of the service users in receiving that care. Such clarity would form the basis for a provider Statement of Purpose and Function, identifying what services will be provided and how this will be supported by ensuring that adequate numbers, of staff with the required competencies are available to provide high quality care, with the ability to hold providers to account if they fail to provide what they have outlined in the Statement of Purpose and Function.	process of developing the guidance.
Leeds City Council	3.2.3	Any set of standards must be as objective as possible and we feel that these standards should apply specifically to people over 65 with a separate set of standards for those under that age. We agree that many areas may be common however there are also areas of difference and any term such as "older people" brings with it a lack of clarity and a requirement for interpretation that may allow variance in the standards applied in different locations and by different providers.	Thank you for your comment. There has been much debate about the focus of the guidance on older people's home care. As a result we have not set a specific age limit to allow some flexibility.
Leeds City Council	3.2.4	There needs to be very clear and concise reference made	Thank you, we agree. NICE provides comprehensive

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		to the dementia quality standards, as well as to the support needed to manage, long term conditions, and mental health issues other than dementia and other standards as they become available All of these standards will introduce specific requirements on those providing care for specific groups and will in some cases require specialist abilities from staff, all of which will once again help in developing a clear picture of the skills and abilities need to provide high quality home care. Beyond these core tasks additional requirements should be identified when providing care to more higher more complex needs client groups. This will also assist in the commissioning and procurement process and in contract compliance, safeguarding and inspection where compliance with such standards can be monitored via a solid evidence base.	links to all related NICE guidance products, using a format known as the NICE pathway. Thank you. People lacking capacity, or who have communication difficulties, or with dementia are cited in the Equalities Impact Assessment which will be published with the final scope.
Leeds City Council	3.2.5	There is also an issue which requires addressing regarding ensuring the safety of individuals and the role of home care provision when in some cases home care staff are the only contact some individuals will have. Clarity should be provided regarding assuring safety, Safeguarding is already clear as to the duties around abuse however there is a requirement to assure more general safety consideration when risks are identified. This is especially the case when individuals choose to undertake risky activities yet have capacity, clarity on what is expected of staff when they identify such issues would be useful.	Thank you for your comment. Safeguarding provisions and safety and risk is within scope. We may set a review question specifically on safeguarding within your wider meaning.
Leeds City Council	3.2.6	Linking to the statement for 3.2.4 above clarity in the outcome requirements for the different service users	Thank you for your comment. Quality and outcomes of services will be central to the Guidance including

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		group quality outcomes will support the move away for time and task slots, especially with payments being linked to achievement of these outcomes. This must include clarity on how different social and environmental situations impact upon the achievement of outcomes for different individuals, for instance accepting at the planning stage that individuals who are socially isolated and lonely may require a longer intervention to achieve outcomes than an individual who has strong social network of support, as will individuals with dementia, mental health issues, depression etc.	reviewing the best available evidence on areas set out in the Scope.
Leeds City Council	3.2.7	A standard for a single integrated common health and social care plan based on clarity of who undertakes which tasks would lead to an improvement in the quality of services. Such a common integrated care or support plan, detailing all aspects of the support being provided with a common jargon free recording format used by all professionals and care staff undertaking interventions with the individual would be a major move forward so that all information related to an individual's health or social care is available and can be integrated.	Thank you – planning, liaison and joint working, and supervision are all within scope.
Leeds City Council	3.4.1	Any standards must complement the inspection regimes of the regulators and be part of that regulation - either through reference to, or being part of any regulatory framework.	Thank you for your comment. NICE is working with the Care Quality Commission to ensure that guidance is taken into account in the development of regulatory frameworks.
Leeds City Council	3.4.3	Self-commissioned care and personal assistants should fall into the guidance, with receiving payment to provide a personal care or support service being the marker for inclusion	Thank you for your comment. Self-commissioned and funded care is included in the scope, and we are also including volunteers provided

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			through a formal agency.
Leeds City Council	4.1.1	We agree with the groups who will be covered. The sub groups mentioned should be covered as per the comments for 3.2.2 possibly in the form of a statement of purpose and function from the provider linking the support they will provide and how they will practically provide that support - for example a provider who provides care for individuals who have specialist communication requirements must have qualified staff to a level which enables a conversation with the individual not just odd words.	Thank you for your comment. The Equality Impact Assessment, which will be published on the NICE site with the final scope, reflects sub groups with different needs.
Leeds City Council	4.3.1	We agree with the areas covered and it is of interest to note that there is support for social and community participation which is more in line with the personal assistant role than home care at present. Though we would welcome more clarity on which of these tasks fall under basic nursing care and what the extent of these would be and which tasks should fall under professional supervision of a nurse or therapist. This is necessary to provide an accurate view of who will be required to meet which care needs, clarifying the competencies required by the staff providing care. This requirement should be modified to a reduced statement of requirements forming the basis of a very clear support plan of how the skills, knowledge and abilities of a PA or other self-commissioned services will meet the needs of the individual. Additionally the requirement to regularly review such a statement or	Thank you, this has been noted. Staff training, supervision and care planning are all in scope.

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		agreement within specific time intervals would assist in the future proofing of any standards and allow much greater personalisation of any standards and scope for innovation at an individual or provider level. We feel that part of the management and supervision arrangement should include a simple but regular direct observation by the registered manager or a delegated individual of the practice of staff which would be used to enhance the individuals practice.	
Leeds City Council	4.3.2	Short term care should be in scope unless there is an alternative set of standards. We are unclear as to why there should be a difference between short and longer term care, especially in terms of reablement as a re-ablement service is required to meet the needs of the individual and should not be a time limited service. Reablement should be defined in terms of the identified outcomes for the service user and not by an arbitrary time limit	Thank you for your comment. We have included the ethos of reablement in the scope, and this is reflected in outcomes (4.4), where we have strengthened the point by referring to maximising and prolonging independence at home. Reablement services as a defined intervention are not in scope but may form part of a future social care guidance topic.
Leeds City Council	4.4	Whilst we fully support the focus on outcomes we are concerned that in many cases satisfaction surveys are not clear enough at looking at the impact care services have, as opposed to a more holistic whole of life measures and would wish to see some form of validation of the findings of questionnaires direct consultation and engagement of service users in a meaningful conversation.	Thank you for this observation. The Guidance may be supported by tools or suggestions for evaluating services, since how they are delivered, as well as outcomes, is important to service users.
Marie Curie	3.2.4	We would urge NICE not to underestimate the impact that access to social care at home can have on someone who is terminally ill and their families. Research by the Nuffield Trust has shown that people who are terminally ill and	Thank you for your comment. The final scope includes access to information, and care and support planning will include assessment.

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		who use local authority funded home care are far less likely to use hospital care. This means that people who are terminally ill and receiving social care are far more likely to die at home. Getting access to social care is, however, a struggle for terminally ill people. Access to NHS Continuing Healthcare is not guaranteed for people who are terminally ill, unless their situation is considered an emergency by hospital staff. Those who apply for local-authority funded care often wait a long time while local authorities carry out care needs and means assessments. We know of cases where terminally ill people have had to wait up to three weeks without care and we have heard of people dying while waiting for care to be put in place. Terminally ill people, who have so little time left, should not face long waits for access to social care. We ask that NICE ensure that the need for terminally ill people to access care swiftly be made explicit in the social care guidance on Home care.	The home care of terminally ill people is included in the scope, and is reflected in the Equality Impact Assessment, which will be published on the NICE website with the final scope. Please also note that there is a separate piece of social care guidance in development on Transitions between health and social care services.
Marie Curie	3.2.7	It is difficult to see how liaison and joint working between social care staff and social care professionals can be fostered, especially for people who are terminally ill. While we provide some services during the day, the bulk of Marie Curie's services are provided to terminally ill people and their families overnight. Given the 'time and task' approach taken by social care providers and commissioners, it's very unlikely that a Marie Curie nurse or healthcare assistant would meet or be with a patient at	Thank you for your comment. The issue of coordination and communication among providers of different care is within scope. We are planning review questions to address this. Older people at the end of life are a key sub-group: this is reflected in the Equality Impact Assessment, which will be published on the NICE site with the final scope.

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		the same time. Social care workers are also commissioned by a different body than Marie Curie nurses and healthcare assistants (we are commissioned to provide care in England by Clinical Commissioning Groups). There is an artificial divide between healthcare workers and social care workers that makes very little sense from the perspective of the patient. The Marie Curie Nursing Service has been proven effective in an evaluation by the Nuffield Trust at reducing hospital admissions for people who are terminally ill. We know that social care can have a similar effect in reducing the use of hospital care by people who are terminally ill. Care could be improved for terminally ill patients if it was regular practice for palliative care nurses and social care workers to share information and expertise. Given the current structure of the way social care, in particular, is delivered, this is a difficult task. This is something that CCGs and local authorities could address, by working more closely when commissioning services and looking at encouraging social care and healthcare providers to liaise, share information, and, where possible, work jointly.	
Motor Neurone Disease Association	1 3.2.3 4.1.1 4.1.2	Although the Association acknowledges the explanation for limiting the scope of this guidance to 'older adults we are never-the-less concerned about the possible implications. Motor neurone disease (MND) largely affects an older	Thank you for your comment. Information from Health & Social Care Information Centre suggests that 80% of recipients of home care are 65+, so this is the majority population. There is also evidence that older people may receive poorer services than younger

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		population; however there is a sizeable minority of people with the condition who are of working age. For many people with MND, the majority of social care needs will be provided for at home. We are concerned at the possibility that people with MND who do not fall into the category of 'older adults' will not benefit from any improvements to social care standards that this guidance may bring. We do not agree with the draft scope's reasoning that only by specifying 'older adults' can the guidance be specific enough to benefit the user group. We believe the scope should be broadened to encompass home care for all adults.	adults. We have deliberately not set a specific age limit to allow some flexibility. We do acknowledge the point that aspects of the guidance will apply to home care generally: we will ask the Guidance Development Group to consider how more generic recommendations can be identified and used to promote better home care for all.
Motor Neurone Disease Association	4.3.1	We welcome the inclusion of support for families, friends and unpaid carers within the scope for this guidance.	Thank you for your comment. There will be focussed review questions on carers experience, views and identified needs where they relate to home care input.
Napier Home care Services Limited	General	I think that the Guidance is very comprehensive and is designed to meet the current and future requirements of home care. However, I think comments from the scoping workshop in respect of Rural residents and Lesbian, Gay, Bisexual, Transgender and Intersex groups is not reflected in the guidance. I think that people may have more confidence, if they read that the guidance related to older adults, irrespective of their sexual orientation, etc. I know this may be seen to be differentiating, but I think at this point in time it would be helpful. We currently are providing specific LGBT training to our workforce to acknowledge the need for carers to be aware of LGBT clients' requirements. I agree that work is commissioned using a 'time and task' approach. This tends to be for older people much more	Thank you for your comment. We agree with these points. Older people are as diverse as any other age group. Issues for LGBT around how personal and social care is delivered will be addressed, as will those living in rural areas. These points are reflected in the Equality Impact Assessment, which will be published on the NICE site with final scope. Thank you also for raising this point, Your comment will be passed onto the guidance development group.

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		so than younger people and this requires to be addressed to ensure equality. There should also be an acknowledgement that as people become older, they generally become slower and therefore commissioned hours need to be reviewed on a more regular basis.	
Sevacare	General	The Scoping Document is well set out and covers the main areas. We are keen to ensure that the work carried out by NICE in all areas looks at where the operational difficulties start, i.e. the way in which services are commissioned by the Local Authorities (the vast majority of originators of service). There is a simple solution: end the practice of time and task commissioning and change to service-based work which looks at personal need in which time plays no part, just as one might see in a hospital setting; no one measures nurses by the time they spend at any individual patient. We look forward to seeing the results in due course.	Thank you for your comment. The implications and impact of a time and task approach to service organisation and individual planning on the quality and outcomes of services is in scope, where evidence is available. NICE typically produces supporting tools for commissioners to accompany guidance.
Shared Lives Plus	1.1	Shared Lives is about people getting support in the home of a Shared Lives carer so it does not fit the definition	Thank you for your comments. It has been agreed to include Shared Lives and Shared Lives Plus schemes in the scope if the care is delivered in the place the service user regards as their home.
Shared Lives Plus	3.1.2	The focus for the descriptions of the people and organisations who deliver Home care seems based on service providers that are registered agencies and also who employ staff. The scope talks about 'personal care' which is delivered by exclusively regulated agencies and 'practical support' which could include a very wide variety of diverse services. The scope as is fails to recognise the many micro-enterprises (typically with five or fewer workers) who are often self-employed. It also does not describe Shared Lives carers, one of the key groups	Thank you for your comment. We had not intended to limit the scope to providers employed by agencies, and have changed some of the wording to reflect your point. We have also expanded the section in 3.2.1 (on practice, not on figures) to reflect the range of arrangements through which home care may be provided.

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		identified as being part of this guidance. All Shared Lives carers are self-employed and frequently own and live in the same home as the people receiving support in a shared arrangement. The whole draft document consistently referring to people as staff, a term which would not to Shared Lives carers and by few micro-providers. Shared Lives is a distinctly different type of Social Care so if included would need to feature in this paragraph	It has been agreed to include the Shared Lives model is in scope.
Shared Lives Plus	3.1.3	All the statistical evidence seem to be based on CQC registered home care services and is missing Shared lives information and taking no account of self-funders and cost saving to people who buy their own care etc.	Thank you for your comment. Unregistered providers, including those employed by self-funders, are in scope. We have made amendments to Section 3.2.1 to make this clearer. We will be searching for evidence on evaluations of Shared Lives schemes during guidance development.
Shared Lives Plus	3.2.1	The list of services, although helpful to set Home care in context is reflective of a traditional model of service delivery. These are need based and service delivery focused categories. If the future of care and support is to be person centred and outcome focused many organisations may deliver support in the home but not fit these descriptions. Many of the micro-enterprise services we know have develop none-traditional approaches to supporting people who formerly received Home care and there is a danger that the guidance will not be flexible enough to incorporate what they provide. This could restrict them form using the guidance or worse restrict them from developing their tailored and diverse services. Recognition of the diversity of potential approaches	Thank you for your comment. We agree. We did not wish to circumscribe activities referred to as 'social care' and want to reflect a range of practice in personalised care in the guidance.

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		should form part of the scope of the guide.	
Shared Lives Plus	3.2.4	The scope does not include any anticipation that older people receiving home care may also have a learning or physical disability, sensory impairment or long term mental or physical health condition.	Thank you for your comment. These issues are referred to in the Equality Impact Assessment which was developed alongside the scope and will be published on the NICE website with the final scope.
Shared Lives Plus	3.2.5	Whilst recognising the account of some of the failings of Home care services none of these reports apply to Shared Lives and by contrast Shared Lives provides consistent care and support from a single carer, is not time limited in the same way as much home care. This is not a picture which includes or reflects Shared Lives arrangements, one of the key groups identified as being part of this guidance. We welcome what the guidance may offer to all providers of relevant services but feel that the current scope fails to appropriately reflect or understand Shared Lives settings. Also the scope does not reflect the recent CQC themed inspection for Domically Care, where the very smallest home care providers (micro-enterprises) were not a susceptible to these generic failings, primarily due to their scale of operation. The scope does not account for the difference between regulated activity and unregulated activity. Also the different operational nature of micro-enterprise providers compared to larger providers and thus does not reflect the proportional approach which is required to ensure any guidance will be inclusive of micro-providers distinctive scale of operation.	Thank you for your comment. The scope does not provide a comprehensive account of home care services. It aims to focus the work on the aspects of the topic where guidance can make the biggest difference to outcomes. We will consider innovative practice during guidance development. Thank you for this information. The final scope includes regulated and unregulated home care services. Section 3.2.1 has been slightly expanded to make this clearer.
Shared Lives Plus	3.2.6	The guide needs to also take into consideration the issue of travel time. Workers need not being paid for travel time	Thank you for your comment, this has been noted. This aspect of delivery is included in the final scope.

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		is not sustainable or conducive to quality care. As for Shared Lives is never task and time focussed but is very flexible and outcome focussed	
Shared Lives Plus	3.2.7 and 3.2.8	It is unclear how any combined health and social carer activities will be delivered in situation where the care activity is not regulated, falling outside of CQC eligibility. Indeed home care has evolved to purposefully provide support which is separate from the sort of enablement support healthcare would deliver. If the reality of today's home care is very limited support based around personal care then addition duties may be undeliverable to any standard. Not such a big issue in Shared Lives because of the family setting in which it happens health care provision is at the same level as for ordinary families in the community. There is a need for clarity about what can be delegated to a Shared Lives carer by a health professional which is progressively increasing even to the extent of giving injections.	Thank you for your comment. The guidance will consider unregulated and regulated activities. Medication support is also within scope.
Shared Lives Plus	3.3	Shared Lives legislation is covered in the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010 we would however ask if the domiciliary care legislation form 2002 is still relevant and applicable.	Thank you for your comment. Please be reassured that the list is intended to be illustrative rather than comprehensive. We will update this and provide additional references, as required, as part of the main phase of guidance development.
Shared Lives Plus	3.4.1	If Shared Lives is to be part of this guidance then there is a need to include Shared Lives here as a Regulated service type. Shared Lives carers do not register with CQC but are approved by a scheme which is registered with CQC. Wording of any guidance needs to be focused	Thank you for this clarification, which will be considered during guidance development.

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		correctly, to ensure the role of carer and scheme are delineated and to avoid burdening Shared Lives carers with aspects of delivery which do not form part of their role.	
Shared Lives Plus	3.4.3	The scope does not adequately encompass the non-regulated support at home that doesn't include personal care. In the real world some regulated providers deliver personal care which is regulated and other support which is not regulated. Still other providers purposefully stick to regulated or none regulated activity with client's requirements falling between providers and resulting in artificially created, disjointed care and support packages.	Thank you. The guidance will cover regulated and unregulated aspects of care. We have made this clearer in section 3.2.1.
Shared Lives Plus	4.1.1	The definition again does not include the usual Shared Lives arrangements which are better described as "Older people living at home 'or in the home of a Shared Lives carer"	Thank you for your comment. If it is the older person's home, both arrangements are considered to be within scope.
Shared Lives Plus	4.2.1	For the purposes of this definition the term 'Shared Lives arrangement' (not Shared Lives schemes) should be used. The other 2 settings in this list involve home care going into the home whereas Shared Lives involves the service user living in or going to the home of the carer. It should be noted that for most Shared Lives arrangements although the person supported would consider the place where they live to be their home in fact the property is owned or rented by the Shared Lives carer.	Thank you for your comment. We have amended the scope wording for clarity. We consider both types of living arrangement as being within scope.
Shared Lives Plus	4.3.1	The scope may be detailing activities which in the real world would be delivered by a broader range of categories	Thank you. We have given more detail in 3.2.1 and this list is intended to be illustrative rather than exhaustive.

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		of professional worker rather than just the two forms of healthcare and home care. In our experience this support is likely to be deliver by a range of providers including: • healthcare worker • home care worker • housing related support worker • (non-regulated) help at home support (gardening, social contact, housework etc.) This list should also include Shared Lives carer as a separate category if they are to be successfully included in the scope.	
Shared Lives Plus	4.3.1b	Commissioning practices impact on all sizes of organisation but we and our network of micro-enterprises have identified that a one size fits all approach to commissioning care and support and a lack of proportionality in contracting services builds significant obstacles for micro-enterprise providers and is a real barrier to the personalised approach delivered by micro-providers. Also the 'workforce issues', as identified in the scope, does not recognise the nature of a Shared Lives carers' role or many of the micro-enterprise services. We appreciate the need for the scope to address workforce issues but the scope might be more relevant to the group we represent if it broadened it terms and reflected their distinct nature. Shared Lives carers are not paid in the same way as workers, rather being remunerated as self-employed people for the support and accommodation they provide. Many micro-providers are managers as well	Thank you for your comment. We will work with the Guidance Development Group to consider available evidence on different and innovative models and practices and on their impact on key outcomes, for example, personalisation, choice and control, We have added a sentence to section 3.2.1 of the scope to clarify the inclusion of different types of provider.

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		as delivers of services and would be alienated by being described as just a worker. Also many micro-enterprises work with volunteers how such roles are understood as part of a service is entirely missing from the scope. All of these areas can be recognised within Shared Lives but how they are applied in practice will, as we stated at the outset, be applied in a way that will require separate explanation throughout the document i.e. the end document could result in needing to be peppered with 'and for Shared Lives this will mean' comments.	
Shared Lives Plus	4.3.2	It is unclear what "person centred care of older people with long term conditions within community and residential care settings" is referring to.	Thank you for your comment. This refers to an additional guidance topic which is also under development. This group is excluded because of this, as it will refer specifically to personalised care for older people with long term conditions but unlike the home care topic, also includes people living in residential settings.
Shared Lives Plus	4.4	All of these activities are fine but for Shared Lives would in addition it would be best to add being integrated into a local community and being active citizens.	Thank you for your comment. We fully agree with the importance of these activities, and if available measures of social involvement are inadequate, we will consider how they can be evidenced.
Shared Lives Plus	4.5	The economic benefits of Shared Lives require an entirely different approach to Home care as the funding of such support and its business model is distinct.	Thank you for your comment, this has been noted. We will pay attention to this in developing the economic plan
Shared Lives Plus	General	We are commenting here on the inclusion of Shared Lives as a specific category and the appropriateness of this inclusion in the scope, when it may, due to its very distinct nature, better sit outside of this guidance. If it is to be included we would also be concerned if representation or evidence cannot be made available to the Home care Guidance Development Group.	Thank you for your comment. Shared Lives is within scope so the Guidance Development Group (GDG) will consider evidence on Shared Lives arrangements where appropriate and available. The GDG can also invite expert testimony to provide additional evidence, if this is required. We welcome signposts to relevant evidence for consideration by the review team.

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		We also comment on the issues of proportionality of the scope and its understanding in the scope for micro-enterprise providers of care and support who, because of the scale they work at, may be disadvantaged by aspect of the guidance. Shared Lives has been included in this document presumably because home care is the closest fit. What separates Shared Lives from all of the other settings is that it takes place in the family home of the Shared Lives carer, is continuous and not task focussed, Whilst all of the activities listed in section 4.3 are relevant in Shared Lives their application how they are applied in Shared Lives is at an ordinary domestic level and this is supported by Care Quality Commission's regulation of Shared Lives. So whilst we can see the rationale for attaching Shared Lives to the Home care guidance it would make a lot more sense to have a parallel document specific to Shared Lives. This would avoid the need to explain how every bit of guidance might be a little different in how it is applied in Shared Lives. Nevertheless here are our comments	We also, welcome signposts to relevant examples of innovative practice.
Skills For Care	General	We are broadly happy with the scope as laid out. What is missing is the links to the wide range of workforce standards that are relevant for Home care workers. These include Common Core Principles, Common Induction Standards, Manager's Induction Standards, National Occupational Standards and Qualification and Credit Framework units and qualifications. A section or at the very least links to these (they are on our website) to	Thank you for highlighting additional references. We have now made reference to the standards in the scope and will also refer the Guidance Development Group to them so they consider where best they fit in the guidance.

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		indicate you are aware of them and have embedded them would, we suggest be the minimum requirement.	
Stroke Association	3.2.4	Report mention Dementia as a sub group here and not stroke. we think we need to highlight that stroke is the leading cause of disability and multi infarct dementia (vascular dementia) is one of the leading forms of dementia. This fits with our recent market research that highlighted that most people aren't aware they need stroke training therefore we really need to tell them in documents such as this	Thank you for your comment. We have not outlined particular conditions, although the need for home care will mean that most people are likely to have one or more challenging condition. Please also note that there is separate piece of social care guidance in development on Older people with long-term conditions.
Stroke Association	3.3 Policy	They do not highlight the stroke strategy which is old now however still a ten year strategy	Thank you for your comment. With the exception of NICE publications, we have not outlined other guidance or policy on particular conditions. If the evidence indicates principles or recommendations that will benefit specific groups, the guidance will highlight this.
Stroke Association	4.3 Activities	We Would be very interested to work with the Dom care Guidance group on the training specs they are planning to look especially in light of the fact there is already a Stroke education frame work that is used within health and how our stroke training fits into this. Adoption of this is social care would aid joined up working between health and social care	Thank you for your comment. NICE works with a variety of workforce development organisations as part of implementation of guidance and we will pass your comment on.
Stroke Association	4.3.2	We would question why the document highlighted not to include re-ablement teams in this? This is fine as long as the work that the home care teams do directly link and compliment the ethos of the re-ablement team to carry on focus on enablement especially for the stroke survivor as for most 6 weeks re-ablement will not be enough.	Thank you for your comment. We have included the ethos of reablement in the scope, and this is reflected in outcomes (4.4), where we have strengthened the point by referring to maximising and prolonging independence at home. Reablement services as a defined intervention are not in scope but may form part of a future social care guidance topic.
Stroke Association	5.1.1	Again this Guidance fails to include the stroke strategy it does have other documents older than this. Plus it does	Thank you for your comment. With the exception of NICE publications, we have not outlined other guidance,

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		include the new rehabilitation guidelines which of course do not include the whole pathway like the strategy and perhaps to most home care workers aren't seen as very relevant.	strategy or policy on particular conditions; although the need for home care will mean that most people are likely to have one or more challenging condition. The Guidance Development Group will need to consider evidence on the application of different approaches to home care support for a range of people who need that support.
Wiltshire Council	4.3.1	Could it not also look at whether a service that is commissioned for outcomes rather than time and task delivers a better service?	Thank you for your comment. We will be working with the GDG to finalise the economic plan and review questions that lend themselves to economic modelling. We will consider this issue as part of that work.
Wiltshire Council	4.3.1	Are we not trying to improve the terms and conditions of care workers because we think there is a relationships between these and the quality of service delivered – do salaried workers deliver better services for customers?	Thank you for your comment. The focus of the guidance is on improving care and outcomes. We will consider evidence about the factors that contribute to these. The guidance development group may wish to consider workforce issues within this.