NICE Collaborating Centre for Social Care

Regaining independence guideline

14/04/15

Stakeholder Scoping Workshop Notes

Break-out group discussions

Eight facilitated break-out groups discussed specific aspects of the draft scope. This paper summarises the themes that emerged.

Priorities for the guidance

The groups discussed the most important issues the guidance should tackle. These are summarised below.

Specific comments on the scope document

Are the right population groups identified and included?

On the whole, the broad population focus was well received; however there were a number of specific groups whom stakeholders felt should also be considered specifically. These included people with dementia or mental capacity problems, people recently discharged from hospital, and people living in care homes (who are viewed as especially likely to experience difficulties in accessing services). One group suggested that the NHS Benchmarking Intermediate Care Audit would provide further clarity on the issue of population. It was suggested by one stakeholder that reablement services (i.e. after a 'crisis') for people who abuse substances might also be included in the scope.

Some stakeholders felt that defining 'older people' may prove problematic and one group suggested that '(including older people)' should be deleted from the text of the 'Groups that will be covered section'. In contrast, one group suggested that the guideline should be 'geared towards' older people.

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There were also concerns regarding the perceived exclusion of people with mental health conditions. One stakeholder noted that for people with multi-morbidities this was especially important.

'... identified as ... at risk'

Many groups discussed the use of the term 'at risk' and how this concept would be operationalised. One group felt that all individuals were 'at risk' to some extent and suggested that the emphasis needed to be on people who had been actively identified. Similarly, other groups suggested that the focus should be on people with the *potential* to be reabled, which was felt to be particularly important in the context of increasing financial constraints. In contrast, one group requested that 'identified' was removed from the text.

Stakeholders were concerned regarding the measurement of risk and the means by which individuals might be identified. It was suggested that the 'potential' for reablement may not always be immediately apparent and that this might be impacted by individual circumstances (e.g. a bereavement).

One group was keen to ensure that the guideline emphasises the importance of early preventive interventions for those 'at risk' suggesting that cross-references to other products could be made in relation to this issue.

'Independence'

One stakeholder suggested that 'autonomy' rather than 'independence' could be used as this more clearly emphasised the importance of control.

There were also comments from one group suggesting that the phrase should be qualified in some way to demonstrate that loss of independence was either absolute or progressive.

Are the excluded population groups justified?

There were a significant number of comments relating to the exclusion of people under the age of 18 as many stakeholders felt that that young people at transition age often experience difficulties in accessing reablement services.

One group also felt it important to be clear that inclusion and exclusion is driven by primary presenting need, therefore prisoners with reablement needs resulting from disability or frailty would be included.

Are there any issues particular to the younger adult population in this context compared with older people?

One group felt that the detail on older people in the 'Groups that will be covered' section risks excluding younger adults by default. They requested that this is removed.

The needs of younger people were discussed by a number of groups who thought that these might be significantly different to those of older people (e.g. education, parenting, relationships, work etc.), however it was generally concluded that although these issues were more likely to be relevant to younger adults this would not always be the case. Stakeholders felt that it was important to remember that being 'older' was relative and that conditions affect individuals in different ways.

One group raised the issue of children transitioning into adult services in relation to this question.

Key activities

The activities section of the scope prompted significant discussion within breakout groups. One group felt that lists of activities and interventions was not necessarily helpful and suggested that the language of this section should be refined to demonstrate that the interventions are part of an educational strategy to enable or reable the person to do the tasks or live their lives as they used to or now wanted to.

Are the right activities and interventions included? Particularly focus on: what is distinctive about reablement or intermediate care?

There was concern that the list of interventions was quite prescriptive and one group described it as overly 'medicalised'. Stakeholders identified a number of themes which they felt were missing from the list such as confidence, life and social skills, and emotional, psychological and spiritual wellbeing. One group also felt that the list did not clearly place the individual at the heart of the reablement process, emphasising that they should have the right to make decisions that professionals may not view as being in the person's best interest. One member of this group emphasised the importance of holistic care and suggested that the <u>eight domains of care</u> used in Canada might provide a suitable structure for section 1.3. It was also suggested that the list should more closely align with outcomes specified in the Care Act.

Another group suggested that the list should be re-written in chronological order i.e. starting with assessment, then care planning, then the intervention itself. In contrast, another group suggested that the points specifying the more traditional activities such as personal care or domestic support should be listed further down.

A significant number of groups asked that the assessment stage is included in this list, with one stakeholder suggesting that this would help to emphasise the importance of the individual and could prove to be empowering in practice. Stakeholders also emphasised that the activities must be acceptable to the individual and should aim to achieve person centred goals - there is no one size fits all – further underlining the importance of the assessment stage.

There were also a significant number of concerns that the list did not adequately capture the reabling ethos and it was suggested that there needed to be a clearer emphasis on how the reabling activity would work in practice (e.g. the recovery of skills through teaching, etc.) rather than a list of packages of care which could be provided. It was suggested that the use of words such as support or self-manage rather than 'help' might solve this problem.

There were also a number of comments on the need for the list to be clear that in addition to regaining skills, reablement services could also support people to learn new skills and to develop 'compensatory strategies'.

A number of stakeholders requested that the list also includes less traditional activities such as befriending services or concepts such 'community access' as a means of addressing isolation and loneliness.

A small number of groups felt that the list focused too heavily on activities which are relevant to older people rather than younger adults and suggested that the inclusion of activities which emphasise an individual's contribution to society such as returning to work or volunteering.

Other themes which stakeholders felt should be emphasised included: the role of carers, the role of the voluntary sector, and the importance of building partnerships.

A number of groups also suggested a range of measurements which could be included in this list including the Barthel score and FIM+FAM; whilst one stakeholder suggested that the CART (Community Assessment Risk Tool) might be useful to identify people at risk.

Specific suggested additions to 1.3a included:

- Support to self-manage conditions.
- Coping strategies and emotional support to improve emotional resilience.
- Advice and support to purchase and access equipment including 'low-level equipment' and wheel chairs.
- Transfers and movements (i.e. moving from bed to lounge or sofa to toilet).
- Health and/or recovery coaching.
- Cognitive development training and mental health related activities. (e.g. CBT publications by Bev Harding and Sharan Kibble)
- Assessment of the home environment and activities to make the home more 'enabling'.
- Nutrition (including accurate and well communicated assessment of nutritional and feeding needs).
- Specific exercises (e.g. Tai Chi).
- 'Increase motivation, confidence and improving wellbeing'.
- 'Support people to live in their own homes'.
- Consideration of needs in relation to sleep.
- Confidence to take control of your own life.

Suggested edits to 1.3a:

- 'Medication prompts ...' should also include text highlighting the importance of links between clinical and social care professionals.
- 'Exercises to help ...' Strength and confidence should be listed as a separate point.
- 'Exercises to help ...' One group suggested 'physical activities to help ...' rather than the more traditional 'exercises'.
- 'Practical and therapeutic solutions to problems that reduce independence'.

'This will include interventions and care packages provided by ...'

There were concerns from some groups that this list did not sufficiently reflect the range of professionals who may be involved in the reablement process. One group was particularly keen that the social care sector was reflected and suggested a number of examples including rehabilitation officers, and deaf blind specialists (social care departments) who it was felt were unlikely to be covered by the term 'allied health professionals'. This group also highlighted the often quite specialised work that volunteers carry out. Another group suggested that the list should include community-based practitioners such as community health champions. Other suggestions included clinicians, 'reablement workers' (as these are now a distinct group), and 'staff who deal with assisted technology/all equipment'.

One group also felt that support workers have a role to play in reablement but were unsure whether this was within the remit of the guideline. This group also suggested that 'Home carers' should be replaced with 'Domiciliary carers' if that is what is meant.

b) Information and support needs of people using services and their families and carers.

A number of groups discussed the importance of information although this was often not specifically in relation to point b. One group felt that the accessibility of information was an important issue to remember and emphasised that information needed to be understandable. It was noted that the Care Act was relevant in this regard as there is provision for advocates to be used in instances where an individual may have difficulty understanding information and making decisions.

One group requested that 'information and support' were defined.

c) Training and competency of staff delivering reablement and intermediate care.

A number of stakeholders felt that this point should make reference to the training of informal carers and volunteers. Other stakeholders felt that intermediate care and reablement teams themselves had a role to play in training staff members of other services e.g. ensuring that home carers are competent in the use of lifting techniques.

A number of stakeholders were keen to ensure that this point emphasised that training and competencies needed to be assessed and evaluated. It was also suggested that this process should be co-productive with the service user identifying the skills and competencies that are most important to them.

Other suggestions on this point included: ensuring that 'competency' is understood and used as defined in the Care Act; addressing the issue of low wages for care workers, and consideration of the impact of the funding available for training.

d) Service organisation and governance – 'Co-ordinating reablement ...'

One stakeholder felt that it should be made explicit that 'other services' could include the voluntary sector as these are often excluded in the drive towards integrated services.

d) Service organisation and governance – monitoring and evaluation.

A small number of stakeholders felt that monitoring and evaluation needed greater focus. These were described as processes which are often tokenistic and do not necessarily guarantee a thorough service review. In addition, it was felt that the place of the service user in this process should be clearer; for example by measuring outcomes which are meaningful to the person.

e) On-going care, including handover to providers of on-going support, follow-up and review.

Two groups suggested that this point should also encompass training, one of whom requested that training for family and informal carers was also considered. Another suggested addition to this point was an emphasis on a shared ethos and language.

One group suggested that when transferring from rehabilitation to reablement the focus should be kept on short-term interventions but a specific time limit should not be used.

Are the excluded activities and interventions justified?

A number of groups felt that the justification for the exclusion of home care was potentially confusing to readers. Although there was general agreement that home care should be excluded there did not appear to be agreement on why this should be the case. A number of groups commented on the description of home care as 'not generally a short-term intervention' requesting that it be reworded to reflect more clearly that home care can be delivered in the short term. One group suggested that this be reworded to 'home care, unless specifically a short-term intervention.' In contrast, another group felt that home care should be excluded because it is not 'a programme designed for reablement' although they also suggested that the point be reworded to be clearer regarding the exclusion of long-term services.

The term 'medically supervised' was queried by one stakeholder who suggested that 'medically indicated' is more appropriate as a doctor may not always be present but a physiotherapist most likely would. Another group requested that that was edited to read 'Rehabilitation programmes for specific medical conditions'. This group also queried whether this would exclude individuals with a terminal diagnosis because their reablement is better managed by specialists and their outcomes are very different. They concluded that it is difficult to define 'end of life' and requested that the guideline covered certain terminal patients.

A small number of groups discussed the exclusion of mental health treatments and mental health recovery which stakeholders felt needed clarification. It was suggested that the guideline should focus on the individual rather than the treatment and reference was made to the wide range of services designed to support people's re-entry into the community which it were viewed as definite 'inclusions'. Another stakeholder suggested that engagement with mental health organisations might be a useful way of resolving this question.

Are any of the key areas viewed as more problematic in practice than others?

Only one group addressed this question specifically noting that not all interventions can be completed within a six-week timeframe. They also suggested that delivering an intervention to someone with multi-morbidities might be more difficult.

Settings

One stakeholder suggested that the list of settings could be determined by using the reablement service specification definition used in the Intermediate Care Audit.

Are the right settings included?

On the whole, stakeholders thought that the list of included settings was acceptable; however there were some specific points that were flagged for clarification or to be edited:

- Does the term 'inpatient hospital settings' include step-down services?
- Use the term 'usual place of residence' rather than people's own homes a person living in a care home will view the home as their own.
- The term 'other housing' should be removed as this is confusing.
- Could 'intermediate care' be listed as a separate bullet point?
- Could 'residential or nursing home' be moved in to the list of community settings (without the 'care home setting' prefix)?

Are excluded settings justified?

A small number of groups thought that it was acceptable to list accident and emergency departments here although one group added the proviso that staff with a reablement related role who work in this setting should be added to the list of audiences (e.g. discharge facilitation or admission avoidance teams.) However, the majority of stakeholders felt that the exclusion of this setting was problematic. Many noted that even though reablement services may not be delivered in this setting, assessments often take place here, and reablement teams (e.g. admission avoidance teams) sometimes work very closely with accident and emergency staff.

Are there any other settings in which intermediate care and reablement are provided?

A number of groups specified a range of community settings which they felt should be listed including community hospitals, community reablement beds, day care centres and GP surgeries. One group felt that the inclusion of both acute and community hospitals needed to be made clearer whilst another noted that hospitals often have beds set aside specifically for reablement. It was also suggested that the list of settings should make some reference to voluntary and third sector settings.

Members of one group suggested that links and transitions between specialist rehabilitation services and community based reablement services needs to be addressed as there is evidence that some people who have been in specialist rehabilitation units (Level 3) cannot access reablement services (e.g. neurological patients – the needs of whom *can* be met by community reablement services).

Two groups discussed care homes as a setting and one group was concerned that even though residence in a care home may be a long-term placement, short-term reablement interventions can still be delivered here. Members commented on the importance of ensuring that staff in care and nursing homes have a reabling ethos and do not simply 'do everything' for residents.

Review questions

Will the review questions allow us to find the right studies to cover the scope?

A number of stakeholders commented on the evidence base which they expected to be retrieved; with one group noting that randomised controlled trials were most likely to originate from Australia, New Zealand and the United States.

Variations in terminology and current practice and the impact these may have on the review work were also a concern for some, and there were a number of comments on the way in which the terms intermediate care, rehabilitation and reablement are used interchangeably. It was suggested that there are services in existence in the United Kingdom which are clearly within scope but are not called 'reablement' services. One stakeholder was keen to note that rehabilitation is generally recognised as a reablement service, whilst another suggested that rehabilitation rather than reablement is more commonly used internationally.

The overlap between intermediate care and reablement was also a concern; and it was thought likely that search results will be dominated by intermediate care. One group suggested that the date limits which the search strategy use should take in to consideration the fact that it is only recently that these terms have begun to be used more distinctly.

One group was concerned that the use of intermediate care was inconsistent throughout the questions (and the scope more generally). They queried why some questions used both reablement and intermediate care and why others only used reablement (e.g. question 4).

Questions on effectiveness prompted significant discussion amongst stakeholders. One stakeholder seemed to be concerned regarding the number of questions which included a cost-effectiveness component. Other stakeholders spoke about effectiveness more generally and how this would be measured, with one group member describing the term as 'woolly'. It was suggested that using the scope outcomes as a guide would help to solve this issue and one stakeholder suggested the Chicago Rehabilitation Measures Database as a useful tool.

Stakeholders also felt it important to emphasise that both the short *and* long-term effects of services should be considered. There were also comments on the importance of retaining the service user perspective in questions of effectiveness, and one stakeholder suggested the Macmillan 'cancer patient experience survey' as a potentially useful resource.

One stakeholder felt that the research evidence was unlikely to consider the whole care pathway and noted that referral routes, and post-intervention support would impact on issues of effectiveness. It was suggested that a review question could be developed to evaluate the impact of 'pathways into social care'.

A number of stakeholders also commented on conceptual issues related to the measurement of outcomes. One stakeholder suggested that the work should consider both expected and unexpected outcomes, particularly given the wide-ranging expectations regarding the effectiveness of reablement services. There was also concern from one stakeholder that it would difficult to disaggregate the effects of a service when it may have been received in conjunction with other packages of care.

There was concern from one stakeholder that none of the review questions make reference to people with learning disabilities, communication difficulties or language barriers.

Comments on specific questions:

Q1. Given that reablement services are often accessed at a time of crisis one group felt that this question would not help us to understand the views of people who had been unable to access services even though they may have benefitted from them.

This group also felt it important to note that service user and carer research may prove to be predominantly negative given current practices in relation to the information which service users are provided with. One member noted that the short-term nature of the intervention is often not clearly explained and this inevitably leads to poor views of the service.

- **Q3.** One group felt that this question (optimal reablement package) would be difficult to answer because it is dependent on the individual. The group suggested that the question would need to consider specific groups and specific types of packages. They also suggested that a better question might be 'What are the key elements of effective reablement'?
- **Q's 4 and 6:** One group queried whether these questions focused clearly enough on 'positive outcomes' for the individual and suggested that this term could be incorporated somehow.
- **Q6:** One group discussed the distinction between services that target specific groups and those that are specifically designed to reable one group in particular. They suggested that a question on the effectiveness of generalised versus specialised services could be included.

One group noted that they were pleased to see that dementia was being considered separately from 'mental health difficulties'.

A small number of stakeholders queried why there was a separate question on mental health and dementia when this was not the case for other conditions such as cancer?

Q7: Some stakeholders felt that this question should also consider the training needs of carers.

Are there any other review questions we could consider (within scope)?

It was suggested by one group that there could be a question which focused on the optimum skill-mix and composition of a reablement team, as well as one focusing on people with multi morbidities and the effectiveness of reablement services for this group.

One group discussed whether there should be a question which focuses on settings; however on reflection they concluded that this would be covered by question 4 (delivery models).

Another group felt it important that a question on joint and integrated working between reablement and other services is included.

One group felt that the list did not clearly show that the concepts of co-production and personalised care would be considered and requested the development of review questions to cover these specifically.

One group suggested that a question on information and support would be useful, particularly given the fact that many reablement service users access these at a time of crisis, making the provision of clear and accessible information even more important.

One stakeholder suggested that it is important to consider the length of time reablement takes, noting that this is currently dictated by financial requirements.

Outcomes

There were some specific comments made in relation to the wording or terminology used in this section and a number of edits were requested by individual groups.

User focused outcomes:

- 'Maximising independence, choice and control over daily life'. It may not be possible to achieve 'full' independence in every case.
- 'User and carer satisfaction with the outcomes of short term interventions'.
- Two groups discussed 'Years of life saved' and asked for clarity on what this meant.
 One of the groups also queried how it would be measured. They assumed that it would be via the QALY, but requested that this was made explicit.

Service outcomes:

- 'Use of health and social care services (secondary, primary and community, including out of hours services)'
- 'Use of health and social care services (secondary, primary and community)'. One stakeholder felt that the use of community was confusing in this context. They suggested that if this is a reference to the voluntary sector then it needs to be made explicit.
- One group felt that 'Hospital readmissions' was a problematic measure as it 'excludes a lot of patients'. They suggested that 'Hospital admissions' be used instead.
- 'Admissions and/or readmissions to nursing and residential care'.

Are the most important outcomes included?

Whilst the main outcomes section was generally well received a number of stakeholders felt that the list should more clearly reflect the wellbeing outcomes used in the Care Act. In addition, a number of stakeholders felt that the concepts of autonomy and 'voice, choice and control' need greater focus.

There were a number of specific additions suggested by individual groups.

User focused outcomes:

- Have the specific goals of the individual been achieved (using SMART goals)?
- Number of falls.
- Two groups suggested that 'timeliness' or the speed of the reablement process should be considered as an outcome. It was suggested that this needed to meet the needs of the individual i.e. did not leave the person 'stuck in a bed in their living room for months'.
- Access and waiting times to reablement services.
- 'How responsive is the reablement to the individual?'
- Two groups felt that community involvement or participation and isolation should be measured. One of the groups went on to discuss how positive outcomes could be achieved in relation to this noting the role which the voluntary sector can play.
- Does the service user feel well informed?
- One group suggested that professional satisfaction should be included as it is an issue relevant to question 2; however they wondered whether this would be covered under the 'continuity of care' outcome.

Service outcomes:

One stakeholder was concerned that 'Need for formal and unpaid care and support' could be impacted by funding mechanisms.

One group felt it important to note that admission to nursing or residential home is not necessarily a negative outcome. They agreed that the key issue was that this should be an active and planned decision which does not occur at a time of crisis. The group felt that terms such as 'appropriate admission' and 'the right support at the right time' were useful terms which could be used.

Other suggestions included:

- The changing demand on services over time.
- 'Changes (if any) to cost'.
- Impacts on support workers.

Are there other outcomes that should be included, for example, linked to National Outcomes Frameworks or measures (ASCOT?)

Suggestions included the Barthel score and DALY/QALY. One group voiced concern regarding ASCOT and the 91 days after discharge measure, asking 'what happens to the person 91 days after intermediate care?' Other groups felt that measures of isolation and loneliness should be included as well as discharge destination; access to reablement services and associated waiting times; formal, unpaid support needs; and delayed transitions of care.

In a discussion on review questions one stakeholder suggested the use of measures provided on the <u>Chicago Rehabilitation Measures Database</u>.

Do the listed outcomes adequately capture the concept of 'independence'?

Only a small number of groups discussed this question specifically and they suggested that the list of outcomes needed to emphasise this concept to a greater extent. In particular, it was thought that the term 'daily life' needed further explanation to clarify that this was about more than making cups of tea and instead was about life in the broadest sense e.g. 'how you live your life' and enabling an individual to make their own contributions to their community.

Some stakeholders also felt that more recent additions to the social care language such as 'preventing, reducing, and delaying' would be useful. Another group felt that the addition of an outcome covering 'increased social contact and decrease loneliness' would provide clarity on the issue of independence.

Equalities

Are there any equalities issues that we should be considering?

Stakeholders identified a number of groups who they felt should be considered in relation to the issue of equality. A number of groups were concerned that people who are homeless may be especially likely to experience difficulties in accessing and receiving services. Other suggestions included:

- People with cognitive difficulties or dementia (particularly older people with dementia).
- Carers.
- Self-funders.
- People with literacy problems.
- Black and minority ethnic groups (particularly in relation to information and access, and the cultural sensitivity of services).
- People with disabilities.
- Older people.
- People with weight management issues services might need to be designed to take into account an individual's level of confidence and how they present themselves.
- 'Hard to reach' groups such as older LGBT people who often struggle within the care system e.g. recognition of partners in residential settings.

Audience

Who should the primary and secondary audiences be for the guideline?

Many stakeholders felt that commissioners should be considered as a primary audience and one group suggested that the wording should also reflect the fact that people who self-fund are considered to be commissioners. However, this group felt that there was no real need to make the distinction between primary and secondary audiences — a point echoed by a number of groups. There was a suggestion from one group that the 'guideline also relevant for' section could be listed as a secondary audience if the distinction were to remain.

A number of groups also suggested that service users and their carers and families should be considered as a primary audience; with one group suggesting that including this group in a combined audience was 'in the spirit of co-production and empowerment of the person'. It was also requested by one group that staff working in nursing or residential homes are included as a secondary audience as there is an increased risk that people living in these settings will lose their independence.

In a discussion regarding section 1.2 'settings that will not be covered' it was also suggested by one group that professionals with a reablement related remit working in accident and emergency departments should be included as an audience.

One group also requested the inclusion of organisations that support advocates as well as voluntary sector services.

Guideline Committee

Discussions on the composition of the Guideline Committee were often shaped by concerns that the group must achieve a balance between the health *and* social care perspectives. Whilst stakeholders were keen to ensure that NHS perspectives were well represented there were worries that composition of the group could reflect the 'medical model' too heavily. A number of groups suggested that the committee could include social workers and other groups felt it important that individuals working in both care homes and the home care field were involved.

A number of groups emphasised that the committee should include frontline reablement practitioners such as occupational therapists and physiotherapists as well as those who may be involved in the process such as care assistants/workers (both paid and unpaid) and support workers. Other suggestions included GPs, nurses and geriatric specialists. When discussing the inclusion of frontline practitioners many groups suggested practitioners who were based in both the community (e.g. community nurses and matrons) and those in acute settings.

Many of the groups felt that it was important to include commissioners on the committee and it was suggested that these should be drawn from both the health and social care fields. One group suggested that a GP who is also a commissioner would be suitable whilst another emphasised that both local authority and CCG commissioners should be included.

A small number of groups discussed the composition of the committee in relation to equality and diversity which was viewed as key issue. Two groups were particularly keen that younger people should be represented, emphasising the importance of family life for this group. A group member drew on their personal experience after surgery - older people are routinely asked about the home environment and support they can draw on but this is not the case for younger people and hospital staff often see reablement as an 'older persons' intervention. The group also underlined the importance of reabling younger people who wish to return to work.

A significant number of groups felt that it was important that providers and service managers were represented on the committee. Three groups suggested that a provider or manager of reablement services specifically should be included, with one of these suggesting that the

service should provide reablement in a domiciliary setting. Other suggestions included providers of housing and equipment adaptations, providers of stepdown beds, telecare providers and providers from both the public, private and voluntary sectors.

Many groups discussed the involvement of service users and carers, with one stakeholder emphasising the importance of 'hearing the individual's voice'. It was suggested that including people who work to support personalisation could be a means of including this perspective. One group felt that the service users involved in the committee should reflect the varied funding arrangements in place e.g. NHS or social services funded and self-funders. One group suggested that it would be important to include a service user who had been successfully reabled.

A number of groups felt that it was important that the voluntary sector should be represented on the committee. Others suggested that it would be useful to ensure that the committee included representation from services in both rural and urban areas.

One group felt that the composition of the committee should not include too many researchers. Another suggestion was to include professionals with experience of innovative models of care.

Current practice

Have we identified current practice correctly?

A number of stakeholders commented on the wide variations in current practice and emphasised the need for the guideline to address this and the inequalities that arise as a result. Disparities in definitions of reablement throughout the country were of particular concern to many.

The overlap between intermediate care and reablement was also discussed and one group felt that the distinctions made in the scope itself were not clear on this issue. The group noted that intermediate care workers do carry out reablement work and that in practice the distinction was also not always clear (with the exception of very specialised clinical rehabilitation). This group also noted that intermediate care services tend to 'cherry-pick' patients in contrast to reablement services which will accept any referral.

A number of groups discussed the importance of setting to current practice. It was noted that reablement services are often not accessible to people living in care home or residential settings. Other stakeholders felt that the care home and residential workforce has little knowledge of reablement care which leads to an overreliance on reablement teams. Some stakeholders felt it was important to note that reablement services are also delivered in community hospitals.

Some groups felt that it was important that this section included information on the preventive potential of reablement. This was felt to be particularly important for the 'at risk' population and members of one group were particularly keen to emphasise that changing the mind-set of residential and nursing home staff in this regard would have a huge impact. It

was noted that some residential homes are designed to 'support' rather than 'do' and it was suggested that reablement staff may be able to help other services to 'able'/reable rather than reablement services accepting 'everyone'. It was also noted that reablement services are increasingly becoming a crisis/reactive service and that helping people to proactively adjust to changes in their health should be a priority.

One group expressed concern that this section did not specifically refer to rehabilitation; however they acknowledged that the title of a service may not be that important and that reablement interventions can be provided by rehabilitation or intermediate care teams.

One group referred to the use of key workers and care navigators in some areas, who they thought were especially effective in non-cohesive systems. They also suggested that independent advocates could fill this role.

Other suggestions regarding current practice included the use of reablement as an admission prevention tool or an alternative to hospital; the use of self-referral in some areas, and the 'discharge to assess' model.

Are there any other unwarranted variations in practice that we should be aware of? NB. No groups commented on this question specifically.

Is there any innovative practice we should be aware of?

Stakeholders provided a number of examples of innovative practice or work which they felt the team should be aware of. These included:

- Reablement services for people with sensory loss.
- Reablement staff based in accident and emergency departments.
- The ICARE/S (Integrated care services) rapid response unit in Birmingham.
- One group suggested that the provision of advocates for older people was important to note because the older person themselves see this as innovative (they don't have to keep repeating their needs to a range of professionals).
- Over 75s care good care model.
- Simon Stevens paper on prevention.
- 29 Vanguard sites hospital in reach to care homes and integrated health services.
- Health coaching.
- Identifying individuals at risk of admission and preventing this by proactively assessing and contacting/referring to reablement teams (Kent and Sussex).
- Community matrons and virtual wards.

Policy and legislation

NB. Many groups did not have time to discuss this section.

Have we identified key policy and legislation?

Those groups (two) that did discuss policy and legislation did not make specific reference to those listed in the scope.

One group suggested that depending on the extent to which mental health issues were covered, the scope should make reference to mental health related legislation such as the Mental Health Act.

It was also suggested that 2011 national guidance on rehabilitation with major trauma – which includes recovery and reablement was of relevance.

The group also discussed the Delayed Discharges Act and the widespread view that reablement is only free of charge for six weeks. It was suggested that the Care Act clarifies that the six week limit is not 'set in stone' and that if the guideline made recommendations on this issue it should reflect this flexibility.

The group also highlighted the relevance of the 'My life, my choice' programme by National Voices.

The second group to discuss policy and legislation noted the distinction between eligibility and access criteria and voiced concerns that people in the 'at risk' group would be unlikely to meet either. It was felt that the issue of cost-effectiveness was also of relevance here.

Is policy or legislation changing in this topic area?

One group noted that the Department of Health now has a National Centre Director for reablement (John Everington).

General comments on scope and hopes for guideline

Wide-ranging comments were received in relation to this question. Many stakeholders took the opportunity to emphasise the significant variations in current practice in terms of access and costs; as well as the overlaps between services which are variously described as either intermediate care or reablement.

There were also comments on the timescale in which reablement took place with one stakeholder suggesting that the focus should be on brief interventions, although allowing for some flexibility (e.g. for a person with multi-morbidities). A second stakeholder felt that there should be further exploration of this issue – is six weeks the correct timescale or would a longer intervention be more successful?

One group felt that the title should be changed to 'Optimising independence (reablement and intermediate care): short-term interventions'.

Other points raised included the importance of access and waiting times, recognition that isolation and access to services varies by age, ethnicity and language, the relevance of communication and training throughout the whole process (including the training of both paid and unpaid carers), and the need to consider how to deal with people who refuse to accept a reablement service

One stakeholder commented that the amount of robust evidence will be limited and that this will be shaped by the structure of health and social care systems internationally. They contrasted the Netherlands to the United States suggesting that a person with severe brain injury in the United States would be discharged from the service in a very short timescale. They also felt that research here was likely to be limited to rich individuals and veterans who could not be considered to be representative.

It was noted that the NIHR had recently commissioned research on reablement.