

NICE Collaborating Centre for Social Care

Older people with long-term conditions social care guidance stakeholder scoping workshop notes

Break-out group discussions

Six facilitated break-out groups discussed specific aspects of the draft scope. The following themes emerged.

Age of target population

All groups agreed that specifying an age limit as a way of defining 'older people', would be incorrect and suggested that '65 and older' was arbitrary. Some groups suggested that this age-limit can be stigmatising and, therefore, that including it in the guidance might reinforce discrimination particularly in respect of resource allocation. One group in particular saw this guidance as providing a huge opportunity to break free of a clearly bounded age distinction.

Some groups questioned why the guidance should focus on older people with long-term conditions when its findings were also likely to be applicable to younger populations e.g. those who are less statistically likely to live as long as 65 (examples provided included travellers and some people with learning disabilities, including Downs Syndrome) and those with 'prematurely ageing' conditions such as early onset dementia. One group suggested that those suffering from particular conditions such as HIV or Aids have not traditionally lived long enough to have generated a big enough evidence base of research, but are now living long enough to need this guidance. Other groups, however, agreed that in order to be specific and focused, the guidance should focus on 'older people with long-term conditions' but signpost when findings could be applicable to younger groups.

Groups discussed a suggestion made in plenary that, rather than specifying a particular age threshold, guidance could instead focus on 'frailty'. There was disagreement about whether this term was a useful alternative criteria. While some agreed that 'frail' older adults with long-term conditions were more likely to have social care needs, other groups felt this was an equally exclusionary term; that according to research older people do not like to be defined as frail; that the language means different things in health and social care settings and that the

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importance of the prevention agenda for people with long-term conditions would be lost if it was used as a defining characteristic. The majority of stakeholders concluded that frailty was not a useful criteria for defining the relevant population.

Finally, most groups during this section of the discussion emphasised that focusing on such a strictly distinguishing factor as age meant the guidance would not reflect one of the principles of good social care, i.e. that care should be provided according to need.

Conditions

The importance of ensuring that guidance supports care that meets people's needs was echoed in the discussions about the focus of the guidance being on those with two or more long-term conditions. All of the groups raised concerns and queries with regards to this criteria for two main reasons.

Firstly, focusing on only those with two or more conditions would exclude those suffering from single long-term conditions, such as epilepsy, who may also have high level of social care needs. The groups felt it was important for people with single long-term conditions to also be able to use the guidance to hold services to account. The groups pointed out that when first accessing care, people may be suffering from a single long-term condition but may go on to suffer "late effects" whereby one condition develops from another. A key question for the scoping team was raised over how the guidance would apply to those with fluctuating conditions

This chimed with the second concern expressed by many groups- that a sizeable number of older adults with one diagnosed long-term condition will actually be suffering from other conditions that have yet to be detected. This was felt to be particularly applicable to depression which is a very common undiagnosed co-occurring long-term condition. Those recommending the 'frailty' concept pointed out that frailty syndromes such as falling/wandering should also be considered as having an impact on a person's social care needs. One group recommended that an interesting question for the guidance to address would be how the combination of multiple long term conditions results in different social care needs than suffering from only one.

As well as the number of conditions, the groups discussed the issue of specific conditions. Primarily these discussions focused on the recommendation that dementia should be not be excluded from the scope, given the paucity of evidence on other long-term conditions. However, some groups recommended that the scope should actively avoid specifying particular conditions in order to ensure that the emphasis in the guidance is on the person rather than the condition. It was emphasised that just as 'older people' do not represent a homogenous group, neither do 'older people with long-term conditions' and that people will have differing social care needs.

The conclusion and recommendation from the groups was that moving away from a medical model and focusing on varying social care needs (and furthermore all needs not just ones that meet social care eligibility criteria) and how to respond to all of

them would be preferable. However, in order to be more specific the scope (and guidance) should address the still broader population of 'older adults with one or more long-term conditions whose impact necessitates high involvement with social care'.

Organisation and delivery of care

Several of the overlapping discussions from across the groups can be understood as referring to the organisation and delivery to care. However there were also distinct areas for discussion, specifically: assessment; integration; other aspects of delivery; and, workforce development.

Assessment

There were differing views on the inclusion of the Single Assessment Process (SAP) within the scope. While some suggested that the guidance should address the inconsistent and incomprehensive way in which it is currently implemented, other groups felt it should be excluded altogether, as it opened up so many related discussions as to make the scope unmanageable. As the first port-of-call for many people however, one group suggested the SAP is an important part of the care planning process and therefore ought to be covered, to the extent that the scope should be edited to discuss 'SAP **and** care planning' rather than SAP alone.

Other discussion points in relation to assessment suggested that:

- *how* people enter the social care system will need to be addressed, as the onset of a particular condition and its effects may lead to the first encounter with social care services, with an associated lack of knowledge and resources.
- self-assessment is an important, and currently missing, first starting point for care planning.
- people can lack proper assessments within particular settings such as residential care, where older people with long-term conditions can struggle to access specialist and primary care services. Furthermore some conditions and issues, such as mental health conditions and continence problems can be undiagnosed or misunderstood, leading to incomplete assessments, and with the latter, a premature and unnecessary transfer to residential care.

Integration

All of the groups discussed the importance of addressing how health and social care services are, and should be, integrated when delivering services to older people with long-term conditions. There was some question over how this related to an additional piece of NICE social care guidance currently in development on the transitions between health and social care services. It was emphasised by NICE and the NCCSC that the current guidance topic ought to relate only to long-term conditions and could legitimately address specific issues related to transitions within this context but not more broadly.

Many of the groups felt it was important for there to be a designated co-ordinator of care whose role is to liaise with the different services, across the health and social care sectors, required by an individual. One group felt this was particularly important when a case has been closed. Several groups touched on the importance of enabling people to explain their situation once rather than repeatedly to different services, the differentiation between them frequently lost or irrelevant to the person accessing services. Some acknowledged the problems of different IT systems hindering integrated working.

Nevertheless there were still concerns in some groups that specialisms within social care are being lost, with the move to integrated care and personalisation. There were concerns that the loss of particular skills and knowledge, such as those held by HIV social workers, will have an impact on the quality of care and the guidance should address this. Other groups focused on the importance of information sharing between specialist services, if an integrated approach is not used.

There was a call for the scope and guidance to be clear, when referring to integrated services, exactly what this means i.e. that it is more than the single assessment process. There was a suggestion from one group that there appeared to be a tension in the scope between an emphasis on integration, the single assessment process in particular and the exclusion from the scope of physiotherapy. Another highlighted that some professionals such as commercial optometrists could be considered to be very useful as part of integrated care packages but do not necessarily fit into either the health and social sectors and so this needs more consideration.

Other aspects of delivery of care

Several groups discussed the importance of the voluntary sector and volunteers to the delivery of care to older people with long-term conditions. This included within the community and residential sectors. It was felt that practitioners with particular knowledge of particular conditions are more likely to be found in the voluntary sector but that health and social care services do not always signpost people to these services.

There was call for the guidance to recommend a general culture change within social care in particular in which older people are discriminated against in terms of allocation of resources. There was a call for an evidence base to be provided showing the benefits of investing in services for older people. Regular reviews should be recommended and put in practice, as families will not always request these.

As discussed with reference to the single assessment process, the groups all raised concerns about the inconsistency in general quality and cohesion of care across localities. One group raised the current practice of 15-minute care slots as an example of bad practice. They also highlighted that a major barrier to the personalisation of care agenda was the inconsistency in choice available, whereby some localities offer limited number and quality of services from which to choose. One group called for the guidance to specifically make recommendations to commissioners on this issue, while another, looking from the alternative perspective

highlighted the problem of organisations unrealistically claiming to be able to deliver to tender specifications.

Workforce development

All of the groups discussed the importance of training for all workers delivering care to older people with long-term conditions. Subjects of training for social care staff highlighted as particularly important included: recognising the symptoms of particular conditions, including depression and urinary tract infections (UTIs); understanding symptoms that are part of old age rather than conditions e.g. the common side effect from sight loss of hallucinations; the benefits of investing in social care for older people; and, understanding the use and application of the Mental Capacity Act.

Other groups discussed the difficulty faced by providers and social care staff in the lack of clarity of roles between health and social care staff and the gaps in provision for good health sector back-up e.g. community practice nurses and continence care professionals. Local community pharmacies were suggested by one group as an example of the better support needed by social care professionals. The risk of staff leaving the sector taking their knowledge with them or working beyond pensionable age and not passing on their expertise was highlighted and again linked with the importance of training and development of the workforce.

Carers

All groups felt that the guidance should acknowledge the important role that family and friends play in providing unpaid care to older people with long-term conditions, although one group felt that the scope was too exclusionary in focusing on 'carers of older people with two or more long-term conditions'. They called for the scope to refer to carers in general. There was strong consensus that, while it delivers a range of benefits, care provided by family and friends should not be referred to as a 'service', in response to a query from the scoping group, and that the guidance should not necessarily provide recommendations that are aimed these informal carers.

All groups pointed out that carers may be suffering from long-term conditions themselves and therefore may be considered as an audience for the guidance in different ways. The issue of interdependence between couples, families and/or friends was considered a key relevant topic for the guidance here, especially as interventions which also support those carers with long-term conditions themselves can prevent unnecessary admissions to residential care and keep families together.

In fact, many groups suggested that support for unpaid carers as well as the person needing care should be part of the care plan or that carers' needs should at least be considered by staff. One group called for the guidance to look specifically at the evidence for cost-effectiveness of support for carers in terms of reducing the resources from statutory care required by individuals with strong and properly supported unpaid care.

The groups made the following further points in relation to carers:

- Carers' assessments can vary in quality and social care professionals can miss cues from carers whose ability to cope has declined.
- Staff need to work closely with unpaid carers and families, in all the settings in which care is taking place, including residential care and when the person needing care and support is permanently admitted to hospital.
- The unpaid caring role may not have been chosen: one group raised the issue of religious obligation, for example. Equally, family support may not be there at all and statutory services should fill this gap.
- Unpaid carers should be made aware of their need to meet the requirements of the Mental Capacity Act.

Person-centred care and personalisation of care

The importance of person-centred care was a cross-cutting theme, deemed critically important to all groups. Rather than approaching this issue from the viewpoint of the quality of care, there was agreement that the guidance should be driven by a bid to improve the quality of life for people, and should be person-centred, and that this should be explicit. The importance of using qualitative evidence from service user and carers was emphasised by one group. Related to the issue of the specific needs of people with long-term conditions, many were anxious that the guidance should focus on the impact of long-term conditions rather than the conditions themselves.

Indeed, many groups expanded on this issue of personalisation of care, suggesting that care for older people with long-term conditions does not need to focus on particular conditions but the needs of a person as a whole, often linked by the groups to wellbeing, discussed further below. They suggested that the definition of personalised care within the scope should be widened to include leisure and community needs. Care should be outcome-focused with care packages fitting the needs of an individual, rather than the individual adapting to the care package available.

Personal budgets, one (but not the only) aspect of personalisation, were discussed as being useful for people with long-term conditions. Many were anxious, however, that those service users who do not want or are unable to use personal budgets should also have adequate support and safeguards and that this too ought to be covered by guidance. One group suggested that guidance should address how resource allocation systems for personal budgets can actually constrain choice and control.

Prevention

Different aspects of prevention were discussed in connection with long-term conditions- how good quality care can prevent people from developing long-term conditions entirely or after developing one condition, prevent another; preventing

long-term conditions from getting worse and how people can be empowered to effectively self-manage their conditions so that both of the previous aspects are possible.

Several groups talked about the potential economic benefits of investing in preventative measures, that is, preventing admissions into hospital or nursing care or preventing a deterioration in wellbeing. There were calls for the guidance to provide economic evidence on whether such investment would be cost-effective, as councils are faced with the dilemma of deciding how much money to invest in either prevention or acute/responsive services.

The principle that care for older people with long-term conditions should maximise independence rather than sustain it was discussed by several groups, with self-management thought to be an important aspect of long-term conditions to address in guidance. Lifestyle changes and assistive technologies were the most common elements of self-management discussed by the groups. Again from a preventative point of view, one group highlighted that technology is easier to adapt to or learn in the early stages of developing a long-term condition suggesting the benefits of good forward-planning and timeliness. One group noted the importance of the role played by families in using assisted technologies.. Finally with regards to self-management, one group highlighted the issue of rights and responsibilities and questioned how guidance can help incentivise people to manage their long-term conditions.

Wellbeing

When discussing prevention, many groups also made links with the issue of promoting wellbeing through good quality social care. There was appreciation for the fact that the scope takes certain aspects of wider wellbeing into account e.g. the negative impact of social isolation and the need for social support although some views expressed that wellbeing more broadly could be more explicitly referenced in the scope. One group called for the scope to clarify what it means when referring to an outcome of preventative effects.

Many groups called for wellbeing as an outcome of care to be a focus of the guidance and highlighted that mood-lifting activities can often be more important for addressing the needs of older people with long-term conditions than clinical interventions. One group discussed the prescription by GPs of leisure activities such as gym memberships, social clubs or particular activities. A participation approach was discussed whereby people set their own aims and outcomes.

Self-management was also linked to wellbeing whereby certain social support activities such as peer support through groups and forums, as well as improving wellbeing, can enable and empower people to develop a sense of personal responsibility. In this way, activities aimed at improving wellbeing, such as healthy living programmes can be understood to also be preventative measures.

Finally, some groups questioned why physiotherapy (PT) and occupational therapy (OT) were excluded from the scope when they are seen to be potentially key to promoting and supporting independence, wellbeing and participation. Others raised the point that OT and PT are as beneficial for mental health conditions as well as physical conditions, are complimentary and can lead to better general outcomes for older people with long-term conditions.

Language

The language and definitions used in the scope were discussed by all groups, in varying detail. One group called for a glossary to be provided, while other groups agreed that certain terms required explicit definitions including, for example: social care; frailty; older people and long-term condition. One group suggested that when disseminating the guidance to an audience of people needing and using services that 'social care' should be replaced with 'care and support'. There was a caution against using language that could be perceived as jargon such as 'single assessment process' or 'care co-ordination.' One group cautioned that a definition of a long-term condition 'that can't be cured but can be managed' excludes slow onset motor neurone disease which is a long-term condition that only deteriorates.

The Guidance Development Group (GDG)

Groups recommended the following in terms of stakeholder representation on the GDG:

- In terms of representation of people needing services, there was a recommendation that this should include self-funders/ those managing their own care and those who can't.
- One group suggested that there should be a person needing services who suffers from the most common of the long term conditions, or someone who cares for someone in this position.
- Providers from across the health and social care sectors, local authority, private and voluntary sectors (large and small). One group pushed for representation of integrated community trusts.
- Experts in different care settings e.g. home care, residential care. In this same vein, one group called for housing provider interests to be represented.
- Umbrella organisations and alliances- professional and issue based.
- A public health pharmacist with social care background
- People with experience in social care practice, policy and/or commissioning
- GP and CCG representatives
- Individuals with a background in advocacy and/or campaigning on these issues
- Regulators including Charity Commission.
- People working for/ with a background in organisations specialising in particular conditions e.g. sensory loss; mental health; physical and mental disability.

- People with experience in human rights and equalities issues e.g. age discrimination, e.g. partners involved in the EHRC report 'Close to Home'.
- Academics from ageing research centres.

Names of nominated particular individuals were noted by scoping group members but it was emphasised that the recruitment would be an open process, following NICE's standard approach.

The groups also made recommendations about the evidence base and gave very useful examples of innovative practice which were noted in order that they could be easily followed up, as appropriate, by the NCCSC team as part of the main phase of guidance development.

Other areas of discussion

Apart from these key themes the groups fed back on the following issues:

- The groups fed back on a number of issues that could be considered as part of the Equality Impact Assessment which will be published with the final scope:
 - ❖ Ethnicity and cultural differences – cultural 'care in the family' role and access. One group urged caution in using older literature which makes inappropriate assumptions around different groups and how care is planned and delivered. They recommended that literature on this issue needs to go beyond prevalence studies. One group raised the point that Romanians do not have GPs and therefore engage with health services differently when they move here.
 - ❖ LGBT individuals in later life can lack the support networks needed to ensure they are able to manage their long-term conditions and whose specific needs are not being met in care homes or nursing homes.
 - ❖ While not a 'protected characteristic' issue, several groups raised the issue of stigmatised conditions such as HIV/AIDS and how this affects engagement of care staff and medical practitioners.
 - ❖ How rural and urban populations have different access to care
 - ❖ The particular but separate needs of migrants, asylum seekers and refugees respectively (since immigration status affects entitlements).
 - ❖ The guidance should look at community groups who support themselves e.g. travellers.
 - ❖ One group questioned whether in looking at carers, younger carers caring for older people might be considered within the scope.

- ❖ One group highlighted that people suffering from mental health conditions are not covered by the regulations on overstaying in hospital beds. This inequality is a challenge for mental health geriatricians.
- ❖ The needs and environment of those with sensory disabilities, including what one group termed the 'deaf community' need to be considered.
- One group discussed in detail the links for this guidance with medicine management, with specific comments regarding social care being:
 - That 60% of carers look after medicine with no support at all
 - That while healthcare professionals manage medicines there is poor communication with social care staff expected to also deliver them. There is a real need for clarification on roles in this area, that health guidance will not necessarily address.
- Several of the groups remarked how important it was for the guidance to fit with the Health and Social Care Bill 2012 and therefore be applicable to self-funders and those having their care funded by the local authority. The guidance will also need to fit with the Vulnerable Older Person's Plan from the Department of Health. The groups discussed how important it was self-funders and their carers to have access to information which can be seen to be lacking at the moment.
- The guidance should also look at: settings funded through continuing healthcare such as hospices and discuss end of life care in general; how care is organised for those moving from prisons into the community; proper and adequate housing and the impact that this can have on the management of long-term conditions; cancer as a long-term condition.
- Finally one group felt that the guidance should highlight the lack of investment in social care research which can make producing evidence-based guidance more difficult.