NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

NICE guidelines

Equality impact assessment

Social care of older people with complex care needs and multiple long-term conditions

The impact on equality has been assessed during guidance development according to the principles of the NICE equality policy.

1.0 Scope: before consultation (To be completed by the developer and submitted with the draft scope for consultation)

1.1 Have any potential equality issues been identified during the development of the draft scope, before consultation, and, if so, what are they?
Equality issues identified during pre-scoping work: **Focus on Older adults**: The particular characteristics of older adults with multiple long-term conditions (LTCs) justify focusing the guideline exclusively on social and integrated care services for them. This guideline will focus on LTCs that are age related, or exacerbated by age, because prevalence of LTCs, and numbers of people with multiple LTCs, is rising within the older population as people live longer. Current estimates suggest that 58% of people aged over 60 have at least one LTC (compared with 14% of people under 40). The number of people with multiple LTCs is expected to rise to 2.9 million in 2018 (from 1.9 million in 2008). This topic focuses on co-morbidities, including mental health problems, and there is reason to suspect that the mental health needs of older people are often not met. Up to 25% of older adults suffer symptoms of depression, and having one or more LTCs is a risk factor for depression. However, older people, especially those in residential care, may not be referred to mental health services, and those that are may not be offered psychological therapies. Carers of older adults with LTCs may also have undiagnosed mental and physical health conditions which jeopardise their ability to carry on caring. Poor access to assessment and treatment services may amount to age discrimination in the allocation of health and social care resources to older people, and the guideline should aim to address that. **Diversity in population**: Older adults are as diverse as the entire population.

Services should be sensitive and accommodating to different cultural, religious and LGBT requirements. People of ethnic minority background, recent migrants and people who do not speak English as their first language are likely to have reduced knowledge of, and hence access to, social care services.

Gender: The Health and Social Care Information Centre figures for 2011-12 shows that 61% of service users (of all ages) receiving community-based social care services are female. Recorded rates of depression and anxiety are between one and a half and two times higher for women than for men. However, three-quarters of people who commit suicide are men (NDTi). There is no reason to assume these differences do not apply to older people. The guideline should consider gender issues relevant to service users and carers.

Older adults with disabilities, including those arising from traumatic injury: People with physical and mental disabilities are affected by a range of issues which limit their ability to lead independent lives, including environmental constraints, and attitudes which limit expectations and aspirations in their care. Disability may be closely associated with one or more LTCs, as a consequence, cause or co-existing factor. The guideline will focus on personalised care, and will therefore consider disability within the context of managing LTCs.

People with a long-term mental health condition: People with mental health problems such as schizophrenia or bipolar disorder die on average 16–25 years sooner than the general population and suffer poorer physical health. They may experience difficulties in accessing good care for physical illness. The guideline should consider this group of older adults.

People who have dementia: Published research and guidelines very often focus exclusively on care for people with dementia, despite the likelihood that the person has other conditions, including depression and anxiety. The guideline will be concerned with the recognition of common treatable mental and physical health problems which co-exist with another long term condition and may be overlooked.

Older adults who may lack capacity: Communication strategies, quality of services, choice and control, and safeguarding are important issues for this group.

People with communication difficulties, and/or sensory impairment: Communication strategies, quality of services, choice and control, and safeguarding are important issues for people with communication difficulties, whatever their cause. Sensory impairment (such as deafness) and communication difficulties may develop with or be exacerbated by age, leading to difficulty in accessing services and information about services. This may be a particular difficulty in mental health diagnosis and service provision, which relies heavily on communication.

Mental health of people from black and minority ethnic backgrounds: People can have difficult relationships with mental health services. Black people are around three times more likely than the general population to experience

compulsory admission for treatment. The rates of mental health problems in particular migrant groups, and subsequent generations, are also sometimes higher. For example, migrant groups and their children are considered to be two to eight times at greater risk of psychosis than the general population (NDTi). Difficulties, trauma and painful transitions experienced at any time of life may cause mental health problems for older people.

People who experience discrimination and stigma: Older people who have mental health problems or another highly stigmatized condition such as HIV/Aids may face lack of understanding, fear and judgmental attitudes from care providers and the wider community. The guideline will consider how care providers can promote equality of access and care to all people, and support staff to address prejudice.

People at end of life: People who are in the last year of life may need enhanced care and regular review. They are likely to need highly dependable care from both health and care professionals, including pain relief and other support, at any time of the day or night.

Social and economic deprivation: Evidence suggests that lower socio-economic status may be associated with poor access to information about care options. There is also evidence that the prevalence of LTCs is twice as high among people from the lowest social class V (60%) when compared to people in the highest social class I (30%) (DH Compendium). The onset and management of LTCs may also be influenced by risky health behaviours associated with lower income groups, such as smoking, poor diet, alcohol consumption and obesity, etc. The health of older people reflects lifetime experience (Marmot, 2010). This illustrates the complicated relationship between socio-economic status and long-term conditions, which can be described as one of two-way causality. Finally, we may want to highlight the recent welfare reforms and identify any evidence related to their likely impact on lower socio-economic groups.

Location: The delivery of social care for people with LTCs in rural environments may be difficult. The guideline, and evidence on which it is based, should ensure that this potential disadvantage is considered.

Residential care: Older adults who live in residential, including nursing, homes may have poor access to primary and community care services, including those that provide mental health assessment and treatment. The guideline should cover their particular circumstances.

People without a home: People who do not have a settled home (e.g. the homeless; gypsies and others with traveller lifestyle) are likely to be excluded from services, although searches oriented to their personal/social care will be undertaken.

Informal carers' gender and ethnicity: There is some evidence of stereotyping that suggests that women and ethnic minority carers are more likely to be expected to provide informal care than their male/white counterparts.

Plans for dealing with these aspects include sensitivity to equality and diversity issues, and search strategies specifically oriented to seek out material on these groups. The guideline will address the organisation and delivery of services that take account of these issues, including the provision of advice and information to support access to personalised services. The guideline will attempt to uncover and address some of the areas where there is well-documented discrimination. The Guideline Development Group may also make recommendations specifically in relation to particular service users and carers.

1.2 What is the preliminary view on the extent to which these potential equality issues need addressing by the Committee? For example, if population groups, treatments or settings are excluded from the scope, are these exclusions justified – that is, are the reasons legitimate and the exclusion proportionate?

Proposed exclusions from pre-scoping work:

We propose excluding younger adults (typically, but not exclusively defined as those under 65) and children with LTCs receiving social care support. There may be a need to apply a more flexible age threshold for older adults, as we do not wish to promote the view that adults of a particular age should have different services and possibly experience different standards of care. The scope of the work is unlikely to do justice to all client groups, so the guideline will be focused on older adults and age-related conditions.
Clinical or health care is excluded given the guideline focuses on social care, unless that health care is delivered in partnership, liaison or joint teams with social care services. All aspects of coordination between health and social care, including referrals for assessment, will be included in scope.

2.0 Scope: after consultation (To be completed by the developer and submitted with the final scope)

2.1 Have any potential equality issues been identified during consultation, and, if so, what are they?
Consultation on the scope: Comments highlighted the following equality issues: 1. That the scope should not be limited to those with multiple (two or more) long-term conditions. 2. That the scope should acknowledge the prevalence of hearing and sight loss amongst older people. 3. That older people with learning difficulties may not receive adequate attention. 4. Several comments encouraged the scope to acknowledge specific conditions such as neurodegenerative conditions, motor neurone disease and many others. 5. Inclusion of incontinence as a long term conditions was a concern. 6. Several comments highlight the absence of mental health in the scope.

2.2 Have any changes to the scope been made as a result of consultation to highlight potential equality issues?
The concerns voiced in the consultation were adequately dealt with in developer responses. 1. The remit for the guideline as specified by the Department of Health specified that the guideline focus on older people with ‘more than one long term condition’. 2. It was confirmed that older people with sensory impairments were within the population of interest for this guideline. 3. It was confirmed that older people with learning difficulties were within the population of interest for this guideline 4. The response to comments about the inclusion of specific conditions was that ‘We have not specified which conditions are of interest in the scope, because we do not intend to exclude any particular conditions’. 5. It was confirmed that incontinence will be part of the guideline and considered by the review questions. 6. As with specific physical conditions, mental health issues are included within the scope and no specific conditions are excluded.

2.3 Is the primary focus of the guideline a population with a specific disability-related communication need? If so, is an alternative version of the 'Information for the Public' document recommended? If so, which alternative version is recommended? The alternative versions available are: • large font or audio versions for a population with sight loss; • British Sign Language videos for a population who are deaf from birth; • 'Easy read' versions for people with learning disabilities or cognitive impairment.
The guideline is aimed at all older people with multiple long-term conditions. Many of the recommendations will also have applicability to older people with health and social care needs more generally. As a result it is highly likely that this guideline should be accessible to older people with specific disability-related communication needs. The guideline should be made available in a variety of alternative versions. Including: • large font or audio versions for a population with sight loss

Updated by Developer **Tony Hunter**

Date **10th January 2014**

Approved by NICE quality assurance lead **Nick Baillie**

Date **13th January 2014**

3.0 Guideline development: before consultation (to be completed by the developer before draft guideline consultation)

3.1 Have the potential equality issues identified during the scoping process been addressed by the Committee, and, if so, how?
The following points relate to all issues listed below: • In conducting searches, the aim was to ensure that we captured literature relevant to all older people with multiple long-term conditions (i.e. including available evidence relating to particular sub-groups of older people). To do this, searches were broad in nature and were based upon retrieving items that referred to older people with long-term conditions or their carers within the settings of service-user's own homes, community/residential care and/or health and social care staff who work with this population. The searches contained a combination of terms and synonyms in relation to the population, settings and workforce, including, for example: 'Aged', 'Older', 'Elder*' combined with terms including: 'Long* term conditions', 'morbidities'. The search terms were a combination of comprehensive free text terms and relevant controlled vocabulary terms, aiming to balance sensitivity and precision, and the strategy was run across a number of economic, health, social care and social sciences databases. • Throughout the guideline development process, the Guideline Committee emphasised the importance of a 'person-centred' ethos, driven by the needs and preferences of people who use care and support and their carers. The guideline also aims to emphasise coherent, integrated working to help ensure people's support is coherent and addresses them as a whole person, rather than a collection of symptoms.

3.2 Have any **other** potential equality issues (in addition to those identified during the scoping process) been identified, and, if so, how has the Committee addressed them?

What issue was identified and what was done to address it?	Mitigations
Focus on Older People: The particular characteristics of older people with multiple long term conditions. Many older people will develop co-morbidities and there are concerns that they may experience age discrimination in the allocation of resources to them.	The recommendations relate to all older people with multiple long term conditions using health and social care services.
Diversity in population: Older people with LTCs come from every sector of society. Health or social care services should be sensitive and accommodating to different cultural, religious and LGBT requirements. People of ethnic minority backgrounds, recent migrants and people who do not speak English as their first language are likely may to have reduced knowledge of, and hence access to, social care services, and may find them more difficult to access.	Recommendations 1.1.1 and 1.1.2 focus on a needs-based approach to assessment and recommendation 1.2.2 emphasises the importance of tailoring care planning to ensure the person has choice and control, and so that it addresses all their needs. Recommendations in section 1.5 emphasise the importance of helping ensure people maintain links to their local community groups and social contacts. The recommendations also address the issue of ensuring people know what they are entitled to and can access peer (or other) support if they wish.
Gender: The Health and Social Care Information Centre figures for 2011-12 shows that 61% of service users (of all ages) receiving community-based social care services are female. The reasons behind this are unclear, and will be investigated so far as possible.	There was insufficient evidence to make recommendations specific to male users. The recommendations relate to all older people.
Disabilities, including those arising from traumatic injury: Older People with multiple long term conditions may have a range of physical and cognitive disabilities. They may be affected by a range of issues which limit their ability to lead independent lives, including environmental constraints, and attitudes which limit expectations and aspirations in their care.	Recommendations in section 1.7 relate to the competence of the workforce supporting people with complex, long-term conditions. These highlight the need for practitioners to be able to recognise a range of common conditions and issues affecting older people with multiple long-term conditions. The recommendations in section 1.2 prompt care coordinators to develop plans that minimise the impact of health problems and maximise quality of life, independence, choice and control.

	Recommendations relating to social isolation and information highlight the importance of assisting older people to access advocacy services.
Older people who may lack capacity: Communication strategies, quality of services, choice and control, advocacy and support to take medication and safeguarding are important issues for this group. **People with communication difficulties, and/or sensory impairment:** Communication strategies, quality of services, choice and control, and safeguarding are important issues.	Recommendation 1.7.2 seeks to ensure practitioners can support people with commonly occurring needs or conditions, including dementia and sensory loss. Throughout, the recommendations make reference to involvement of carers (as appropriate) recognising the critical role they play in supporting older people with long-term conditions. There is also reference throughout to the need to provide (and review provision of) information. Recommendation 1.5.8 prompts care home managers to consider signposting people to advocacy services, recognising that people in care homes may find it particularly difficult to exercise choice and control.
Socio-economic status: Older people who do not have independent means may feel excluded from choosing the nature of their care. Evidence suggests that lower socio-economic status is associated with increased difficulty in (a) accessing information about care options; and (b) ability to pay for care.	The recommendations relate to all older people with multiple long term conditions Recommendation 1.2.7 highlights the need to provide people with information about, and support to test, different mechanisms for managing the budget available to them and a number of the recommendations (1.2.7, 1.5.5) highlight the need to give people information about what support they are entitled to and its costs.
Location: The delivery of health and social care services for older people with a complex range of conditions may be logistically difficult in rural areas, and rural patients may find themselves isolated due to a lack of public transport.	The recommendations on preventing social isolation (1.6) and on delivering care in care homes make explicit reference to ensuring older people are supported to remain engaged in their communities.
Informal careers' gender and ethnicity: There is some evidence of stereotyping that suggests that women	The recommendations within section 1.3 relate to supporting carers, who are also referenced throughout the

and ethnic minority carers are expected to provide informal care more than their male/white counterparts	recommendations, recognising the important role they play. There was insufficient evidence to make recommendations for specific minority groups.
Social care workforce: Workers need training on recognising common long-term conditions.	Recommendations on training (section 1.7) are intended to help ensure workers have the appropriate training and skills to deal with common conditions and are competent to manage medication, if that will be part of their role.

3.3 Were the Committee's considerations of equality issues described in the consultation document, and, if so, where?

Considerations of equality issues are addressed in the EIA document.

3.4 Do the preliminary recommendations make it more difficult in practice for a specific group to access services compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?

See mitigations in 3.2

3.5 Is there potential for the preliminary recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?

See mitigations in 3.2

3.6 Are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access to services identified in questions 3.1, 3.2 or 3.3, or otherwise fulfil NICE's obligation to advance equality?

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See mitigations in 3.2

4.0 Final guideline (to be completed by the Developer before GE consideration of final guideline)

4.1 Have any additional potential equality issues been raised during the consultation, and, if so, how has the Committee addressed them?

4.2 If the recommendations have changed after consultation, are there any recommendations that make it more difficult in practice for a specific group to access services compared with other groups? If so, what are the barriers to, or difficulties with, access for the specific group?

4.3 If the recommendations have changed after consultation, is there potential for the recommendations to have an adverse impact on people with disabilities because of something that is a consequence of the disability?

4.4 If the recommendations have changed after consultation, are there any recommendations or explanations that the Committee could make to remove or alleviate barriers to, or difficulties with, access to services identified in questions 4.2, 4.3 and 4.4, or otherwise fulfil NICE's obligations to advance equality?

4.5 Have the Committee's considerations of equality issues been described in the final guideline document, and, if so, where?

Updated by Developer ____

Date____

Approved by NICE quality assurance lead _________________________________

Date____

5.0 After Guidance Executive amendments – if applicable (To be completed by appropriate NICE staff member after Guidance Executive)

5.1 Outline amendments agreed by Guidance Executive below, if applicable:

Approved by Developer ____

Date____

Approved by NICE quality assurance lead _________________________________

Date____