NATIONAL INSTITUTE FOR HEALTH AND CLINICAL EXCELLENCE

GUIDELINES EQUALITY IMPACT ASSESSMENT FORM
RECOMMENDATIONS

As outlined in the guidelines manual NICE has a duty to take reasonable action to avoid unlawful discrimination and promote equality of opportunities. The purpose of this form is to document that equalities issues have been considered in the recommendations of a clinical guideline.

Taking into account **each** of the equality characteristics below the form needs:

- To confirm that equality issues identified in the scope have been addressed in the evidence reviews or other evidence underpinning the recommendations
- To ensure the recommendations do not discriminate against any of the equality groups
- To highlight areas where recommendations may promote equality.

This form is completed by the National Collaborating Centre and the Guideline Development Group **for each guideline** before consultation, and amended following consultation to incorporate any additional points or issues raised by stakeholders.

The final version is submitted with the final guideline, signed by the NCC Director and the Guideline Development Group (GDG) Chair, to be countersigned by the GRP chair and the guideline lead from the Centre for Clinical Practice.

EQUALITY CHARACTERISTICS
Sex/gender • Women • Men
Ethnicity • Asian or Asian British • Black or black British • People of mixed race • Irish • White British • Chinese • Other minority ethnic groups not listed
Disability • Sensory • Learning disability • Mental health • Cognitive • Mobility • Other impairment
Age[1] • Older people • Children and young people • Young adults [1.] Definitions of age groups may vary according to policy or other context.
Sexual orientation & gender identity • Lesbians • Gay men • Bisexual people • Transgender people
Religion and belief
Socio-economic status Depending on policy or other context, this may cover factors such as social exclusion and deprivation associated with geographical areas (e.g. the Spearhead Group of local authorities and PCTs, neighbourhood renewal fund areas etc) or inequalities or variations associated with other geographical distinctions (e.g. the North/South divide, urban versus rural).
Other categories[2] • Gypsy travellers • Refugees and asylum seekers • Migrant workers • Looked after children • Homeless people [2.] This list is illustrative rather than comprehensive.

GUIDELINES EQUALITY IMPACT ASSESSMENT FORM: RECOMMENDATIONS

Guideline title: Spasticity in children and young people with non-progressive brain disorders

1. Have the equality areas identified in the scope as needing attention been addressed in the guideline?

Please confirm whether

- the evidence reviews addressed the areas that had been identified in the scope as needing specific attention with regard to equalities issues.

Please note this also applies to consensus work in or outside the GDG

- the development group has considered these areas in their discussions

Note: some issues of language may correlate with ethnicity; and some communication issues may correlate with disability

The following text summarises equalities issues identified at scoping and proposed actions during development.

Equality issues were considered by the scoping group before and after discussion with stakeholders at the stakeholder workshop and following stakeholder consultation on the draft scope. No gender, ethnicity, age, sexual orientation, religious or socio-economic equality issues were identified by the scoping group or the stakeholders as being of particular concern in this guideline.

Following receipt of stakeholder comments the scope was revised to take account of other motor disorders (dystonia, muscle weakness, choreoathetosis) that co-exist with spasticity in children and young people. This inclusion allowed a broader, more clinically meaningful perspective of the management of the child or young person's overall mobility disability.

The scoping group recognised that a child or young person with a mobility disability can have co-existing disabilities or conditions that may affect management of their spasticity. With regard to co-existing disabilities, the scoping group identified the following as potentially relevant:

- cognitive and learning disabilities

- visual, hearing and speech impairments or other communication disability.

The scoping group acknowledged that the assessment of some subjective outcomes, particularly acceptability or tolerability of a treatment would be dependent on the child or young person's ability to communicate. The scoping group recognised that such assessments could be aided by presenting relevant information in an appropriate way and undertook to ensure that children and young people with communication disabilities would not be disadvantaged by the guideline recommendations.

The scoping group noted further that any evidence of co-existing disabilities affecting management of the child or young person's mobility disability would be noted during each systematic review conducted for the guideline. Where evidence was not available, the guideline development group (GDG) would be expected to use its clinical expertise and experience.

With regard to co-existing conditions, the scoping group identified the following as potentially relevant:

- epilepsy
- disorders of nutrition and growth
- impaired bone mineralisation (osteoporosis)
- urological disorders (voiding difficulties or incontinence)
- pressure sores
- respiratory disorders (including apnoea, airway obstruction and chronic aspiration)
- feeding difficulties (including enteral tube feeding)
- gastrointestinal disorders (including gastro-oesophageal reflux and constipation)
- obesity.

Stakeholders raised the last three points as being part of 'the mainstay of management'. The scoping group agreed that the GDG would not consider evidence for management of these co-existing conditions, but would only consider evidence for management of the child or young person's mobility

disability. Whilst the scoping group did not think that the co-existing conditions were strictly pertinent to the equalities process (because they were not disabilities), it agreed that the GDG should consider whether any differences in management would be required for children and young people with these co-existing conditions compared to children and young people without these difficulties. The scoping group noted that separate recommendations should be made if necessary.

The following text outlines how the equalities issues identified at scoping were addressed by the GDG during development.

During development of the guideline recommendations, the GDG considered all the issues outlined in the equality form completed as part of the scoping process. At a general level the GDG, through the phrasing of its recommendations, sought to ensure that children and young people with spasticity and co-existing motor disorders who have the capacity to make decisions should have the opportunity to make informed decisions about their care and treatment in partnership with their healthcare professionals. As in other NICE clinical guidelines for children and young people, the recommendations include reference to parents and carers involved in taking decisions about the care and treatment of their children.

The guideline includes a specific recommendation for healthcare professionals to identify and agree with children and young people, and their parents or carers, goals and assessments that are appropriate for the child or young person's age and development. The recommendations also state that goals should focus on the following domains of the World Health Organization's International Classification of Functioning, Disability and Health (ICF; http://www.who.int/classifications/icf/en/):

- body structure and function
- activity and participation.

The GDG considered co-existing conditions that may affect children and young people with spasticity and other motor disorders and, whilst these conditions are

not strictly pertinent to the equalities process (as they are not disabilities), the GDG has emphasised in a number of recommendations how care should be adapted for children and young people with co-existing conditions. Specifically, the GDG's recommendations include considering whether any equipment or technique used in a physical therapy programme is safe and appropriate in children and young people with poorly controlled epilepsy, respiratory compromise, risk of aspiration, or risk of bone fracture due to osteoporosis. The GDG emphasised that healthcare professionals should be aware that children and young people who are non-ambulatory, malnourished or taking anticonvulsant therapy may be at increased risk of osteoporosis and bone fractures and that in such cases sustained low-load stretching to prevent or limit contractures and joint deformity should be considered. The GDG also emphasised that healthcare professionals should be aware that certain co-existing medical conditions are potential contraindications to treatment with continuous pump-administered intrathecal baclofen (for example, uncontrolled epilepsy, coagulation disorders and some respiratory conditions). The GDG emphasised that healthcare professionals should be cautious when considering treatment with botulinum toxin type A in children and young people with co-existing bleeding disorders, including disorders due to anti-coagulant therapy.

A further issue raised by the GDG in relation to equalities was that when formulating physical therapy programmes for children and young people, healthcare professionals should take account of any possible difficulties in implementing the programme and its implications for the individual child or young person and their family, including the time and effort involved and potential individual barriers. Although the GDG did not identify any direct evidence of individual barriers to implementation, they considered that there was a wide range of cultural, social and economic circumstances that should be taken account of. For example, cultural norms might discourage activities such as swimming and hydrotherapy, or group activities with members of the opposite sex. These considerations are documented in the 'Evidence to recommendations' section that accompanies the recommendation (see Chapter 4 of the full guideline).

The GDG reconsidered all the draft recommendations in the light of stakeholder comments. As part of this process, the GDG provided clear guidance in relation to access to care for children and young people with cognitive impairments and/or communication difficulties. They strengthened the recommendations in relation to transfer to adult services to ensure that all young people receive appropriate support and continuity of care during transition. They also provided more comprehensive recommendations for children and young people with co-existing dystonia, for example for children and young people with spasticity in whom dystonia is causing significant problems with posture, function, pain and self-care (or ease of care for parents).

2. Do any recommendations make it impossible or unreasonably difficult in practice for a specific group to access a test or intervention?

For example:

- Does access to the intervention depend on membership of a specific group?
- Does using a particular test discriminate unlawfully against a group?
- Do people with disabilities find it impossible or unreasonably difficult to receive an intervention?

No

3. Do the recommendations promote equality?

Please state if the recommendations are formulated so as to promote equalities, for example by making access more likely for certain groups, or by tailoring the intervention to specific groups?

Yes (see Section 1 above for details)