

# National Institute for Health and Care Excellence

## Surveillance Review of CG170 Autism spectrum disorder in under 19s: support and management

### Stakeholder Comments Form

<b>Please enter the name of your registered stakeholder organisation below.</b>	
NICE is unable to accept comments from non-registered organisations. If you wish your comments to be considered please register via the <a href="#">NICE website</a> or contact the <a href="#">registered stakeholder organisation</a> that most closely represents your interests and pass your comments to them.	
<b>Stakeholder Organisation:</b>	Optical Confederation, Local Optical Committee Support Unit and SeeAbility
<b>Name of commentator:</b>	Richard Knight (LOCSU)

*Please note an overview of the process for reviewing NICE published clinical guidelines can be found [here](#)*

#### Contents:

- Comments on proposal not to update the guideline – page 2
- Comments on the proposal to remove research recommendations from the NICE version of the guideline and the NICE research recommendations database – page 2
- Comments on equality issues or areas excluded from the guideline scope – page 3

## **Proposal not to update the guideline**

In order to guide your comments, please refer to the following questions:

1. Do you agree that the guidance should not be updated?
2. Do you agree with our proposal to remove the listed research recommendations from the NICE version of the guideline and the NICE research recommendation database?

If a stakeholder wishes to draw our attention to published literature, please supply the full reference. Please add extra rows as needed

<b>1. Do you agree the guideline should not be updated?</b>	<b>Comments</b> <b>If you disagree, please explain why</b>
Disagree	<p>We note that the guidelines suggest that it is ensured that there is equality of access to health care services for children and young people with autism.</p> <p>We also note that mention is made of providing visual supports e.g. words, pictures or symbols that are meaningful to an individual to reinforce communication.</p> <p>The findings in the SeeAbility Children in Focus Campaign second year report— <a href="https://www.seeability.org/uploads/files/Children_in_Focus_campaign/CiF-full-report-2016.pdf">https://www.seeability.org/uploads/files/Children_in_Focus_campaign/CiF-full-report-2016.pdf</a>— show that 75% of children who had no history of previous sight tests had autism.</p> <p>These early results lead us to believe that there is a risk of under detection of sight problems in children and young people with autism. Any undetected visual problem may in turn lead to inappropriate means of communication being used by many people working with and caring for these children, and also their refractive errors remaining uncorrected.</p> <p>It may be helpful to add further emphasis on the need to establish the visual status of children and young people with autism in these guidelines.</p>

2. Do you agree with the proposal to remove these research recommendations from the NICE version and research database?		Comments  If you disagree, please explain why
What is the value of a key worker approach (defined by protocol and delivered in addition to usual care) for children and young people with autism in terms of parental satisfaction, functioning and stress and child psychopathology?	Agree / Disagree (please delete as appropriate)	Comments on proposal to remove these research recommendations from the NICE version and research database – No comments on Question 2.
Is a sleep hygiene intervention or melatonin clinically and cost effective in the management of sleep onset, night waking and reduced total sleep in children (aged 4–10 years) with autism?		
What is the comparative clinical and cost effectiveness of pharmacological and psychosocial interventions for anxiety disorders in children and young people with autism?		
Are comprehensive early interventions that combine multiple elements and are delivered by parents and teachers (for example, the Learning Experiences – an Alternative Program for Preschoolers and their Parents [LEAP] model) effective in managing the core symptoms of autism and coexisting difficulties (such as adaptive behaviour and developmental skills) in pre-school children?		

**Do you have any comments on equality issues or areas excluded from the original scope?**

No comments.

**Please email this form to: [surveillance@nice.org.uk](mailto:surveillance@nice.org.uk)**

**Closing date: 5:00pm 1 June 2016**

**PLEASE NOTE:** The Institute reserves the right to summarise and edit comments received during consultations, or not to publish them at all, where in the reasonable opinion or the Institute, the comments are voluminous, publication would be unlawful or publication would be otherwise inappropriate.