# Attention deficit hyperactivity disorder (standing committee update)

## Consultation on draft guideline - Stakeholder comments table

## 6 November 2015 – 4 December 2015

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| Royal College of General Practitioners | Addendum | General | General | The RCGP welcomes this document and has no comments at this stage. | Thank you. |
| Royal College of Paediatrics and Child Health | addendum | General | General | Based on clinical experience provided, we have been informed that there is no effect of few foods diet and risk of impact on behaviour due to restriction. This guideline will help in talking to parents with more confirmatory evidence. | Thank you. |
| Royal College of Psychiatrists | Addendum | General | General | NICE recommendations in the addendum sound sensible and in line with practice. | Thank you. |
| Royal College of Psychiatrists | Addendum | General | General | The recommendations in the Addendum make sense. | Thank you. |
| Royal College of Paediatrics and | Addendum | | 1.2 point 3 | Challenges may be:<br>a) the availability of paediatric dieticians<br>b) in the important concept of 'working jointly' between the professionals ( as well as parents) in light of this availability and the way paed, camhs and paediatric dietetic services are | Thank you for raising these suggestions. We will pass these comments on to the NICE implementation team. |

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| Child Health | | | | organised and link . Trusts should consider if they can and how they will provide for these expectations or guidance across boundaries . | |
| Royal College of Psychiatrists | Addendum | 1.2 | 1.2 | A very timely set of recommendations for questions that are frequently asked by young people, parents and carers. The College supports this. | Thank you. |
| Royal College of Psychiatrists | Addendum | 2.1.1 | 2.1.1 | The extant evidence in this area - relating to "few foods diet" - is very limited, and the recommendations seem reflective of this. It is important to emphasise that this limited evidence suggests some short-term benefits. | Thank you. The Committee agrees that the evidence relating to the 'few foods diet' is limited, although suggests some benefit in the short term. This is reflected in recommendation 1.4.2.5 of the short version (recommendation 3 in the addendum) which recommends that family members and carers should be advised that there is some evidence of short term benefits, but no evidence about long-term benefits. |
| Royal College of Psychiatrists | Addendum | 2.2 | 2,2 | Evidence in this area is not limited. However it is not extensive enough to conclude regarding long-term efficacy or cost-effectiveness of these interventions. Hence the recommendations of the Addendum in this respect are also pragmatic. | Thank you. |
| British Psychological Society | Addendum | 7 | 9 | The Society believes that talking about 'ADHD symptoms' takes a reductionist approach to what is a complex set of difficulties encountered by people who have been given a diagnosis of ADHD. | Thank you. We agree that ADHD symptoms are not the only factor to consider. We have changed the wording of the introductory text to read 'There has been considerable interest in the effect of diet on ADHD' rather than 'There has been considerable interest in the effect of diet on ADHD symptoms'. |

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| Royal College of Paediatrics and Child Health | Addendum | 8 | As above | Is the short term evidence of benefit of few food diets really robust ?<br><br>This recommendation may generate dietetic work for short term gain so is that economic?<br><br>It implies some ambiguity. | Thank you. The Committee discussed your comment and agreed that the recommendation may unintentionally generate dietetic work. The recommendation has therefore been reworded to emphasise that the short term evidence of benefit is limited (it was based on only 2 trials from the same research group), and to remove reference to the harms of treatment without dietary advice, as this could lead to the assumption that advice should be sought in relation to the few food diet. The recommendation now reads 'Advise the family members or carers of children with ADHD that there is only limited evidence of short-term benefits of a 'few food' diet for children with ADHD and there is no evidence about long-term effectiveness.' |
| Royal College of Paediatrics and Child Health | Addendum | 8 | 1.2<br><br>And later: | Practical clear [2016] update<br><br>Useful [new 2016] advice | Thank you |
| Royal College of Paediatrics and Child Health | Addendum | 8 | 1.2 ie Recommendations update | What might help:<br>a) Local pathways and agreed protocols between dieticians and clinicians on ADHD food advice and what works, on clinical review of any interventions and responsibilities, communication.<br>b) Updated accessible on line practical literature for parents / carers which professionals are aware of and can offer. | Thank you for raising these suggestions. We will pass these comments on to the NICE implementation team. |

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| | | | plus in general | c) Food Diary and Symptom cards given to parents by clinicians and or sent out with appointments and returned pre appointments with dieticians. | |
| British Psychological Society | Addendum | 8 | 19 | The Society welcomes the guidance for clinicians to explicitly ask about food or drinks that appear to influence hyperactive behaviour as part of the clinical assessment of ADHD in children and young people. | Thank you. |
| British Psychological Society | Addendum | 8 | 19 | The recommendations state 'if there is a clear link' but we would prefer to see this worded so that it reflects situations where parents may see a clear link that would benefit from a food diary being kept. Similarly, the Society would recommend rewording the second bullet point to reflect situations where parents and the clinician do not agree whether any diary supports a relationship between specific food, drinks and behaviour.<br><br>The third bullet point reflects the idea that further management should be jointly managed between parents and clinicians and we would like to see this collaborative approach adopted more widely in throughout the recommendations. | Thank you. The recommendation referred to has been carried forward (with wording changes to bring it in line with current NICE style) from the original NICE guideline on ADHD, where it was made based on the consensus of original guideline development group members. The standing committee for the update felt that there was no new evidence to contradict this recommendation, and therefore it should stand. |
| British Psychological Society | Addendum | 9 | 7 | The Society welcomes the statement that 'patients should have the opportunity to make informed decisions about their care and treatment, in partnership with their healthcare professionals. | Thank you. |

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| British Psychological Society | Addendum | 9 | 8 | The Society welcomes the recognition that family and carers are a crucial part of the support process for children and young people, but we would like to see this extended to young people over 16 if this is what the young person believes that this would be beneficial.<br><br>The Society has concerns that there is an expectation that young people aged over 16 are able to, or may want to be solely responsible for their healthcare. This is certainly not the case for young people aged over 16 with complex presentations of neurodevelopmental disorders, such as ADHD, where co-occurrence of neurodevelopmental conditions is the norm (Gillberg, C. 2010; Lundstrom, S. et al, 2015), or where the young person has intellectual difficulties. We also believe that young people over 16 should be explicitly asked if they want their parents or carers to continue to be involved in their healthcare management as they navigate the transition to adult mental health services, rather than it being assumed that they do not; this is especially the case for young people with any degree of vulnerability. | Thank you. The comments refer to the section of the addendum on patient-centred care, which include information about how care should be delivered that applies to all NICE guidance. Specific recommendations on the transition of care between paediatric and adult services were outside of the scope of the current update, which was limited to dietary interventions for ADHD in children and young people. However, a wider update of the ADHD guideline is also currently underway. Details of this update can be found on the NICE website (http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0798). We will also pass your comments on to the developers of this update. |
| British Psychological Society | Addendum | 9 | 22 | The Society welcomes the recommendation that 'adult and paediatric healthcare teams should work jointly to provide assessment and services to young people with ADHD'. However, we have concerns that more clarity or guidance | Thank you. The comments refer to the section of the addendum on patient-centred care, which include information about how care should be delivered that applies to all NICE guidance. Specific recommendations on the transition of |

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| | | | | in the document about how this should happen. It is all too familiar to hear from young people of a complete breakdown in provision as they move from paediatric focused services with a philosophy of care that involves the young person and their family, to adult services where provision is focused only on the individual. | care between paediatric and adult services were outside of the scope of the current update, which was limited to dietary interventions for ADHD in children and young people. However, a wider update of the ADHD guideline is also currently underway. Details of this update can be found on the NICE website (http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0798). We will also pass your comments on to the developers of this update. |
| British Psychological Society | Addendum | 10 | 41 | It is of concern that there was insufficient data to assess any subgroup effects since this may limit the applicability of the recommendations to some groups. | Thank you. We agree that data on subgroups could have been useful for making recommendations and acknowledge that the lack of data may limit the applicability of the recommendations to some groups. We have now emphasised this in the 'evidence to recommendations' sections of the addendum (sections 2.1.7 and 2.2.7). |
| Neonatal and Paediatric Pharmacists Group | General | General | General | No comments | Thank you |
| Hyperactive Children's Support Group | General | General | General | The HACSG is delighted to see that there will be an opportunity for Consultants and parents to consider any possible Food Reactions/ Intolerances, We hope that this actually happens in practice. | Thank you. No studies on the exclusion or restriction of artificial food colourings were found that met the inclusion criteria specified in the review protocol (appendix C of the addendum). The articles cited in your comment were not included in the evidence review for the following |

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| | | | | The HACSG is bitterly disappointed that and Additive/ Artificial Colouring Free Diet is still not recommended, we cannot understand this view, considering the following research and opinions.<br><br>Professor Andrew Kemp, University of Sydney said in the BMJ Volume 363 24th May 2008 that he feels a Trial of an Additive Free Diet should be considered part of the standard treatment for Hyperactivity.<br>The Isle of Wight Study, Archives of Disease in Childhood, 2004:89 : 506-511 and The Southampton Study : Published in the Lancet 6/9/2007 found Artificial Colourings and Sodium Benzoate caused Hyperactivity.<br>Also the Institute of Child Health found during their Diet and ADHD research that whilst certain foods caused problems Additives came top of the list, published in The Archives of Disease in Childhood July 1993: 69 : 564-568.<br>The HACSG findings were 89% of 357 Diagnosed Children had a problem with Artificial Colourings, so we are totally puzzled as to why an additive free diet should be dismissed. Considering that pre- school Attention Deficit HYPERACTIVE Children are not to to be prescribed the Medications as discussed in the Update, why not suggest some simple changes to their diets for a few weeks, just in case there is a benefit.<br><br>The HACSG is also dismayed to learn that the role of Omega | reasons:<br><br>**BMJ Volume 363 24th May 2008** (we have assumed that this citation refers to BMJ 2008; 336:1144, Food additives and hyperactivity). This article is an editorial review, and therefore was not the correct study type for inclusion (included studies were restricted to randomised controlled trials and systematic reviews).<br><br>**Archives of Disease in Childhood, 2004:89 : 506-511**<br>This study was on a general population of children rather than children or young people with ADHD; it therefore did not meet the population criteria for the review. Additionally the study described dietary challenge with benzoate and artificial food colourings rather than elimination of these products from the diet; the intervention in the study therefore also did not match that set out in the review protocol.<br><br>**The Lancet, 2007: 370: 1560-1567**<br>Like the study described above, this study was also on a general population of children |

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| | | | | Oils/ Essential Fatty Acids is also dismissed as an approach to try, in addition there is no mention of the role played by Zinc, Magnesium, Vitamin B6, surely it would be, in view of the research carried out,in to the importance of nutrition for Hyperactivity/ ADHD to give these no drug avenues a trial.<br><br>In the Times on 25/11/2015 Concerns were again being expressed about the use of Methylphenidate for ADHD after reviewing all the available evidence published by the Cochrane Library.<br><br>The HACSG has sent a package of literature to each of the ADHD Update Committee Members. | rather than children or young people with ADHD; and the study described dietary challenge with benzoate and artificial food colourings rather than elimination of these products from the diet.<br><br>**The Archives of Disease in Childhood 1993: 69 : 564-568**<br>This study described a 'few foods elimination diet', but was not included in the review because the treatment duration was less than 2 weeks, which was an inclusion criterion for the review (1 week treatment duration in randomised phase). The study also described a dietary challenge phase, which did not match the intervention specified in the review protocol (elimination or restriction of foods in the diet).<br><br>However, the Committee agreed that the elimination of artificial colours and preservatives is an important issue and warrants specific research on its long-term effectiveness in the management of ADHD in children and young people. The Committee have therefore added a research recommendation recommending that a |

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| | | | | | randomised controlled trial is conducted to address this question.<br><br>The Committee did not recommend omega-3 fatty acids as a treatment for ADHD because they concluded that the balance of evidence did not show a clinically important benefit over placebo. The Committee noted that dietary interventions can be associated with harms, burdens on families, and costs. Therefore the Committee were unable to recommend interventions without clear evidence of benefit for children and young people with ADHD.<br><br>Supplementation with Zinc, Magnesium, Vitamin B6, and pharmacological treatments were outside of the scope of the current update, which had a narrow focus on restriction/elimination diets and supplementation with polyunsaturated fatty acids. Therefore, these interventions were not considered. |
| NHS England | General | General | General | No comments | Thank you. |
| Association of | General | General | General | No comments | Thank you. |

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| School and College Leavers | | | | | |
| British Psychological Society | General | General | General | The Society welcomes the recognition of the importance of diet for children and young people who have been diagnosed with ADHD, as this is something that is frequently discussed with clinicians by children, young people and their parents. | Thank you. |
| British Psychological Society | General | General | General | The Society has concerns about the lack of self-report measures of 'ADHD symptoms'; evidence suggests that young people can feel detached from the management of ADHD (Brinkman et al, 2012) with important implications for treatment compliance. We would like to see recognition that solely relying on parents and teacher report of 'ADHD symptoms' may lead to only a partial picture of the distress and difficulty experienced by children and young people who have a diagnosis of ADHD. | Thank you. Self-reported ADHD symptoms was included as an important outcome to consider in the evidence review. However, no evidence that met the criteria specified in the review protocol reported this outcome. The Committee acknowledges that self-reported symptoms are important to consider, but is only able to make recommendations based on the available evidence. |
| British Psychological Society | General | General | General | **References**<br><br>Brinkman, W.B., Sherman, S.N., Zmitrovich, A.R., Visscher, M.O., Crosby, L.E., Phelan, K.J. & Donovan, E.F. (2012). In their own words: Adolescent views on ADHD and their evolving role managing medication. *Academic Pediatrics* ***12*****(1)**, 53–61. | Thank you. The cited references were not included in the current update because they were outside of the scope of the current update, which was limited to dietary interventions for ADHD. Full details on the inclusion and exclusion criteria for study selection are provided in the review protocol (Appendix C of the addendum). |

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| | | | | Lundstrom, S., Reichenberg, A., Melke, J., Rastam, M., Kerekes, N., Lichtenstein, P,. Gillberg, C. & Anckarsater, H. (2015). Autism spectrum disorders and co-existing disorders in a nationwide Swedish twin study. *Journal of Child Psychology and Psychiatry,* ***56*****(6)**, 702–710.<br><br>Gillberg, C. (2010). The ESSENCE in child psychiatry: Early symptomatic syndromes eliciting neurodevelopment. *Research in Developmental Disabilities,* ***31***, 1543–1551<br><br>Lundstrom, S., Reichenberg, A., Melke, J., Rastam, M., Kerekes, N., Lichtenstein, P,. Gillberg, C. & Anckarsater, H. (2015). Autism spectrum disorders and co-existing disorders in a nationwide Swedish twin study. *Journal of Child Psychology and Psychiatry,* ***56*****(6)**, 702–710. | However, a wider update of the ADHD is also currently underway. Details of this update can be found on the NICE website (http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0798). We will also pass your comments on to the developers of this update. |
| Department of Health | General | general | General | No comments | Thank you. |
| Royal College of Nursing | General | General | General | No comments | Thank you. |
| North East London NHS | Short | General | General | Consider including guidance on the use of Lisdexamfetamine as an alternative treatment option in children who do not respond to methylphenidate and atomoxetine | Recommendations on the use of pharmacological treatments were outside of the scope of the current update, which was limited to dietary interventions for ADHD in children and young |

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| Foundation Trust | | | | | people. However, a wider update of the ADHD guideline is also currently underway. Details of this update can be found on the NICE website (http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0798). We will also pass your comments on to the developers of this update. |
| North East London NHS Foundation Trust | Short | General | General | Consider including guidance on the use of guanfacine for ADHD as an alternative to stimulants | Recommendations on the use of pharmacological treatments were outside of the scope of the current update, which was limited to dietary interventions for ADHD in children and young people. However, a wider update of the ADHD guideline is also currently underway. Details of this update can be found on the NICE website (http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0798). We will also pass your comments on to the developers of this update. |
| NHS Havering CCG | Short | General | General | Consider including guidance on the use of Lisdexamfetamine as an alternative treatment option in children qwho do not respond to methylphenidate and atomoxetine | Recommendations on the use of pharmacological treatments were outside of the scope of the current update, which was limited to dietary interventions for ADHD in children and young people. However, a wider update of the ADHD guideline is also currently underway. Details of this update can be found on the NICE website (http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0798). We will also pass your comments on to the developers of this update. |
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| North East London NHS Foundation Trust | Short | 4 | 25 - 27 | Our Trust is recommending that there be an emphasis on the psychological intervention options for children.<br>Consider amending the statement:<br>"ensure age-appropriate psychological services are available, and are offered to, [for] children, young people and adults with ADHD, and to [for] parents or carers." | Recommendations on the use of psychological treatments were outside of the scope of the current update, which was limited to dietary interventions for ADHD in children and young people. However, a wider update of the ADHD guideline is also currently underway. Details of this update can be found on the NICE website (http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0798). We will also pass your comments on to the developers of this update. |
| NHS Havering CCG | Short | 4 | 25<br><br>27 | Our Trust is recommending that there be an emphasis on the psychological intervention options for children. Consider the statement: 'Ensure age appropriate psychological services are available and are offered to children, young people and adults with DHD and to parents or carers' | Recommendations on the use of psychological treatments were outside of the scope of the current update, which was limited to dietary interventions for ADHD in children and young people. However, a wider update of the ADHD guideline is also currently underway. Details of this update can be found on the NICE website (http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0798). We will also pass your comments on to the developers of this update. |
| Royal College of Paediatri | Short | 13 | 1.4.2.3 bullet point | We are concerned about the implication it will have on dietetic service in terms of limited resources suggest specialist dietitian and leaflets about diet produced which can be used in clinics by Paedatric/CAMHs colleagues when needed | Thank you. The recommendation that you refer to is carried over from the original NICE guidance on ADHD, published in 2008 (with updated wording to bring it in line with current NICE style). |

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| cs and Child Health | | | 3 | | Therefore we do not anticipate additional resources or changes to leaflets will be needed as a result of this recommendation. |
| Royal College of Paediatrics and Child Health | Short | 39 | 3 | We now have DSM V so DSM!V is out of date. They should score> 6/9 in inattentiveness and > 6/9 on combined impulsivity and hyperactivity screening criteria. They should have the symptoms for at least 6 month persistent in different settings before the age of 12years (new to DSM V). | Thank you. We have updated the information in the 'context' section of the short version of the guideline to include the new diagnostic criteria. |
| Royal College of Paediatrics and Child Health | Short | 39 | 14 | The comorbidity can be up to 75% includes DCD(development coordination disorder/Dyspraxia),SPD9sensory processing difficulties/attachment difficulties ,oppositional defiant disorder, autism spectrum disorder, learning difficulties in addition. | Thank you. The 'context' section of the guideline is taken from the original NICE guideline on ADHD. We are unable to make changes to this section that are outside of the scope of the current update on dietary interventions (other than to correct factual inaccuracies) and so have not made the suggested change. However, a wider update of the ADHD guideline is also currently underway. Details of this update can be found on the NICE website (http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0798). We will also pass your comments on to the developers of this update. |
| Royal College of Paediatrics and Child Health | Short | 40 | 12 | Restlessness and taking longer to complete task. | Thank you. The 'context' section of the guideline is taken from the original NICE guideline on ADHD. We are unable to make changes to this section that are outside of the scope of the current update on dietary interventions (other than to correct factual inaccuracies) and so have not made the suggested change. However, a |

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| | | | | | wider update of the ADHD guideline is also currently underway. Details of this update can be found on the NICE website (http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0798). We will also pass your comments on to the developers of this update. |
| Royal College of Paediatrics and Child Health | Short | 40 | 23 | It is much more common in looked after children population and is under recognised ref: *Matt Woolgar[1,2] and Emma Baldock[1] Article first published online: 22 JAN 2014 The Child and adolescent mental health ,20: 34-40.* | Thank you. The 'context' section of the guideline is taken from the original NICE guideline on ADHD. We are unable to make changes to this section that are outside of the scope of the current update on dietary interventions (other than to correct factual inaccuracies) and so have not made the suggested change. However, a wider update of the ADHD guideline is also currently underway. Details of this update can be found on the NICE website (http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0798). We will also pass your comments on to the developers of this update. |
| Royal College of Paediatrics and Child Health | Short | 42 | 25 | There is evidence from a large study that the effect size of medication is much more than even very structured intensive behavioural programmed ref: *Multimodal Treatment of Attention Defici1t Hyperactivity Disorder (MTA) Study 1999 to 2009.* | Thank you. The research recommendation that is referred to is taken from the original NICE guideline on ADHD. We are unable to make changes to this section that are outside of the scope of the current update on dietary interventions (other than to correct factual inaccuracies) and so have not made the suggested change. However, a wider update of the ADHD guideline is also currently underway. Details of this update can be found on the NICE website |

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| | | | | | (http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0798). We will also pass your comments on to the developers of this update. |
| Royal College of Paediatrics and Child Health | Short | 43 | 15 | Details of resources such as website www.addiss.co.uk or www.adhdandyou.com should be given to staff to refer. | Thank you. NICE does not usually direct clinicians to external websites in the short version of the guideline, because websites can quickly become out of date, and NICE does not have control over external content and so cannot guarantee the accuracy of any information provided. |
| College of Occupational Therapists | Short version | 13<br>14 | 14-27<br>1-8 | The College of Occupational Therapists recommends that consideration be given to the potential additional burden of drastic diet changes to the functioning of the family and the relationship between the parent/carer and child. | Thank you. The Committee considered the burden of dietary changes on families and relationships when considering the evidence and making recommendations. For example, the committee discussed the burden of a restrictive diet on families because of the need to prepare separate foods and ensure compliance. The committee also discussed the possibility that a very restricted diet could be seen as a punishment, and therefore be counterproductive in the long term. The details of this discussion are documented in the 'Evidence to recommendations' section of the addendum (Section 2.1.7, trade-off between benefits and harms). |
| College of Occupational Therapist | Short version | 42 | 14-23 | Research recommendations could include the effectiveness of parent/carer and child group intervention approaches and not be limited to delivery of training to families. For example, positive results have been shown with social and play skill interventions: | Recommendations on the use of parenting interventions were outside of the scope of the current update, which was limited to dietary interventions for ADHD in children and young people. Therefore research recommendations |

**Attention deficit hyperactivity disorder (standing committee update)**
**Consultation on draft guideline - Stakeholder comments table**
**6 November 2015 – 4 December 2015**

***Comments forms with attachments such as research articles, letters or leaflets cannot be accepted.***

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| s | | | | Wilkes-Gillan S, Bundy A, Cordier R, et al. (2014a) Child outcomes of a parent-delivered intervention for improving the social play skills of children with ADHD and their playmates. Developmental Neurorehabilitation 2: 1–8.<br><br>Wilkes-Gillan S, Bundy A, Cordier R, et al. (2014b) Eighteen month follow-up of a play-based intervention to improve the social play skills of children with attention deficit hyperactivity disorder. Australian Occupational Therapy Journal 61(5): 299–307.<br><br>Wilkes-Gillan S, Bundy A, Cordier R, et al. (2014c) Evaluating a pilot parent-delivered play-based intervention for children with ADHD. American Journal of Occupational Therapy 68: 700–709. | could not be made in this area. However, a wider update of the ADHD guideline is also currently underway. Details of this update can be found on the NICE website (http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0798). We will also pass your comments on to the developers of this update. |

*Comments received in the course of consultations carried out by NICE are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the submissions that NICE has received, and are not endorsed by NICE, its officers or advisory committees*