

Date and Time: 1st December 2009 (10:00 – 16:00)

Minutes: Confirmed

Guideline Development Group Meeting Autism Spectrum Disorder (ASD)

Place: *RCPCH, London*

GDG present: *Gillian Baird (GB) (Chair)*
 Susan Anderson (SA)
 Carol Bagnall (CB)
 Tony Charman (TC)
 Diana Howlett (DH)
 Ann Le Couteur (ALC)
 Jamie Nicholls (JN)
 Sharon Richman (SR)
 Lorraine Scott (LS)
 Emily Simonoff (ES)
 Zoe Thompson (ZT)
 Penny Williams (PW)
 Anne Marie McKigney (AM)

NCC-WCH staff in attendance: *Hannah Rose Douglas (HRD)*
 Shona Burman-Roy (SBR)
 Gemma Malin (GM)
 Sarah Latreille (SL)
 Lily Jin (LJ)
 Stephen Murphy (SM)
 Hugh McGuire (HM)
 Manveet Patel (MP)
 Ed Peston (EP)

NICE Staff:	Nick Staples (NS)	
Observers:	N/A	
Invited speaker:	N/A	
Apologies:	None	

Notes

(GB) welcomed the group to the third meeting of this GDG. No apologies were received. (GB) said farewell to (SL) who was leaving the NCC-WCH and thanked her for all her work during the GDG and welcomed (MP) who was the interim Project Manager. (GB) asked all GDG members to declare any relevant conflicts of interest. All declared that they knew of no personal specific, personal non-specific, non-personal specific or non-personal non-specific interest in the development of this guideline.

Notes

(GM) gave a mini presentation to the GDG on statistics and the GDG discussed the relative importance of sensitivity and specificity and how its relative importance will differ along the pathway from initial signs and symptoms to definitive diagnosis. Points were raised around the benefits of early diagnosis.

(GM) presented and reviewed the evidence for Question 1 and discussion followed of the draft GDG translation and recommendations for Question 1. It was agreed that this should be a question put out to Delphi consensus.

(SBR) led a discussion on how to make recommendations; concern was raised on how the GDG could make recommendations on evidence based on a single study of poor quality. (SBR) explained that the GDG would have to justify why it would *not* be recommending tools where evidence was available but of poor quality. (SM) suggested that the recommendations be worded such as 'suggest the possibility of' ASD or 'raises concerns' about ASD. It was agreed that the recommendations for question1 should focus on signs and symptoms that would be recognisable by non –specialists in ASD. It was further agreed that a table of recommendations based on the available evidence and GDG consensus of opinion would be developed by the Chair and the topic group for presentation at GDG 4. The table will focus on signs and symptoms that would help non-experts to decide whether to refer a child or young person for screening, for diagnostic assessment or no action with further monitoring. It will identify those signs based on observation and those requiring a history.

(SL) presented and reviewed the evidence for Question 2 and discussion followed of the draft GDG translation and recommendations for Question 2. It was agreed that any additional studies that used ICD 9 and DSM 3 would be included in question 2 evidence review.

(SBR) gave an update on the Delphi Process and explained that we would be following a similar process to the fever guideline and that it is a two stage consultation process. (HRD) gave an update on user involvement and explained that ethics approval needed to be sought from the RGOG if the NCC-WCH were collecting information from users on their experiences, as it is regarded as original research. The other alternative was to ask another organisation NAC to do it for us. (ZT, HRD and SA) agreed to put together a list of questions for the NAC.

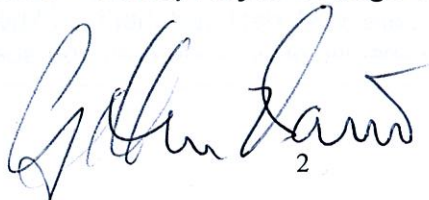
(LJ) and (HG) gave a presentation on the research protocol for Questions 3 and 4. It was agreed to take Erb's Palsy off the list and combine some of the terms that are synonymous. .

Discussion arose over the use of the term PDD and papers that had been excluded which mentioned PDD. It was agreed that PDD is now synonymous with ASD. (ES) agreed to go through the papers that had been excluded. (HM) agreed to review excluded papers to include those where the mean age under 18 years.

The health economics model was briefly discussed and it was agreed that HRD should get together a small topic group to help develop the decision pathway for the model. SR, ES, A-MM and DH agreed to be contacted about this before the next GDG.

(GB) closed the meeting at 4.07pm

26th January 2010 (10:00 – 16:00) Royal College of Paediatrics and Child Health


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