

Date and Time: 26th January 2010 (10.00am-4.00pm)

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:** *Wendy Riches (WR) (item 1 only)*
 Hannah Rose Douglas (HRD)
 Shona Burman-Roy (SBR)
 Gemma Malin (GM)
 Lily Jin (LJ)
 Stephen Murphy (SM)
 Manveet Patel (MP)

NICE Staff:	<i>Sue Latchem (SL)</i>	
Observers:	<i>N/A</i>	
Invited speaker:	<i>Shehla Mohammed</i> <i>Neil Dalton</i>	
Apologies:	<i>None</i>	

Notes

(GB) welcomed the group to the fourth meeting of this GDG. No apologies were received. The GDG introduced themselves (GB) said farewell to (GM) who was moving to work on another guideline at NCC-WCH and thanked her for all her work during the GDG.

(WR) addressed the topic of declarations of interest. There was a discussion and clarification about the importance of non-pecuniary interests (WR) emphasised that any such interests including research publications relevant to the guideline should be declared. The group were

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informed that (GB) had declared published research as personal non-pecuniary interests. The potential relevance of those declarations was under consideration and in the meantime as a precautionary measure it was agreed that (SM) should act as facilitator for the discussions on any related topics.

(TC), (ALC) and (ES) also declared personal non-pecuniary interests in relation to memberships of societies, select committees and regarding publications. These were not considered by (GB) or (SM) to be a bar to participation in the GDG deliberations.

(ALC) also declared non-personal pecuniary interests in relation to royalties and reviewing fees paid to Newcastle University. These were not considered (by GB or SM) to be a bar to participation in the GDG deliberations.

The minutes and project notes of the previous meeting were confirmed with one minor amendment.

(ZT) and (SA) gave a presentation on the value of diagnosis and shared their personal/educational and emotional experiences of raising children with ASD

An invited speaker Shehla Mohammed, (geneticist) gave a presentation about investigative tools that are now available with a particular focus on 'Arrays'.

The topic groups updated the GDG on questions 1 and 2. The topic group addressing questions 2 A & C were making progress. Evidence for 2b was ongoing and would be presented at a future meeting.

An invited speaker Neil Dalton (expert advisor, paediatric biochemist) gave a presentation.

(GM) presented the evidence for question 3A. SM facilitated the subsequent discussion. Potential recommendations were discussed. It was agreed that the topic group would draft further recommendations and translations for future discussion.

SL gave an update on the matter of Delphi consensus and user involvement. She suggested that the GDG focus on specific questions for a Delphi survey rather than all questions.

(SL) reported that no additional survey work is required from user groups during the development phase of the guideline. She suggested that the NAS could help to make sure that the consultation is as wide as possible by ensuring that young people know of the stakeholder consultation process and its dates.

Items 10, 11 and 13 on the agenda were not presented, due to time constraints.

(GB) closed the meeting at 4.10pm

**Next meeting: 9th March Royal College of Obstetrics and Gynaecology (RCOG)
10.00am-4.00pm**