NICE National Institute for Health and Care Excellence

Minutes: Confirmed

Guideline Development Group Meeting		Diabetes in children and young people guideline update	
Date and Time:	Wednesday 1 and Thursday 2 April 2015		
	10:00 – 16:30		
Place:	Royal College of Obstetric London	cians and Gynaecologists	
Present:	Jerry Wales (Chair) (JW) Francesca Annan (FA) Jo Dalton (JD) Jacqui Double (JDo) Sarah Eaton (SE) Julie Edge (JE) Nikhil Gokani (NG) William Lamb (WL) Carol Metcalfe (CM)	(Present for notes $1 - 32$) (Present for notes $1 - 13$ and $23 - 28$) (Present for notes $1 - 32$) (Present for notes $1 - 32$)	

In attendance:

Expert adviser: Katharine Barnard (KB)	(Present for notes 10 – 11)
NCC-WCH staff: Lilian Stevens (LS) Paul Jacklin (PJ) Moira Mugglestone (MM)	(Present for notes 1 – 29) (Present for notes 1 – 6) (Present for notes 1 – 16 and
Stephen Murphy (SM) Sadia Janjua (SJ) Yelan Guo (YG)	(Present for notes $1 - 32$) (Present for notes $1 - 32$) (Present for notes $1 - 27$) (Present for notes $1 - 9$)
Grammati Sarri (GS) NICE attendees:	(Present for notes 17 – 21)
Katie Perryman-Ford (KPF) James Hall (JH)	(Present for notes 1 – 32) (Present for notes 1 – 32)

Observers:

Gemma Villanueva (GV), NCC-	(Present for notes 17 – 24)	
WCH		

Notes

<u>Day 1</u>

- 1. JW welcomed the group to day 1 of the thirteenth meeting of this guideline development group (GDG). There were no apologies.
- 2. The minutes from GDG 12 were agreed.
- 3. JW asked all the GDG members and other attendees to declare any new interests that they had accrued since GDG 12 and reiterate any interests declared previously that were relevant to the meeting agenda. The GDG members were reminded that NICE had revised its policy on conflicts of interest, and all members were asked to complete a declaration form even if they had no new interests to declare.

<u>FA</u>

Personal pecuniary interest

Received funding from the Juvenile Diabetes Research Foundation (JDRF) to cover travel, accommodation and an honorarium to attend a JDRF PEAK programme expert panel meeting on exercise and diabetes.

Received funding from the organisers of an Italian paediatric diabetes meeting to cover travel, accommodation and an honorarium as an invited speaker on the International society for Pediatric and Adolescent Diabetes (ISPAD) nutrition guidelines. The meeting was sponsored by Eli Lilly.

<u>JD</u>

Personal pecuniary interests

Received funding from her employer (a hospital trust) to attend the Diabetes UK annual Professional Conference.

Received funding from her employer (a hospital trust) to attend a study day on insulin pump therapy sponsored by Roche.

Received funding from the organisers of an international group called BEYOND TEENS to attend a meeting as a member of the group. The group is taking forward results of the TEEN project, focusing on wellbeing and quality of life for adolescents and young adults, and is sponsored by Sanofi Aventis.

<u>SE</u>

Personal pecuniary interest

Honorarium from the University of York as a panel member for a discussion regarding the GP's role in transition care.

Non-personal pecuniary interest

Continues to be a member of a conference planning group as declared previously.

<u>JE</u>

Personal pecuniary interest

Honorarium from the University of York as an invited speaker at a master's module on diabetic ketoacidosis (DKA).

Non-personal pecuniary interest

Chief investigator on a study of a new glucose sensor funded by Abbots Diabetes Care. Local principal investigator on the same study. The funding contributes to a research trust fund managed by JE.

Personal pecuniary interests

Researcher in public health and law with consultancy in the same field but not related to diabetes.

Honorarium from the National Institute for Health Research (NIHR) for peer review of research applications on topics not related directly to any areas covered by the guideline scope.

Honorarium from the NIHR for peer review of a Health Technology Assessment (HTA) on psychological interventions in children and young people with long-term health conditions.

Personal non-pecuniary interests

Supporting member, group and committee member, and volunteer at Diabetes UK.

Continues to be a member of the Partnership Board of the National Diabetes Audit at the NHS Health and Social Care Information Centre as declared previously.

Continues to be a member of the Joint Speciality Committee on Endocrinology and Diabetes Mellitus, a joint committee of the Royal College of Physicians, the Society for Endocrinology, Diabetes UK, and the Association of British Clinical Diabetologists as declared previously.

Member of the Specialist Advisory Committee on Diabetes and Diabetes Mellitus at the Joint Royal Colleges of Physicians Training Board.

Member of the Delphi Consensus Panel on pressure ulcers in children and young people at the National Clinical Guideline Centre (NCGC).

BL

Personal pecuniary interest

Received funding from Diabetes UK to cover accommodation and conference fees to attend the Diabetes UK annual Professional Conference as an invited speaker. Did not speak about any topics related directly to any areas covered by the guideline scope.

No other new declarations of interest were received from the GDG members or the other attendees. It was agreed that no interests declared at the meeting or previously warranted exclusion of any GDG members from discussions of evidence or formulation of recommendations at the meeting.

- 4. JW gave an overview of the stakeholder comments received in response to the consultation on the draft guideline and outlined the plan for the meeting.
- 5. JW led the GDG through stakeholder comments about blood glucose and HbA1c monitoring and targets. The group revised recommendations and other guideline text as appropriate and drafted responses to comments.
- 6. JW led the group through stakeholder comments about health economics and the group agreed with PJ how to progress responding to these.
- 7. JW led the group through stakeholder comments about insulin regimens. The group revised recommendations and other guideline text as appropriate and drafted responses to comments.
- 8. JW led the group through stakeholder comments about diagnosis. The group revised recommendations and other guideline text as appropriate and drafted responses to comments.
- 9. JW led the group through issues raised by the expert adviser (KB) about psychological and social factors and education. The group agreed steps to take account of these comments.

- 10. JW led the group through stakeholder comments about psychological and psychosocial factors with KB in attendance. The group revised recommendations and other guideline text as appropriate and drafted responses to comments.
- 11. JW led the group through stakeholder comments about education and information with KB in attendance. The group revised recommendations and other guideline text as appropriate and drafted responses to comments.
- 12. JW led the group through stakeholder comments about restricted sports. The group revised recommendations and other guideline text as appropriate and drafted responses to comments.
- 13. JW led the group through stakeholder comments about research recommendations. The group revised recommendations and other guideline text as appropriate and drafted responses to comments.
- 14. MM explained to the group the process for managing stakeholder comments about topics excluded from the update.
- 15. JW led the group through an update on the additional guideline products being developed by NICE (information for the public and NICE pathway). KP-F and JH informed the group about steps taken by NICE to seek support from patient support organisations to produce additional material based on the guideline that would be accessible to children and young people with diabetes. There was a further discussion on this topic on day 2 (see item 28).
- 16. JW led the group through an initial discussion of stakeholder comments about DKA. The group revised recommendations and other guideline text as appropriate and drafted responses to comments.

<u>Day 2</u>

- 17. JW welcomed the group to day 2 of the meeting.
- 18. JW led the group through stakeholder comments about diet. The group revised recommendations and other guideline text as appropriate and drafted responses to comments.
- 19. JW led the group through stakeholder comments about monitoring for complications. The group revised recommendations and other guideline text as appropriate and drafted responses to comments.
- 20. JW led the group through stakeholder comments about the format of the guideline and terminology. The group revised recommendations and other guideline text as appropriate and drafted responses to comments.
- 21. JW led the group through stakeholder comments about intercurrent illness and ketone monitoring. The group revised recommendations and other guideline text as appropriate and drafted responses to comments.
- 22. JW led the group through stakeholder comments about metformin for type 2 diabetes. The group revised recommendations and other guideline text as appropriate and drafted responses to comments.
- 23. JW led the group through stakeholder comments about glucagon. The group revised recommendations and other guideline text as appropriate and drafted responses to comments.

- 24. JW led the group through stakeholder comments about weight and age as determinants of dosage of medicines. The group revised recommendations and other guideline text as appropriate and drafted responses to comments.
- 25. MM reminded the group about the NICE publications policy for guideline developers. The group discussed possibilities for publications based on the guideline.
- 26. JW led the group through stakeholder comments about equalities. The group revised recommendations and other guideline text as appropriate and drafted responses to comments.
- 27. JW led the group through a further discussion of stakeholder comments about DKA. The group revised recommendations and other guideline text as appropriate and drafted responses to comments.
- 28. JW led the group through a further discussion about the potential for NICE to coordinate production of additional material based on the guideline that would be accessible to children and young people with diabetes. The group expressed disappointment with the attempts that had already been made with regard to this and their perception of lack of support from NICE for the patient group to whom the guideline applies especially as there was an initial expression of support from NICE. KP-F emphasised that NICE had already gone further than is its usual practice in terms of exploring the potential for additional documents aimed at children and young people with diabetes but that consultation with patient groups indicated to NICE that such material was not thought to be required. NG discussed the amount of work he had put into an attempt to develop accessible guidance and wanted to further explore sponsorship of the production of such material from charitable sources with an external writer.
- 29. JE updated the group on the discussions at the Diabetes Oversight Group (DOG) meeting held on 24 February.
- 30. JW led the group through the identification of a list of issues to be raised at the final DOG meeting on 14 April.
- 31. MM outlined the next steps of the guideline development process, including the expected timescale for publication of the guideline. The group was reminded to contact the NICE media relations team if they received any media enquiries about the guideline.
- 32. There were no items of other business. JW thanked the group for attending and closed the meeting.

Date, time and venue of the next meeting

No further meetings were planned for this GDG.