

**Minutes: confirmed**

**Guideline Development Group Meeting 1<sup>st</sup> Cerebral Palsy in children and young people Guideline Development Group meeting**

**Date and Time:** 5<sup>th</sup> November 2014 – 10:00 – 16:00

**Place:** Broadway House, London

**Present:**

Charlie Fairhurst (CF) (Chair)	(Present for notes 1 - 13)
Athena Logothetis (AL)	(Present for notes 1 - 13)
Bidisha Lahoti (BL)	(Present for notes 1 - 13)
Cheryl Davis (CD)	(Present for notes 1 - 13)
Duncan Walsh (DW)	(Present for notes 1 - 13)
Elspeth Dixon (ED)	(Present for notes 1 - 13)
Helen Cockerill (HC)	(Present for notes 1 - 13)
Laura Middleton (LM)	(Present for notes 1 - 13)
Liz (Elizabeth) Keenan (LK)	(Present for notes 1 - 13)
Margaret Mayston (MM)	(Present for notes 1 - 13)
Neil Wimalasundera (NW)	(Present for notes 1 - 13)
Paul Eunson (PE)	(Present for notes 1 - 13)
Valerie Stevenson (VS)	(Present for notes 1 - 13)
Zoe Connor (ZC)	(Present for notes 1 - 13)

**GDG Apologies:** None

**In attendance:**

<b>NCC-WCH:</b> Vanessa Delgado Nunes (VDN) Kate Coles (KCs) Katherine Cullen (KCn) Omnia Abdulrazeg (OA) Valentina Ricci (VR) Zoisia Beckles (ZB)	Guideline Lead Project Manager Health Economist Research Associate Research Associate Information Scientist	(Present for notes 1 – 13) (Present for notes 1 – 13) (Present for notes 1 – 9) (Present for notes 1 – 13) (Present for notes 1 – 13) (Present for notes 1 – 13)
<b>NICE:</b> Oliver Bailey (OB)  Emma Chambers (EC)	Guideline Commissioning Manager Public Involvement Adviser	(Present for notes 1 – 13)  (Present for notes 1 – 13)
<b>Apologies:</b> Stephen Murphy (SM)	Clinical Co-Director	

**Observers:**

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## Notes

1. CF welcomed the group to the first cerebral palsy GDG meeting and completed housekeeping. Introductions were made by all attendees and GDG members. Apologies were received from Stephen Murphy (Clinical Co-Director from NCC-WCH). For the first meeting, the Chair explained that at this stage in the meeting any potential interests would usually be declared but as this was the first meeting, the GDG would be first given a presentation on the NICE declarations of interest policy.
2. The update to the NICE policy for conflicts of interest was presented by VDN. Questions were taken from the group. Declarations were outlined by the GDG and the NCC-WCH attendees. It was agreed that due to the change to the NICE policy all attendees would resubmit their declarations of interest forms on email or by hard copy to KCs following discussion in the meeting. Declarations made are listed below and held on record at the NCC-WCH.

HC declared Personal Financial Nonspecific interest - Paid/unpaid lectures in NHS/university context including opinions on treatment options, based on own reading of the literature – feeding, saliva control and speech.

ZC declared Personal Financial Nonspecific interest - Ongoing freelance work under the umbrella of nutritionnutrition Ltd (director and sole employee). Includes private consultations, medico-legal work, consultancy work, speaking and writing and having an online presence via website and social media. None of this work has been specific to cerebral palsy or commissioned by the NHS in the 12 months prior to this appointment.

ZC declared Personal Financial Nonspecific interest - To be confirmed - speaker fees for presentation at Nestle in March 2015 on fussy eating in toddlers.

ZC declared Personal Financial Nonspecific interest - Attended Nutrition and Health conference in Barcelona in January 2014 with travel and accommodation and attendance fees funded by Danone.

ZC declared Personal Non-Financial Nonspecific interest - Ongoing lecturing on Dietetics and Nutrition to undergraduates and post graduate nutrition and dietetic students at London Metropolitan University.

ZC declared Personal Non-Financial Nonspecific interest - Author of chapter on autism in the text Clinical Paediatric Dietetics edited by Vanessa Shaw, published November 2014.

CD declared Personal Financial Nonspecific interest - Runs a private practice as a paediatric neuropsychologist/clinical psychologist. As part of this work sees children with cerebral palsy.

CD declared Personal Financial Nonspecific interest - Employee of Sheffield children's NHS Foundation Trust

PE declared Personal Non-Financial Specific interest - Paper accepted for publication in supplement of Developmental medicine and Child neurology on " Long term health, social, and financial burden of Hypoxic-ischemic Encephalopathy"

PE declared Personal Non-Financial Specific interest - Trustee of Castang Foundation, a charity that funds research into prevention and management of developmental disorders in children including cerebral Palsy.

CF declared no shareholdings or financial interests in commercial sector/products. No private income with regard to cerebral palsy 2014. No competitor interests.

CF declared Personal Financial Specific interest - Flight and accommodation paid for as part of faculty for European Movement Therapy Guidelines – Budapest 4-6th April 2014. No faculty fee accepted by CF. Management of spasticity in children. Within NICE hospitality policy.

CF declared Personal Financial Specific interest - Flight paid for as speaker invitation to German Cerebral Palsy Group (ZEBRA) Munich – 5th December 2014. No speaker fee accepted by CF. Within NICE hospitality policy.

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CF declared Non-Personal Financial Specific interest - Chief Investigator Trial – Use of Sativex (Cannabinoid) in children with spasticity-payment from institution for trial work 2012-2016. Accommodation and food paid for at trial meeting, Maidstone 29-30 April 2014.

CF declared Personal Non-Financial Specific interest - Talks (no fees, hospitality or travel allowance) National Association of Paediatric Charter Physiotherapists 2013 – Pain in Cerebral Palsy.

CF declared Personal Non-Financial Specific interest - Coauthored A Colver, C Fairhurst, P Pharoah. Cerebral Palsy. Lancet 2013; 382:1-10

CF declared Personal Non-Financial Specific interest - Coauthored H Cockerill, D Elbourne, E Allen, D Scrutton, E Will, A McNee, C Fairhurst, G Baird. Speech, Communication and the use of augmentive communication in young people with Cerebral Palsy: The SH&PE population study, Child Care, Health and Development 2013 Pub online May.

CF declared Personal Non-Financial Specific interest - Coauthored D Lumsden, C Lundy, C Fairhurst, JO Lin. Dystonia severity Action Plan: a simple grading system for medical severity of status dystonicus and life threatening dystonia. Dev Med Child Neurol 2013;55(7):71-673

CF declared Personal Non-Financial Specific interest - Authored C Fairhurst. Cerebral Palsy the whys and how. Arch Dis Child Educ Pract. 2012; 97: 122-131.

CF declared Personal Non-Financial Specific interest - Coauthored J Parr, C Buswell, K Benerjee, C Fairhurst et al. Management of drooling in children: a survey of UK paediatricians clinical practice. Child Care, Health and Development. 2012; 38(2): 287-291.

CF declared Personal Non-Financial Specific interest - Chair of the National College Specialist Advisory Committee, RCPCH 2012-2017

CF declared Personal Non-Financial Specific interest - Executive Committee's – British Paediatric Neurology Association and British Academy of Childhood Disability – 2013-2016

CF declared Personal Non-Financial Specific interest - Trustee (unpaid) Whizz Kids – mobility Charity 2013-2016

CF declared Personal Non-Financial Nonspecific interest - Drug Monitoring Committee for European Medicines Agency, Botulinum Toxin A (Xeomin) in children with spasticity 2012-15. Spasticity not covered in these guidelines.

BL declared Personal Financial Specific interest - Teaches postgraduate students, GP trainees and medical students locally about Cerebral Palsy.

BL declared Personal Non-Financial Specific interest - Member of the Advocacy Committee of the Royal College of Paediatrics and Child Health. The work of this committee is very general and not specific to cerebral palsy.

AL declared Non-Personal Non-Financial Specific interest - Employed by the Bobath Centre for children with cerebral palsy and uses the Bobath concept as the main part of treatment approach.

AL declared Non-Personal Non-Financial Specific interest - Provides training to medical students about the Bobath approach and cerebral palsy

LM declared Personal Non-Financial Nonspecific interest - Works part time as a speciality doctor at Helen and Douglas house hospice. Partly charitably funded.

LM declared Personal Non-Financial Nonspecific interest - Gives a yearly palliative care lecture to GP trainees and is due to give a lecture on transition to the local transition group in December.

VS declared Personal Financial Specific interest - In the previous 12 months has received teaching honoraria from Almirall and received payment for participation in Bayer Healthcare's advisory board regarding Sativex.

VS declared Personal Financial Specific interest - Editor and author of Spasticity Management: A Practical Multidisciplinary Guide (2006). Eds. VL Stevenson and L Jarrett. Informa Healthcare. ISBN 1-84184-560-4. Receives recognition and royalties.

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VS declared Non-Personal Financial Specific interest - My spasticity management team at UCLH runs an annual course on spasticity management which receives an educational grant from Medtronic as well as sponsorship from other organizations including Dysport and Allergan (botulinum toxin manufacturers), Symetriket (sleep systems), Bayer (Sativex). I have no personal financial interest.

VS declared Personal Non-Financial Specific interest - Through both the study day and other lectures I give I speak about spasticity management including the use of botulinum toxin and intrathecal baclofen.

VS declared Personal Non-Financial Nonspecific interest - Works closely with the MS Charities

VS declared Personal Non-Financial Nonspecific interest - Member of the British Association of Neurologists.

DW declared Personal Financial Nonspecific interest - Wife employed as Area Sales Manager by Sunrise Medical Ltd - a designer and manufacturer of disability products.

DW declared Personal Non-Financial Nonspecific interest - Employee of PACE - a charity that works with children and families of children with Cerebral Palsy and other motor disorders.

NW declared Non-Personal Financial Specific interest - Department is part of an industry funded trial into Sativex a drug used to manage spasticity.

NW declared Non-Personal Financial Specific interest - Department is part of a research trial looking at brain imaging in cerebral palsy.

NW declared Non-Personal Financial Specific interest - Ipsen (drug company) is paying department at Great Ormond Street Hospital to provide lectures for cerebral palsy specialists from Sweden on 27.11.14. Money goes to the departmental charity fund. There is no product endorsement.

NW declared Personal Non-Financial Specific interest - Academic convenor of the British Academy of Childhood Disability. Duties include organising the annual scientific meeting on all disability topics including cerebral palsy. Unpaid.

NW declared Personal Non-Financial Specific interest - Coauthored a paper on the management of symptoms in Cerebral palsy in the BMJ in October 2014. Unpaid.

3. An introductory presentation on NICE guideline development was made by OB.
4. An introductory presentation on the role of patient involvement was made by EC.
5. CF explained to the group about the process involved in developing the scope in consultation with stakeholders, early GDG members, the NCC-WCH and NICE. CF confirmed that the scope was submitted to NICE prior to the first GDG meeting.
6. An introductory presentation on the role of information scientist was made by ZB.
7. A presentation on the cerebral palsy scope was made by CF.
8. An introductory presentation on the role of the Health Economist was made by KCn.
9. An introductory presentation on the process of reviewing evidence was made by VR. This was followed by an introductory presentation by VDN on the process of linking evidence to recommendations.
10. CF and KCs took the GDG through the wording for the review questions. Minor amends for grammar were made and some wording was amended on screen. It was agreed that three questions would be discussed outside of the meeting on email with KCs.
11. VR took the GDG through the draft protocol on saliva control. Changes were made on the

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protocol documents on screen to be finalised after the meeting.

12. OA took the GDG through the draft protocol on nutritional optimisation. Changes were made on the protocol document on screen and it was agreed that the GDG would respond on email with further inputs to the protocol to KCs.
13. CF thanked all for attending and closed the meeting.