

Cerebral Palsy in Adults, Guideline Committee meeting 1

Date: 22nd and 23rd February 2017

Location: Royal College of Obstetricians and Gynaecologists (RCOG)

Minutes: Confirmed

Committee members present	
Paul Eunson	Present for items 1-21
Ruth Kent	Present for items 1-21
Richard Bunn	Present for items 1-21
Elsbeth Dixon	Present for items 1-21
Mohammed Jeewa	Present for items 1-21
Jill Scarisbrick	Present for items 1-21
Val Stevenson	Present for items 1-21
Duncan Walsh	Present for items 1-21
NGA staff	
Katharina Dworzynski	Present for items 1-21
Sabine Berendse	Present for items 1-21
Bishal Bhandari	Present for items 1-21
Nathan Bromham	Present for items 1-21
Charlie Fairhurst	Present for items 1-21
Gemma Marceniuk	Present for items 1-21
NICE staff	
Rupert Franklin	Present for items 1-21
Apologies	
Lloyd Bradley	GC member
Susan Hourihan	GC member

1. Welcome, housekeeping, introductions, apologies

The Chair welcomed the Committee members and attendees to the 1st committee meeting for Cerebral Palsy in Adults Guideline committee.

All committee members and NGA staff introduced themselves

2. Aims of today's meeting

The Chair outlined the objectives of the meeting.

3. Declarations of Interest

Katharina Dworzynski (Guideline lead) gave the Committee and introductory presentation on Declarations of Interest. Members of the Committee declared Declarations of interest, these are noted in the below table.

Name	Job title, organisation	Declaration of interest	Type of interest	Decision taken
Jill Scarisbrick	Paediatric Physiotherapist, Blackpool Fylde and Wyre Hospitals Trust. Children and Families Community North NHS	Private Practitioner working with Cerebral Palsy	Personal financial, specific	Declare and participate
Jill Scarisbrick	Paediatric Physiotherapist, Blackpool Fylde and Wyre Hospitals Trust. Children and Families Community North NHS	Company re. referral for private patients do work with FES closely and do have some financial incentives (nb sub-contracting)	Personal financial, specific	Declare and participate
Jill Scarisbrick	Paediatric Physiotherapist, Blackpool Fylde and Wyre Hospitals Trust. Children and Families Community North NHS	Responsibility of purchase equipment re. Recommendations within hospital trust – not limited to specific companies.	Non-personal financial, specific	Declare and participate
Lloyd Bradley	Consultant in Rehabilitation Medicine, Western Sussex Hospitals NHS Trust (WSHT).	Executive committee member BSRM- representing the interests of the medical specialty of rehabilitation medicine.	Personal non-financial, non-specific	Declare and participate

Lloyd Bradley	Consultant in Rehabilitation Medicine, Western Sussex Hospitals NHS Trust (WSHT).	President of Headway in West Sussex	Personal non-financial, non-specific	Declare and participate
Paul Eunson	Consultant Paediatric Neurologist & Honorary Senior Lecturer, Royal Hospital for Sick Children, Sciennes Road, Edinburgh	Trustee of Castang Foundation, a charity that supports research and management of Cerebral Palsy	Personal non-financial, specific	Declare and participate
Paul Eunson	Consultant Paediatric Neurologist & Honorary Senior Lecturer, Royal Hospital for Sick Children, Sciennes Road, Edinburgh	I have published a paper on long term and social impact of hypoxic-Ischemic Encephalopathy	Personal non-financial, specific	Declare and participate
Ruth Kent	Department of Neurosciences Mid Yorkshire NHS Hospital Trust	Attend CPD meetings which are generally sponsored by Botulinum Toxin Manufacturers /Medtronic/Solicitors providing legal services	Personal non-financial, non-specific	Declare and participate
Ruth Kent	Department of Neurosciences Mid Yorkshire NHS Hospital Trust	Expert witness in CP litigation cases	Personal financial, non-specific	Declare and participate
Ruth Kent	Department of Neurosciences Mid Yorkshire NHS Hospital Trust	Published on transitions for CP/given talks on services	Personal non-financial, specific	Declare and participate
Mohammed Saeed Jeewa	Lay member	Trustee of shaping our lives – National user led organisation	Personal non-financial, non-specific	Declare and participate
Mohammed Saeed Jeewa	Lay member	Member of HE service user and carer group , promotes services and user experience	Personal financial, non-specific	Declare and participate
Mohammed Saeed Jeewa	Lay member	Improving Adults' experience of social care services Guideline Committee member	Personal financial, non-specific	Declare and participate

Susan Hourihan	Clinical Specialist Occupational Therapist, The National Hospital for Neurology and Neurosurgery, Queen Square, London	Chapter on positioning and splinting in splinting book	Personal non-financial, specific	Declare and participate
Susan Hourihan	Clinical Specialist Occupational Therapist, The National Hospital for Neurology and Neurosurgery, Queen Square, London	MS trust & MSC module 2x/ year – fee goes to departmental training budget	Personal non-financial, non-specific	Declare and participate
Susan Hourihan	Clinical Specialist Occupational Therapist, The National Hospital for Neurology and Neurosurgery, Queen Square, London	ACPIN- presentation on impacting fatigue on participation in neuro-conditions	Personal non-financial, specific	Declare and participate
Susan Hourihan	Clinical Specialist Occupational Therapist, The National Hospital for Neurology and Neurosurgery, Queen Square, London	Regular contact in splinting and lycra companies providers	Non-personal financial, specific	Declare and participate
Susan Hourihan	Clinical Specialist Occupational Therapist, The National Hospital for Neurology and Neurosurgery, Queen Square, London	Publication on models of vocational rehabilitation in neuro conditions	Personal non-financial, specific	Declare and participate
Susan Hourihan	Clinical Specialist Occupational Therapist, The National Hospital for Neurology and Neurosurgery, Queen Square, London	Therapists in MS (TiMS) - committee member (affiliated with MS trust)	Personal non-financial, specific	Declare and participate
Susan Hourihan	Clinical Specialist Occupational Therapist, The National Hospital	Working on outcome re splinting and botox pathways in adults	Personal non-	Declare and participate

	for Neurology and Neurosurgery, Queen Square, London		financial, specific	
Susan Hourihan	Clinical Specialist Occupational Therapist, The National Hospital for Neurology and Neurosurgery, Queen Square, London	Co-author in: Buchanan & Hourihan, Chapter 4 Physical and postural management of spasticity. In "Spasticity Management: A Practical Multidisciplinary Guide". Second Edition (2016) (Editors Stevenson & Jarret) CRC Press, Taylor and Francis Group, Florida.	Personal non-financial, specific	Declare and participate
Valerie Stevenson	Clinical Lead for Rehabilitation, The National Hospital for Neurology and Neurosurgery, UCLH	Lecturing on the MS trust module £150 once or twice a year	Personal financial, non-specific	Declare and participate
Valerie Stevenson	Clinical Lead for Rehabilitation, The National Hospital for Neurology and Neurosurgery, UCLH	Local lead and joint applicant for the following grant from the NIHR RfPB funding stream: <ul style="list-style-type: none"> • PB-PG-1014-35012 – The Effectiveness of Peroneal Nerve Functional Electrical • STimulation (FES) for Improving Mobility in Parkinson's Disease: A Pragmatic Two Site • Feasibility Study for an Assessor Blinded Randomised Control Trial (STEPS) This allows funding for a 0.5 physiotherapist post for our department for 2 years.	Non-personal financial, non-specific	Declare and participate
Valerie Stevenson	Clinical Lead for Rehabilitation, The National Hospital for Neurology and Neurosurgery, UCLH	Support (£500 – £1000 educational grant per company) from pharmaceutical companies (Medtronic, Allergan, Merz, Ambu) to the Spasticity management team at UCLH to run a 2 day course on spasticity	Non-personal financial, specific	Declare and participate

		management (2nd and 3rd Feb 2017)		
Valerie Stevenson	Clinical Lead for Rehabilitation, The National Hospital for Neurology and Neurosurgery, UCLH	Historically I have received teaching honoraria from Bayer Healthcare (Nov 2011), Almirall (May 2014) and Medtronic (Oct 2008). I have received payment for participation in Bayer Healthcare's advisory board (Sativex, 2012-2014)	Personal financial, non-specific	Declare and participate
Valerie Stevenson	Clinical Lead for Rehabilitation, The National Hospital for Neurology and Neurosurgery, UCLH	I am a member of the Association of British Neurologists and the Royal College of Physicians.	Personal non-financial, non-specific.	Declare and participate
Duncan Walsh	Lay Member	I am an employee of PACE a charity that works with Children and young people with Cerebral Palsy and other motor disorders and their families.	Personal financial, non-specific	Declare and participate
Duncan Walsh	Lay Member	My wife works for Sunrise Medical as an Area Sales Manager	Personal non-financial, specific	Declare and participate
Elsbeth Dixon	Lay Member	I have submitted a paper on determinants of carers' support for physical activity in clients with learning disability (including some with CP) to a health psychology journal. This has not yet been accepted for publication. The study has been accepted for presentation at the European Health Psychology conference.	Personal non-financial, specific	Declare and participate
Elsbeth Dixon	Lay Member	I have been accepted as a member of a SCIE Collaboration committee working on designing and implementing an evaluation of Integrated Personal Commissioning. Some of the users of IPC are adults with CP.	Personal non-financial, non-specific	Declare and participate
4. Guideline scope				

Paul Eunson gave a presentation on the guideline scope.
5. The role of the systematic reviewer and information scientist in guideline development
Nathan Bromham presented on the role of the reviewer and the information scientist in the review process and took questions from the Committee.
6. The role of the Health economist in guideline development
Gemma Marceniuk presented on the role of the Health economist in guideline development and took questions from the Committee.
7. What is a review protocol and why do we need it
Katharina Dworzynski presented on the protocol development process and took questions from the committee.
8. Review question and protocol discussion (Topic D.1)
Nathan Bromham took the committee through the draft protocol for topic D.1. The committee finalised the review question and PICO for this question.
9. Review question and protocol discussion (Topic D.2 Which interventions are effective for maintaining physical function in adults with cerebral palsy)
Nathan Bromham took the committee through the draft protocol for topic D.2. The Committee finalised the review question, the PICO and assigned contacts for the topic.
10. Review question and protocol discussion (Topic D.3 What is the role of assistive technology in promoting independence in adults in cerebral palsy)
Katharina Dworzynski took the committee through the draft protocol for topic D.3. The Committee finalised the review question, the PICO and assigned contacts for the topic.
11. Review of action log & Preview of day 2
Katharina Dworzynski reviewed the actions agreed during the meeting and provided an overview of the agenda for day 2.

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12. Welcome
13. Presentation from NICE
Rupert Franklin gave a presentation on How NICE guidelines are developed
14. Preliminary prioritising of Health Economic topics
Gemma Marceniuk took the Committee through which topics were being prioritised for Health Economic evaluation.

<p>15. Review question and protocol discussion (Topic A. 1 Which Pharmacological treatments for spasticity (for example, enteral baclofen, titandine, diazepam, cannabinoids, botulinum toxin injections) are most effective for improving motor function, participation and quality of life in adults with Cerebral Palsy?)</p>
<p>Katharina Dworzynski took the committee through the draft protocol for topic A.1 The Committee finalised the review question, the PICO and assigned contacts for the topic.</p>
<p>16. What is GRADE?</p>
<p>Katharina Dworzynski gave a presentation on GRADE methodology and its role in the review process.</p>
<p>17. Review question and protocol discussion (Topic A.2 Which interventions are effective for maintaining physical function in adults with cerebral palsy, for example : sporting activity, strengthening programmes of training, orthotics, task-oriented upper limb training, orthopaedic surgery (including tendon lengthening and orthopaedic bony procedures in adulthood)</p>
<p>Nathan Bromham took the committee through the draft protocol for topic A.1 The Committee finalised the review question, the PICO and assigned contacts for the topic.</p>
<p>18. Agreeing review questions (Document 4, Topics B.1. B.2 and B.3)</p>
<p>The committee agreed the working of the questions for the above topics.</p>
<p>19. Review of action log & Preview of day 2</p>
<p>Katharina Dworzynski reviewed the actions agreed during the meeting and provided an overview of the agenda for day 2.</p>
<p>20. AOB and Close</p>
<p>No Other business was raised. The next Committee meeting was confirmed as the 10th April 2017. The Chair closed the meeting.</p>
<p>21. Next steps</p>
<p>The date of the next Committee meeting is the 10th April 2017 The Committee were asked to spread the work regarding recruitment to the guideline as there still remained some vacancies on the Committee.</p>