

## Cerebral Palsy in Adults Committee Meeting 9

**Date:** 26<sup>th</sup> and 27<sup>th</sup> April 2018

**Location** RCOG, London

**Minutes:** Final

<b>Committee members present:</b>	
Paul Eunson	Present for items 1 - 14
Ruth Kent	Present for items 1 – 14
Jill Scarisbrick	Present for items 1 – 14
Val Stevenson	Present for items 1 – 5, 8 – 14
Elsbeth Dixon	Present for items 1 – 14
Richard Bunn	Present for items 1 – 5, 8 – 14
Susan Hourihan	Present for items 1 – 14
Lloyd Bradley	Present for items 1 – 14
Rosie Werner	Present for items 1 – 14
Umesh Chauhan	Present for items 1 – 14
Duncan Walsh	Present for items 1 – 14

<b>In attendance:</b>		
Katharina Dworzynski	NGA Guideline Lead	Present for items 1 – 14
Offiong Ani	NGA Project Manager	Present for items 4 – 10, 11 – 14
Nathan Bromham ( <b>via videoconference</b> )	NGA Senior Systematic Reviewer	Present for items 1 – 14
Ferruccio Pelone	NGA Systematic Reviewer	Present for items 5, 8 – 12
Anuja Pandey	NGA Systematic Reviewer	Present for items 1 – 11
Gemma Simmons ( <b>via videoconference on Day 2</b> )	NGA Clinical Fellow	Present for items
Charlie Fairhurst	NGA Clinical Advisor	Present for items 1 – 14
Ben Doak	NICE Guideline Commissioning Manager	Present for items 1 – 14
Catherine Baden-Daintree	NICE Senior Medical Editor	Present for items 1 – 14
Adam Storrow ( <b>Day 1</b> )	NICE Business Analyst	Present for items 1 – 5

**Observers:**

None

**Apologies:**

Nick Staples

NICE Guideline Commissioning Manager

James Hawkins

NGA Health Economist

**Day 1:**

**1. Welcome and objectives for the meeting**

The Chair welcomed the Committee members and attendees to Day 1 of the 9th Guideline Committee meeting on Cerebral Palsy in Adults. The Committee members and attendees introduced themselves.

The Chair informed the Committee that apologies had been received. These are noted above.

The Chair outlined the objectives of today's meeting, which included: overview of updated search results, guideline structure and review and sign-off of evidence reports.

**2. Confirmation of matter under discussion, and declarations of interest**

The Chair confirmed that, for the purpose of managing conflicts of interest, the matter under discussion was Cerebral Palsy in Adults.

The Chair asked everyone to verbally declare any interests that have arisen since the last meeting. No new interests were declared.

**3. Minutes of last meeting**

The Chair asked the committee if it wanted any changes made to the minutes of the last meeting. The committee agreed that the minutes were a true and accurate account of the meeting.

**4. Morning presentations**

The Chair introduced Katharina Dworzynski, Guideline Lead, who discussed the overview and objectives of today's meeting with the GC.

The Chair and Guideline Lead also discussed the structure and layout of the recommendations for the Committee to bear in mind when concluding on the short

guideline.

The Chair introduced Anuja Pandey, Systematic Reviewer, who presented an overview of updated search results and the impact on guideline documents for review question **D2: Which interventions are effective for maintaining physical function and mobility in adults with cerebral palsy?**

- **Sporting activity**
- **Strengthening programmes or training**
- **Orthotics**
- **Task-oriented upper limb training**
- **Orthopaedic surgery (including tendon lengthening and orthopaedic bone procedures in adulthood)**

The Chair introduced Nathan Bromham, Senior Systematic Reviewer, who presented the rationale and impact, and committee discussion sections of review question **E1: What is the value of self-support and observational techniques for providing a standardised way of identifying and localising pain in adults with cerebral palsy?**

The Committee discussed the draft recommendations, reviewed the rationale and impact, and committee discussion sections and signed them off.

## **5. Afternoon presentations**

Anuja presented the rationale and impact, and committee discussion sections of review question **B1: What is the most effective protocol for monitoring the following disorders of bones and joints in adults with cerebral palsy?**

- **osteoarthritis**
- **osteoporosis (including osteopenia and osteomalacia)**
- **hip displacement**
- **spinal deformity, including scoliosis, kyphosis and lordosis**
- **cervical instability leading to cervical myelopathy?**

and **B2: Which mental health assessment tools are clinically useful for adults with cerebral palsy?**

The Chair introduced Ferruccio Pelone, Systematic Reviewer, who presented the rationale and impact, and committee discussion sections of review question **B3: What is the best way to assess and monitor the safety (of swallowing and risk of aspiration) and effectiveness of feeding and maintaining nutrition in adults with cerebral palsy?**

Anuja presented the rationale and impact, and committee discussion sections of review questions:

- **C1: What is the most effective protocol for monitoring for respiratory**

*health in adults with cerebral palsy?*

- ***C2: Does assisted ventilation improve quality of life in adults with cerebral palsy who have a chronic respiratory disorder (including respiratory failure)?***
- ***C3: Are prophylactic treatments (for example, antibiotics, chest physiotherapy, cough assistance) effective in preventing respiratory infections in adults with cerebral palsy?***

**6. Questions and discussions**

The Committee discussed the results of the updated search for review question D2 and found no new evidence that was enough to make changes to or affect the guideline documents.

The Committee discussed the draft recommendations, research recommendations (as appropriate), reviewed the rationale and impact, and committee discussion sections for review questions E1, B1, B2, B3, C1, C2, and C3 and signed them off.

**7. Any other business & close**

The Chair reminded the Committee that the next meeting would hold tomorrow, 27<sup>th</sup> April 2018

**Day 2:**

**8. Welcome and objectives for the meeting**

The Chair welcomed the Committee members and attendees to Day 2 of the 9<sup>th</sup> Guideline Committee meeting on Cerebral Palsy in Adults.

The Chair informed the Committee that apologies had been received. These are noted above.

The Chair outlined the objectives of today's meeting, which included: review and sign-off of evidence reports, possible publications.

**9. Confirmation of matter under discussion, and declarations of interest**

The Chair confirmed that, for the purpose of managing conflicts of interest, the matter under discussion was Cerebral Palsy in Adults.

The Chair asked everyone to verbally declare any interests that have arisen since the last meeting. No new interests were declared.

<b>10. Minutes of last meeting</b>
N/A
<b>11. Morning presentations</b>
<p>The Chair introduced Katharina Dworzynski, Guideline Lead, who discussed with the GC the process involved with getting involved in writing possible research publications.</p> <p>The Chair introduced Ferruccio Pelone, Systematic Reviewer, who presented the rationale and impact, and committee discussion sections of review question <b>D4: <i>Which interventions (for example augmentative and alternative communication systems) are effective in promoting effective communication for adults with cerebral palsy who have communication difficulties?</i></b></p>
<b>12. Afternoon presentations</b>
<p>The Chair introduced, Nathan Bromham, Senior Systematic Reviewer, who presented the rationale and impact, and committee discussion sections of review questions:</p> <ul style="list-style-type: none"> <li>• <b><i>D1: Which interventions (for example, vocational and independent living skills training) promote participation in adults with cerebral palsy?</i></b></li> <li>• <b><i>D3: What is the effectiveness of electronic assistive technology in promoting independence in adults with cerebral palsy?</i></b></li> <li>• <b><i>A1: Which pharmacological treatments for spasticity (for example, enteral baclofen, tizanidine, diazepam, cannabinoids, botulinum toxin injections) are most effective for improving motor function, participation and quality of life in adults with cerebral palsy?</i></b></li> <li>• <b><i>A2: Are neurosurgical procedures (intrathecal baclofen pump and selective dorsal rhizotomy) effective in adults aged 19 and over with cerebral palsy to reduce spasticity and or dystonia?</i></b></li> <li>• <b><i>A3: Which treatments (pharmacological treatment (levodopa, anticholinergic drugs, and botulinum toxin injections), neurosurgical procedure (deep brain stimulation, ITB) are most effective for managing dystonia in adults with cerebral palsy where dystonia is the predominant abnormality of tone?</i></b></li> </ul> <p>Ferruccio presented the rationale and impact, and committee discussion sections of review questions:</p> <ul style="list-style-type: none"> <li>• <b><i>F1: What is the most clinical and cost-effective configuration of services (setting and staffing) for adults with cerebral palsy?</i></b></li> <li>• <b><i>F2: What service configuration and what interventions can facilitate</i></b></li> </ul>

*access to health care in adults with cerebral palsy, and what are the perceived barriers and facilitators for access to care in adults with cerebral palsy?*

**13. Questions and discussions**

The Committee discussed the draft recommendations, research recommendations (as appropriate), reviewed the rationale and impact, and committee discussion sections for review questions D1, D2, D4, A1, A2, A3, F1 and F2 and signed them off.

**14. Any other business & close**

Katharina discussed with the GC the next steps on the guideline development process. The Chair reminded the Committee of the date and venue of the post-consultation meeting.

**Date of next meeting:** 10<sup>th</sup> September 2018

**Location of next meeting:** Broadway House, Tothill Street, London SW1H 9NQ