

## Cerebral Palsy in Adults, Guideline Committee meeting 5

**Date:** Tuesday 12<sup>th</sup> & Wednesday 13<sup>th</sup> September 2017

Location: Royal College of Obstetricians and Gynaecologists (RCOG)

Minutes:

Committee members present	
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Paul Eunson	Present for items 1-18
Ruth Kent	Present for items 1-18
Jill Scarisbrick	Present for items 1-18
Val Stevenson	Present for items 1-18
Elspeth Dixon	Present for items 1-18
Duncan Walsh	Present for items 1-18
Susan Hourihan	Present for items 1-18
Lloyd Bradley	Present for items 1-18
Rosie Werner	Present for items 1-18
Richard Bunn	Present for items 1-18
Andrew Roberts (Co-opt member)	Present for items 1-11
NGA staff	
Katharina Dworzynski	Present for items 1-18
Gemma Simmons	Present for items 1-18
Nathan Bromham	Present for items 1-18
Gemma Marceniuk	Present for items 1-18
Victoria Rowlands	Present for items 1-18
Charlie Fairhurst	Present for items 1-15
Anuja Pandey	Present for items 1-18
Ferruccio Pelone	Present for items 1-18
NICE staff	
Nick Staples	Present for items 1-9 (Day 1 only)
Adam Storrrow	NICE Business Analyst Present for Items 1- 9 (Day 1 only)
Apologies	
Sabine Berendse	NGA Information Scientist

## 1. Welcome, housekeeping, introductions, apologies

The Chair welcomed the Committee members and attendees to the 5th committee meeting for Cerebral Palsy in Adults Guideline committee.

All committee members and NGA staff introduced themselves. Minutes of the previous meeting were confirmed.

## 2. Discussion of Topic groups and structure plan for reviewing LETR's

The Chair outlined the objectives of the meeting.

#### 3. Declarations of Interest

There were no new declarations of interest declared.

#### 4. Resource impact presentation

Adam Storrow took the Committee through the role of the Resource impact lead at NICE.

5. Presentation on "Cerebral Palsy in Adults from the perspective of the Orthopaedic surgeon"

Andrew Roberts took the committee through a presentation on the perspectives of cerebral palsy in adults from an Orthopaedic surgeons perspective. He responded to all questions.

6. Health Economics: Question 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?

Gemma Marceniuk presented to the committee the results on question A3. Gemma responses to questions from the committee on the results.

- 7. Review question B2: Which mental health assessment tools are clinically useful for adults with cerebral palsy?
- Clinical evidence
- Discussion and review of draft recommendations
- Agreeing the content of the LETR

Nathan Bromham presented on Question B2 and took questions from the Committee. The committee drafted recommendations for the area.

- 8. Review question D2: Which interventions are effective for maintaining physical function in adults with cerebral palsy, for example sporting activity strengthening programmes or training orthotics Task-oriented upper limb training Orthopaedic surgery (including tendon lengthening and orthopaedic bony procedures in adulthood)?
- Clinical evidence
- Discussion and review of draft recommendations

## Agreeing the content of the LETR

Anuja presented on the evidence for question D2 and took questions from the Committee. The committee drafted recommendations and discussed the rationale and impact of the recommendations.

## **Review of NICE Recommendation Edits (D topics)**

9.

The Committee reviewed and discussed the edits from the NICE editor. The Committee accepted the relevant editor changes.

#### Close

## Day 2 Wednesday 13th September 2017

## 10. Welcome, housekeeping, introductions, apologies

The Chair welcomed the Committee members and attendees to the 2<sup>nd</sup> day of the 5th committee meeting for Cerebral Palsy in Adults Guideline committee.

#### 11. Declarations of Interest

There were no new declaration of Interest declared

12. Health Economics F1: What are the necessary components (for example, an adult cerebral palsy multidisciplinary team [MDT], requisite skills for doctors with an interest in cerebral palsy in adults) in the network of care and support for adults with cerebral palsy?

Gemma Marceniuk took the Committee through the Health Economics results for F1

#### 13. Review question F1

The committee drafted recommendations and discussed the rationale and impact of the recommendations.

## 14. NICE Edits to Recommendations – A topics

The Committee reviewed the edits made by the NICE editor on the A topics, appropriate edits were accepted by the Committee.

15. Protocol sign off E1: What is the most effective sequence of tests to identify causes of pain in an adult with cerebral palsy?

Nathan Bromham confirmed the details of the Protocol for E1 with the Committee.

#### 16. Videoconferencing equipment Presentation

Victoria Rowlands took the Committee through over the details of the Video conferencing equipment and how this can be used if committee members aren't able to attend certain dates in person.

# 17. Protocol Sign off F2: What are the barriers to access to primary and secondary care for adults with cerebral palsy?

Nathan Bromham confirmed the details of the Protocol for F2 with the Committee.

#### 18. AOB & Close

The Chair closed the meeting. The next meeting will be on the 24<sup>th</sup> November 2017.