

Supplementary 5 – Consensus meeting minutes and participants

Table S5.1 – Participants present at the consensus meeting

Initials	Meeting role	Stakeholder Group	Membership
CM	<b>Meeting facilitator/chair</b>	n/a	<b>Research team</b>
HC	<b>Assistant Facilitator</b>	n/a	<b>Research team</b>
SI	<b>Assistant</b>	n/a	<b>King's College London</b>
SL	<b>Family Engagement Officer</b>	n/a	<b>Research team</b>
DKP	<b>Participant</b>	<b>Professional (Paediatric neurologist)</b>	<b>Delphi survey participant/ Research team</b>
PG	<b>Participant</b>	<b>Professional (consultant in sleep medicine)</b>	<b>Delphi survey participant/ Research team</b>
BC	<b>Participant</b>	<b>Professor of children's nursing</b>	<b>Research team/voted in meeting</b>
JH	<b>Participant</b>	<b>Professional (Paediatrician)</b>	<b>Delphi survey participant</b>
DJ	<b>Participant</b>	<b>Professional (Consultant in sleep medicine)</b>	<b>Delphi survey participant</b>
CT	<b>Participant</b>	<b>Professional (Clinical Psychologist)</b>	<b>Delphi survey participant (R1)</b>
SM	<b>Participant</b>	<b>Professional (Physiologist)</b>	<b>Delphi survey participant</b>
RW	<b>Participant</b>	<b>Professional (Paediatric neurologist)</b>	<b>Delphi survey participant</b>
DG	<b>Participant</b>	<b>Professional (Paediatrician)</b>	<b>Delphi survey participant</b>
MS	<b>Participant</b>	<b>Parent of AS</b>	<b>Delphi survey participant</b>
AS	<b>Participant</b>	<b>Young Person</b>	<b>Delphi survey participant</b>
CT	<b>Participant</b>	<b>Parent of BT</b>	<b>Delphi survey participant</b>
BT	<b>Participant</b>	<b>Young Person</b>	<b>Parent was a Delphi survey participant</b>
DR	<b>Participant</b>	<b>Parent</b>	<b>Research team</b>
JC	<b>Participant</b>	<b>Parent</b>	<b>Research team</b>

## S5.2 Minutes of consensus meeting

### **CHOICE – Core Health Outcomes in Childhood Epilepsy Consensus Meeting**

#### **Facilitators:**

1. Christopher Morris
2. Holly Crudgington

#### **Assistants:**

1. SL (Family Engagement Officer)
2. SI (Assistant)

#### ***Eligible to vote:***

##### **Professionals (n=9)**

1. RW (Paediatric neurologist)
2. DJ (Consultant in Sleep medicine)
3. BC (Professor of Children's Nursing)
4. CT (Clinical Psychologist)
5. PG (Consultant in Sleep medicine)
6. DP (Paediatric neurologist)
7. JH (Paediatrician)
8. DG (Paediatrician)
9. SM (Physiologist)

##### **Parents (n=4)**

1. JC
2. DR
3. CT
4. MS

##### **Young People (n=2)**

1. AS
2. BT

**Total present at meeting: 19**

**Total voting: 15**

### **Outcomes in from the Delphi, prior to meeting (n=11)**

- Outcome 1. Seizure Freedom
- Outcome 2. Seizure Frequency
- Outcome 3. Seizure duration
- Outcome 4. Memory
- Outcome 5. Self-harm
- Outcome 6. Fears of having a seizure
- Outcome 7. Learning
- Outcome 8. Concentration
- Outcome 9. Overall Quality of Life
- Outcome 10. Adverse events or reactions
- Outcome 11. Drug treatment failure events (adverse events or poor seizure control)

### **Outcomes voted in after the meeting (n= 28)**

- Outcome 12. Seizure Severity
- Outcome 5. Total time spent asleep at night
- Outcome 6. Total time spent asleep in 24 hours
- Outcome 7. Awakenings from sleep
- Outcome 8. Breathing difficulties
- Outcome 9. Daytime Sleepiness
- Outcome 13. Movement ability – Gross motor function
- Outcome 14. Manual ability (fine motor function)
- Outcome 16. Ability to join activities with others
- Outcome 18. Friendships
- Outcome 19. Engagement in school life
- Outcome 16. Ability to join activities with others
- Outcome 17. Experience of other people's attitudes towards epilepsy
- Outcome 22. Behavioural concerns
- Outcome 23. Impulsivity
- Outcome 25. Feelings about having epilepsy
- Outcome 31. Self-esteem
- Outcome 32. Mood swings
- Outcome 34. Concealment
- Outcome 36. Literacy
- Outcome 37. Speech & Language
- Outcome 41. School attendance
- Outcome 42. Academic attainment
- Outcome 43. Executive functioning
- Outcome 46. Relationships with parents & siblings
- Outcome 47. Family life
- Outcome 48. Parental health
- Outcome 51. Epilepsy specific attendance at A&E and/or unplanned admission to the ward

**Total: 39**

## Voting Results:

### **Outcome 4 – Seizure Severity**

*Definition: How bad seizures are in terms of effects on the person during and after seizures – such as falls or injuries, incontinence, confusion and time to recover afterwards*

Comments:

- AS (young person): ‘Very important’

*Votes in*

Professionals: 9/9

Parents: 4/4

Young People: 2/2

Total: 15/15

Result: CONSENSUS IN

### **Outcome 5 – Time to fall asleep**

*Definition: Time it takes to fall asleep from snuggling down*

*Votes in*

Professionals: 0/9

Parents: 0/9

Young people: 0/9

Total: 0/15

Result: CONSENSUS OUT

### **Outcome 6 – Time spent asleep in 24 hours**

*Definition: Total time spent asleep each day*

Comments:

- AS (Young Person) – Time spent asleep not that important – not critical to research
- JH (Professional) – Sleep deprivation is a strong driver for seizures and probably severity
- RW (Professional) – Day and night should be split
- CM (Facilitator) – Can re define if we want to. Could change to ‘total time spent asleep at night’

Vote on ‘Time spent asleep each day’

*Votes in*

Professionals: 7/8 (BC didn’t answer)

Parents: 4/4

Young People: 0/2

Total: 11/14

Result: CONSENSUS OUT

Vote on 'Time spent asleep in 24 hours': CONSENSUS IN

Vote on 'Time spent asleep at night': CONSENSUS IN

**Outcome: Time spent asleep at night**

*Definition: Total time spent asleep at night*

*Votes in*

Professionals: 8/8

Parents: 4/4

Young People: 2/2

Total: 14/14

Result: CONSENSUS IN

**Outcome 7 – Awakenings from sleep**

*Definition: Waking in the night that parents/carers are aware of*

Comments:

- JC (Parents): Critical

*Votes in*

Professionals: 9/9

Parents: 4/4

Young People: 2/2

Total: 15/15

Results: CONSENSUS IN

**Outcome 8 – Breathing difficulties during sleep**

*Definition: Might include snoring or gasping for breath*

Comments: PG (Professional) Important, epilepsy or not

First vote

*Votes in*

Professionals: 7/9

Parents: 4/4

Young People: 0/2

Total: 11/15

Second vote  
Votes in  
Professionals: 9/9  
Parents: 4/4  
Young People: 2/2  
Total: 14/15

Result: CONSENSUS IN

### **Outcome 9 – Daytime sleepiness**

*Definition: Feeling sleepy or actually sleeping during the day*

Votes in:  
Professionals: 9/9  
Parents: 3/4  
YP: 2/2  
Total: 14/15

Results: CONSENSUS IN

### **Outcome 10 – Fatigue**

*Definition: Lacking in energy*

Votes in:  
Professionals: 0/9  
Parents: 0/4  
Young People: 0/2  
Total: 0/15

Result: CONSENSUS OUT

### **Outcome 11 – Pain**

*Definition: Unpleasant, physical sensation*

Comments:

- JC (Parent) – felt pain fitted in with severity of seizure

Professionals: 0/9  
Parents: 0/4  
Young People: 0/2  
Total: 0/15

Result: CONSENSUS OUT

### **Outcome 13 – Movement ability – Gross motor function**

**\*Combined Coordination & Balance outcome and definition.**

*Definition: Using parts of the body together efficiently, such as to ride a bike, or stand on one leg, catching and throwing. Running, jumping, hopping, throwing.*

Comments:

- AS (Young person) felt it was very important for school especially for moving around to different lessons.

Professionals: 9/9

Parents: 4/4

Youn People: 2/2

Total: 15/15

Result: CONSENSUS IN

### **Outcome 14 -Manual ability (fine motor function)**

*Definition: Dexterity (skill) in handling objects, handwriting*

Comments:

- DR (Parent) thinks movement ability, coordination & balance, and manual ability are all the same.
- CT (Professional) Wondered if it was 'critical' to measure
- CT (Parent) In order to get support for a child, anything that can support an application for parents.

*Vote in*

Professionals: 8/9

Parents: 4/4

Young People: 2/2

Total: 14/15

Result: CONSENSUS IN

### **Outcome 15: Self care**

*Definition: Daily routines such as eating, washing, dressing and toileting.*

Note: RW left the meeting. Total out of 14 professionals.

Professionals  
Parents  
Young People  
Total

Results: CONSENSUS OUT

### **Outcome 16: Ability to join activities with others**

*Definition: Joining in with people such as playing out with friends, sleepovers, doing sports, joining in things*

\*Combined Social life with this outcome, added in the word 'sleepovers'.

*Vote in (when combined)*

Professionals: 8/8

Parents: 4/4

Young People: 2/2

Total:

Result: CONSENSUS IN

### **Outcome 17: Ability to play on one's own**

*Definition: Reading, computer games, imaginary play etc.*

*Professionals: 0/8*

*Parents: 0/4*

*Young People: 0/2*

*Total: 0/14*

Result: CONSENSUS OUT

### **Outcome 18: Friendships**

*Definition: Forming and maintaining friendships*

*Vote in:*

*Professionals: 7/8*

*Parents: 4/4*

*Young People: 2/2*

*Total: 13/14*

Result: CONSENSUS IN

### **Outcome 19: Engagement in school life**

*Definition: Feeling part of the school community*



Vote in  
Professionals: 8/8  
Parents: 4/4  
Young People: 2/2  
Total: 14/14

Result: CONSENSUS IN

### **Outcome 21: Experience of other people's attitudes towards epilepsy**

*Definition: How people behave towards someone with epilepsy which could include things like bullying or social exclusion*

Vote in  
Professionals: 8/8  
Parents: 4/4  
Young People: 2/2  
Total: 14/14

Result: CONSENSUS IN

### **Outcome 22: Behavioural Concerns**

**\*Name changed from Behaving appropriately**

*Definition: Being able to control emotions and respond to situations in context*

Vote in  
Professionals: 8/8  
Parents: 4/4  
Young People: 2/2  
Total: 14/14

Result: CONSENSUS IN

### **Outcome 23: Impulsivity**

*Definition: Acting without thinking*

Vote in  
Professionals: 7/8  
Parents: 3/4  
Young People: 1/2  
Total: 11/14

Result: CONSENSUS IN

### **Outcome 24: Fidgeting**

**Definition:**

*Vote in*

*Professionals: 0/8*

*Parents: 0/4*

*Young People: 0/2*

*Total: 0/14*

Result: CONSENSUS OUT

**Outcome 25: Feelings about having epilepsy**

*Definition: Feeling like other people of the same age*

**\*combination of Feeling normal, Feelings about having epilepsy, Happiness, Sadness, Worried, Annoyed.**

*Definition:*

*Vote in*

*Professionals: 8/8*

*Parents: 4/4*

*Young People: 2/2*

*Total: 14/14*

Result: CONSENSUS IN

**Outcome 31: Self esteem**

*Definition: Overall feelings about yourself*

*Vote in*

*Professionals: 8/8*

*Parents: 4/4*

*Young People: 2/2*

*Total: 14/14*

Result: CONSENSUS IN

**Outcome 32: Mood swings**

*Definition: Quick unexplained changes of mood*

*Vote in*

*Professionals: 8/8*

*Parents: 4/4*

*Young People: 2/2*

*Total: 14/14*

Result: CONSENSUS IN

### **Outcome 34: Concealment**

*Definition: Quick unexplained changes of mood*

*Vote in*

*Professionals: 6/8*

*Parents: 4/4*

*Young People: 2/2*

*Total: 12/14*

Result: CONSENSUS IN

### **Outcome 36: Literacy**

*Definition: Reading, writing, spelling*

*Vote in*

*Professionals: 8/8*

*Parents: 4/4*

*Young People: 2/2*

*Total: 14/14*

Result: CONSENSUS IN

### **Outcome 37: Speech & language**

*Definition: Making yourself understood and understanding when spoken to*

*Vote in*

*Professionals: 7/8*

*Parents: 4/4*

*Young People: 2/2*

*Total: 13/14*

Result: CONSENSUS IN

### **Outcome 41: School attendance**

*Definition: Turning up and engaging in school curriculum*

*Vote in*

*Professionals: 8/8*

*Parents: 4/4*

*Young People: 2/2*

*Total: 14/14*

Result: CONSENSUS IN

#### **Outcome 42: Academic attainment**

*Definition: Reaching potential through studying and completing assigned tasks and projects and advancing to next stage of education*

*Vote in*

*Professionals: 8/8*

*Parents: 4/4*

*Young People: 2/2*

*Total: 14/14*

Result: CONSENSUS IN

#### **Outcome 43: Executive functioning**

*Definition: The ability to plan and organise complex activities and set goals and manage your time. Executive functions help you manage life tasks such as organizing a trip, homework and school projects.*

*Vote in*

*Professionals: 8/8*

*Parents: 4/4*

*Young People: 2/2*

*Total: 14/14*

Result: CONSENSUS IN

#### **Outcome 46: Relationships with parents & siblings**

**Definition: Getting along well with and feeling close to other members of the family**

*Vote in*

*Professionals: 8/8*

*Parents: 4/4*

*Young People: 2/2*

*Total: 14/14*

Result: CONSENSUS IN

#### **Outcome 47: Family life**

*Definition: Impact of epilepsy on family life such as parent work opportunities or/leisure time*

Vote in  
Professionals: 8/8  
Parents: 4/4  
Young People: 2/2  
Total: 14/14

Result: CONSENSUS IN

### **Outcome 48: Parental health**

*Definition: Parents physical and emotional health*

Vote in  
Professionals: 8/8  
Parents: 4/4  
Young People: 2/2  
Total: 14/14

Result: CONSENSUS IN

### **Outcome 50: Epilepsy specific attendance at A&E and/or unplanned admission to the ward**

*Definition: unexpectedly need to be admitted to hospital*

Vote in  
Professionals: 8/8  
Parents: 4/4  
Young People: 2/2  
Total: 14/14

Result: CONSENSUS IN