# National Institute for Health and Care Excellence

**Final** 

# Cerebral palsy in adults

[D2] Interventions that improve function and participation: physical function

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Evidence reviews
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Final

These evidence reviews were developed by the National Guideline Alliance hosted by the Royal College of Obstetricians and Gynaecologists



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# Interventions that improve or maintain physical function and participation for adults over 25 with cerebral palsy.

## **Review question**

D2 Which interventions are effective for maintaining physical function and mobility in adults with cerebral palsy?

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

#### Introduction

Physical function and mobility can be reduced in adults with cerebral palsy due to a number of factors. These include musculo-skeletal weakness, disorders of tone, development of contracture and deformity as well as cognition and mood. Maintenance of strength and range of movement is therefore important. Current practice is based on physiotherapy such as stretching and occupational therapy, rehab engineering, and orthotics. This review question aims to look at the efficacy and cost of available interventions.

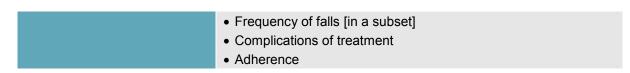
#### **PICO Table**

Please see Table 1 for a summary of the Population, Intervention, Comparison and Outcome (PICO) characteristics of this review.

Table 1: PICO table

| Population   | Adults aged 16 and over with cerebral palsy   |
|--------------|---|
| Intervention | <ul> <li>Physical activity</li> <li>Strengthening programmes or training</li> <li>Orthotics</li> <li>Task-oriented upper limb training</li> <li>Orthopaedic surgery (including tendon lengthening and orthopaedic bony procedures in adulthood)</li> <li>Powered mobility aids and wheelchairs</li> </ul> |
| Comparison   | <ul><li>Each other</li><li>Usual care</li></ul>   |
| Outcome      | <ul> <li>Critical</li> <li>Participation (incorporating mobility)</li> <li>Physical function</li> <li>Health related quality of life &amp; psychological wellbeing Important</li> <li>Independence</li> <li>Fatigue</li> </ul>  |

Interventions that improve or maintain physical function and participation for adults over 25 with cerebral palsy.



For full details see the review protocol in appendix A.

#### Methods and process

This evidence review was developed using the methods and process described in <a href="Developing NICE guidelines: the manual 2014">Developing NICE guidelines: the manual 2014</a>. Methods specific to this review question are described in the review protocol in appendix A.

Declaration of interests were recorded according to NICE's 2014 conflicts of interest policy from May 2016 until April 2018. From April 2018 onwards they were recorded according to NICE's 2018 conflicts of interest policy. Those interests declared until April 2018 were reclassified according to NICE's 2018 conflicts of interest policy (see Interests Register).

#### Clinical evidence

#### Included studies

Ten studies (number of participants, N=229) were included in the review, including 5 randomised controlled trials (Lorentzen 2017, Maeland 2009, Morgan 2015, Taylor 2013 and Teixeira-Machado 2017), 4 before-and-after studies (Ballaz 2011, Brown 2010, Houdek 2017 and Schroeder 2010) and 1 non-randomised controlled study (Hutzler 2013).

The comparisons included:

- 1. physical activity before versus after
- 2. physical activity versus standard care
- 3. strengthening or training programmes versus standard care
- 4. task-oriented upper limb training versus standard care
- 5. task-oriented upper limb training before versus after
- 6. orthopaedic surgery before versus after.

The clinical studies included in this evidence review are summarised in Table 2 and evidence from these is summarised in the clinical GRADE evidence profiles in Table 3 to Table 8.

See also the literature search strategy in appendix B study selection flow chart in appendix C, forest plots in appendix E and study evidence tables in appendix D.

#### **Excluded studies**

Studies excluded from this systematic review, with reasons for their exclusion, are provided in appendix K.

#### Summary of clinical studies included in the evidence review

Table 2 provides a brief summary of the included studies.

Table 2: Summary of included studies

| Study       | Design                               | Participants   | Comparisons                 | Outcomes  |
|-------------|--------------------------------------|--|-----------------------------|---|
| Ballaz 2011 | Observational before-and-after study | 12 ambulatory adults with cerebral palsy, average age 17 years | Aquatic training programme, | <ul><li>Participation</li><li>Physical function</li></ul> |

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| Study                     | Design                               | Participants   | Comparisons  | Outcomes  |
|---------------------------|--------------------------------------|--|--|---|
|                           |                                      | Canada   | before versus after  |   |
| Brown 2010                | Observational before-and-after study | 12 adults with<br>cerebral palsy, mean<br>age, 33 years and 11<br>months ± 10 years<br>United States | Home and<br>Internet-based<br>upper limb<br>training, before<br>versus after<br>(N=12) | <ul><li>Participation</li><li>Physical function</li></ul>   |
| Houdek 2017               | Observational before-and-after study | 39 adults with<br>cerebral palsy, mean<br>age 49 years<br>United States                              | Total hip<br>arthroplasty<br>surgery,<br>before versus<br>after (n=39)                 | <ul><li>Participation</li><li>Physical function</li></ul>   |
| Hutzler 2013              | Non randomised controlled trial      | 17 adults with cerebral palsy Spain  | Upper<br>extremity<br>strength<br>training (n=10)<br>versus usual<br>care(n=7)         | <ul><li>Participation</li><li>Physical function</li><li>Independence</li></ul>  |
| Lorentzen<br>2017         | Randomised controlled trial          | 32 adults with<br>cerebral palsy, mean<br>age 38 years<br>Denmark                                    | Treadmill<br>training (n=16)<br>versus usual<br>care(n=16)                             | Participation   |
| Maeland 2009              | Randomised controlled trial          | 12 ambulatory adults<br>with cerebral palsy,<br>age range 27-65 yrs<br>Norway                        | Progressive<br>resistance<br>exercise (n=6)<br>versus usual<br>care(n=6)               | <ul><li>Participation</li><li>Physical function</li></ul>   |
| Morgan 2015               | Randomised controlled trial          | 17 ambulatory adults with cerebral palsy, mean age 37 years, Australia                               | Balance<br>training (n=9)<br>versus seated<br>attention(n=8)                           | <ul> <li>Participation</li> <li>Health related quality of life</li> <li>Fatigue</li> <li>Frequency of falls</li> <li>Treatment related complications</li> <li>Compliance</li> </ul> |
| Schroeder<br>2010         | Randomised controlled trial          | 14 adults with cerebral palsy with severe functional limitation Germany                              | Hip<br>arthroplasty,<br>before versus<br>after) (N=14)                                 | <ul><li>Participation</li><li>Independence</li></ul>  |
| Taylor 2013               | Randomised controlled trial          | 48 adults with cerebral palsy, mean age 18 years, 1 month Australia                                  | Progressive<br>resistance<br>training(n=23)<br>versus Usual<br>care(n=25)              | <ul><li>Participation</li><li>Physical function</li></ul>   |
| Teixeira-<br>Machado 2017 | Randomised controlled trial          | 26 young ambulatory<br>adults with cerebral<br>palsy<br>Brazil                                       | Dance therapy<br>(n=13) versus<br>Kinesiotherapy<br>exercise(n=13)                     | <ul><li>Physical function</li><li>Independence</li></ul>  |

N: number of participants in the study; n: number of participants in intervention/control groups; RCT: randomised controlled trial.

See appendix D for the full evidence tables.

#### Quality assessment of clinical outcomes included in the evidence review

The clinical evidence profiles for this review question are presented in Table 3 to Table 8.

Table 3: Summary clinical evidence profile: Comparison 1: Physical activity intervention, before versus after outcomes

|  | Illustrative compara  | ative risks* (95% CI)  |                                |  |                                 |
|--|---|--|--------------------------------|--|---------------------------------|
| Outcomes   | Before physical activity intervention   | After physical activity intervention   | Relative<br>effect<br>(95% CI) | No of<br>Participants<br>(studies)               | Quality of the evidence (GRADE) |
| Participation:<br>Walking<br>efficiency(Gait<br>energy expenditure<br>index) <sup>1</sup><br>follow up: post-test at<br>10 weeks | The mean gait<br>energy<br>expenditure index<br>before intervention<br>was<br>1.77 (SD=1.3) | The mean gait energy<br>expenditure index after<br>intervention was<br>0.24 lower<br>(1.3 lower to 0.82<br>higher) | -                              | 10 <sup>5</sup><br>(1<br>observational<br>study) | Very low <sup>2,3</sup>         |
| Physical function<br>Gross Motor Function<br>Measure (GMFM) <sup>4</sup> D<br>& E<br>follow up: post-test at<br>10 weeks         | The mean gross<br>motor function<br>measure before<br>intervention was<br>59 (SD=34.69)     | The mean gross motor function measure after intervention was 5.00 lower (35.31 lower to 25.31 higher)              | -                              | 10 <sup>5</sup><br>(1<br>observational<br>study) | Very low <sup>2,3</sup>         |
| Health related quality of life- not reported   | -   | -  | -                              | -  | -                               |
| Independence- not reported   | -   | -  | -                              | -  | -                               |
| Fatigue- not reported  | -   | -  | -                              | -  | -                               |
| Frequency of falls-<br>not reported  | -   | -  | -                              | -  | -                               |
| Complications of treatment- not reported   | -   | -  | -                              | -  | -                               |
| Adherence- not reported  | -   | -  | -                              | -  | -                               |

CI: confidence interval; GRADE: grading of recommendations assessment development and evaluation; GMFM: gross motor function measure; SD: standard deviation.

- 1. Gait energy expenditure index: Lower values indicate better gait efficiency
- 2. Downgraded for serious risk of bias due to lack of blinding during assessment
- 3. Downgraded for serious imprecision as confidence interval includes one MID threshold
- 4. Higher GMFM scores indicate better motor function
- 5 10/12 participants completed the training intervention

Table 4: Summary clinical evidence profile: Comparison 2: Physical activity interventions versus standard care

|   | Anticipated absolute   | pated absolute effects* (95% CI)   |                                |                                    | Quality of                 |
|---|--|--|--------------------------------|------------------------------------|----------------------------|
| Outcomes  | Standard care  | Physical activity interventions  | Relative<br>effect<br>(95% CI) | No of<br>Participants<br>(studies) | the<br>evidence<br>(GRADE) |
| Participation Change in maximal gait speed <sup>1</sup> | The mean change<br>in maximal gait<br>speed in the control<br>group was<br>-0.01 (SD=0.07) | The mean change in maximal gait speed in the intervention groups was 0.28 higher (0.23 to 0.33 higher) | -                              | 32<br>(1 RCT)                      | Low <sup>2,3</sup>         |
| Physical function<br>ICF Total score                    | The mean physical<br>function score in<br>the control group<br>was 69.55<br>(SD=4.39)      | The mean physical function score in the intervention group was 29.65 lower (33.6 to 25.7 lower)        | -                              | 26 (1 RCT)                         | Low <sup>3,4</sup>         |
| Health related quality of life- not reported            | -  | -  | -                              | -                                  | -                          |
| Independence  | The mean independence score in the control group was 3.64 (SD=0.38)                        | The mean independence score in the intervention group was 1.74 higher (1.4 to 2.08 higher)             | -                              | 26 (1 RCT)                         | Low <sup>3,4</sup>         |

|  | Anticipated absolut | e effects* (95% CI)             |                                | Quality of                         |                            |
|--|---------------------|---------------------------------|--------------------------------|------------------------------------|----------------------------|
| Outcomes                                 | Standard care       | Physical activity interventions | Relative<br>effect<br>(95% CI) | No of<br>Participants<br>(studies) | the<br>evidence<br>(GRADE) |
| Fatigue- not reported                    | -                   | -                               | -                              | -                                  | -                          |
| Frequency of falls- not reported         | -                   | -                               | -                              | -                                  | -                          |
| Complications of treatment- not reported | -                   | -                               | -                              | -                                  | -                          |
| Adherence- not reported                  | -                   | -                               | -                              | -                                  | -                          |

CI: confidence interval; GRADE: grading of recommendations assessment development and evaluation; ICF: International Classification of Functioning; NGA: National Guideline Alliance; RCT: randomised controlled trial; SD: standard deviation

- 1. Higher mean change in maximal gait speed indicates better participation; change in maximal gait speed calculated by NGA team
- 2. Downgraded for serious risk of bias as information on withdrawal/dropouts is not reported for control group
- 3. Downgraded for serious imprecision as number of participants <400
- 4. Downgraded for serious risk of bias due to lack of blinding of assessors

Table 5: Summary clinical evidence profile: Comparison 3: Strengthening or training programmes versus standard care

| program   | mes versus star  |   |                                |                                    | Quality of                 |
|---|--|---|--------------------------------|------------------------------------|----------------------------|
| Outcomes  | Standard care  | Strengthening or training programmes  | Relative<br>effect<br>(95% CI) | No of<br>Participants<br>(studies) | the<br>evidence<br>(GRADE) |
| Participation: Change<br>from baseline in 2 min<br>walk test <sup>1</sup><br>follow up: 24 weeks                          | The mean participation - change from baseline in 2 min walk test in the control groups was 5.5 (SD=37.33)      | The mean participation - change from baseline in 2 min walk test in the intervention groups was 5.5 lower (34.74 lower to 23.74 higher) | -                              | 15 <sup>12</sup><br>(1 RCT)        | Low <sup>3</sup>           |
| Participation:<br>Change from baseline<br>in 6 min walk test <sup>4</sup><br>follow up: 8 to 24<br>weeks                  | The mean participation - change from baseline in 2 min walk test in the control groups was 11.3(SD=30.4)       | The mean participation in the intervention groups was 0.07 higher (20.25 lower to 20.39 higher)   | -                              | 60<br>(2 RCTs)                     | Low <sup>3</sup>           |
| Physical function:<br>Change from baseline<br>in Stair Climbing <sup>5</sup><br>(adapted from GMFM)<br>follow up: 8 weeks | The mean change<br>from baseline in<br>stair climbing in the<br>control groups was<br>1 (SD=12.72)             | The mean change from baseline in stair climbing in the intervention group was 2.00 lower (23.27 lower to 19.27 higher)                  | -                              | 12<br>(1 RCT)                      | Low <sup>3</sup>           |
| Physical function:<br>Change from baseline<br>in GMFM 66 <sup>6</sup><br>follow up: 24 weeks                              | The mean change<br>from baseline in<br>GMFM 66 in the<br>control groups was<br>1.3 (SD=7.6)                    | The mean change from baseline in GMFM 66 in the intervention group was 0.65 lower (4.4 lower to 3.1 higher)                             | -                              | 48<br>(1 RCT)                      | Low <sup>3</sup>           |
| HrQOL:<br>Change from baseline<br>in AQOL-6D <sup>7</sup><br>follow up: 24 weeks  | The mean change<br>from baseline in the<br>AQOL-6D score in<br>the control group<br>was<br>-1.9 (SD=8.06)      | The mean change from baseline in the AQOL-6D score in the intervention group was 0.30 higher (7.07 lower to 7.67 higher)                | -                              | 15 <sup>12</sup><br>(1 RCT)        | Very Low <sup>3,8</sup>    |
| Independence- not reported  | -  | -   | -                              | -                                  | -                          |
| Fatigue:<br>Change from baseline<br>in Fatigue Severity<br>Scale <sup>9</sup><br>follow up: 24 weeks                      | The mean change<br>from baseline in<br>fatigue severity<br>scale in the control<br>group was<br>-1.9 (SD=12.5) | The mean change from baseline in fatigue severity scale in the intervention group was 1.30 higher (9.22 lower to 11.82 higher)          | -                              | 15 <sup>12</sup><br>(1 RCT)        | Very low <sup>3,8</sup>    |

|  | Anticipated absolut   | e effects* (95% CI)  |                                |                                    | Quality of                 |
|--|---|--|--------------------------------|------------------------------------|----------------------------|
| Outcomes   | Standard care   | Strengthening or training programmes   | Relative<br>effect<br>(95% CI) | No of<br>Participants<br>(studies) | the<br>evidence<br>(GRADE) |
| Frequency of falls:<br>Change from baseline<br>in Falls Efficacy<br>Scale <sup>10</sup><br>follow up: 24 weeks | The mean change<br>from baseline in the<br>falls efficacy scale<br>in the control group<br>was<br>-3.5 (SD=4.8) | The mean change from baseline in the falls efficacy scale in the intervention group was 5.3 lower (12 lower to 1.4 higher) | -                              | 15 <sup>12</sup><br>(1 RCT)        | Low <sup>3</sup>           |
| Complications of<br>treatment:<br>Participants reporting<br>new soreness<br>follow up: 24 weeks                | Events in intervention 2/8  | Events in control 0/8  | RR 5.00<br>(0.28 to<br>90.18)  | 15 <sup>12</sup><br>(1 RCT)        | Low <sup>3</sup>           |
| Adherence to<br>treatment:<br>Number of sessions<br>attended<br>follow up: 24 weeks                            | 828 per 1000  | 860 per 1000<br>(702 to 941)   | RR 1.04<br>(0.89 to<br>1.20)   | 15 <sup>12</sup><br>(1 RCT)        | Low <sup>2,11</sup>        |

AQOL-6D: Assessment of Quality of Life Instrument-6D; CI: confidence interval; GMFM: gross motor function measure; GRADE: grading of recommendations assessment development and evaluation; HrQOL: health related quality of life; RR: risk ratio; NGA: National Guideline Alliance; RCT: randomised controlled trial; SD: standard deviation

- 1. Higher change from baseline in 2 minute walk test indicates better participation; change from baseline scores calculated by NGA team
- 2. Downgraded for serious risk of bias due to unit of analysis issues there were 8 observations for this outcome from each participant which are likely to be correlated
- 3. Downgraded for very serious imprecision due as confidence interval includes both MID thresholds
- 4. Change from baseline in 6 minute walk test: Higher value indicates better participation
- 5. Change from baseline in stair climbing: Higher value indicates better motor function
- 6. Change from baseline in GMFM 66: higher value indicates better motor function
- 7. Change in baseline in HrQOL: higher value indicates better health related quality of life
- 8. Downgraded for serious risk of bias due to lack of blinding in this subjective outcome
- 9. Change from baseline in fatigue severity scale: Lower value indicates better outcome
- 10. Change from baseline in falls efficacy scale: lower value indicates better outcome
- 11. Downgraded for serious imprecision as the confidence interval includes one MID threshold
- 12. Outcome data at week 24 were available for 15/17 participants.1 participant was lost to follow-up and 1 withdrew (both in the intervention group)

Table 6: Summary clinical evidence profile: Comparison 4: Task-oriented upper limb training versus standard care

|   | Anticipated absolute of  | effects* (95% CI)   |                                |                                    | Quality of                 |
|---|--|---|--------------------------------|------------------------------------|----------------------------|
| Outcomes  | Standard care  | Task-oriented upper limb training   | Relative<br>effect<br>(95% CI) | No of<br>Participants<br>(studies) | the<br>evidence<br>(GRADE) |
| Participation:<br>Change from baseline<br>in Jebsen Hand<br>Function Test <sup>1</sup><br>follow up: post-test at<br>12 weeks | The mean participation in the control groups was -1.99 (SD=15.08)      | The mean participation<br>in the intervention<br>groups was<br>22.03 lower<br>(52.25 lower to 8.19<br>higher) | -                              | 17<br>(1 observational<br>study)   | Very low <sup>2,6</sup>    |
| Physical function<br>Change from baseline<br>in Nine hole peg test <sup>4</sup><br>follow up: post-test at<br>12 weeks        | The mean physical function in the control groups was -2.274 (SD=32.78) | The mean physical function in the intervention groups was 20.91 lower (48.99 lower to 7.18 higher)            | -                              | 17<br>(1 observational<br>study)   | Very low <sup>2,3</sup>    |
| Health related quality of life- not reported  | -  | -   | -                              | -                                  | -                          |
| Independence<br>Change from baseline<br>in Barthel Index <sup>5</sup><br>follow up: post-test at<br>12 weeks                  | The mean independence in the control groups was 0 (SD=0)               | Not estimable   | -                              | 17<br>(1 observational<br>study)   | Very low <sup>2,7</sup>    |
| Fatigue- not reported   | -  | -   | -                              | -                                  | -                          |

|  | Anticipated absolute | effects* (95% CI)                 |                                |                                    | Quality of                 |
|--|----------------------|-----------------------------------|--------------------------------|------------------------------------|----------------------------|
| Outcomes                                 | Standard care        | Task-oriented upper limb training | Relative<br>effect<br>(95% CI) | No of<br>Participants<br>(studies) | the<br>evidence<br>(GRADE) |
| Frequency of falls-<br>not reported      | -                    | -                                 | -                              | -                                  | -                          |
| Complications of treatment- not reported | -                    | -                                 | -                              | -                                  | -                          |
| Adherence- not reported                  | -                    | -                                 | -                              | -                                  | -                          |

CI: confidence interval; GRADE: grading of recommendations assessment development and evaluation; SD: standard deviation; SMD: standardized mean difference

- 1. Jebsen hand function test: Lower score indicates greater function. Change from baseline values calculated by NGA team
- 2. Downgraded for serious risk of selection bias, as the baseline characteristics of intervention and control groups are not reported (and no adjustments were made for confounders) and it is unclear how they were selected
- 3. Downgraded for serious imprecision as confidence interval includes one MID threshold
- 4. Nine hole peg test: lower scores indicate better function. Change from baseline values calculated by NGA team.
- 5. Barthel Index: Higher scores indicate more independence. Change from baseline values calculated by NGA team.
- 6. Downgraded for very serious imprecision as confidence interval includes both MID thresholds.
- 7. Mean and standard deviation of change from baseline in the standard care group were both zero, so mean difference could not be estimated.

Table 7: Summary clinical evidence profile: Comparison 5: Task oriented upper limb training, before versus after outcomes

| training, before versus after outcomes                   |   |   |                             |                                  |                         |
|--|---|---|-----------------------------|----------------------------------|-------------------------|
|  | Anticipated absolute effects* (95% CI)  |   |                             | No of                            | Quality of the          |
| Outcomes   | Before Upper limb training  | After Upper limb training   | Relative effect<br>(95% CI) | Participants (studies)           | evidence<br>(GRADE)     |
| Participation -<br>Motor Activity Log<br>(amount of use) | The mean motor<br>activity log<br>score(amount of<br>use) in the control<br>group was<br>1.4 (SD=0.8) | The mean motor activity log score(amount of use) in the intervention groups was 0.20 higher (0.76 lower to 1.16 higher) | -                           | 12<br>(1 observational<br>study) | Very low <sup>1,2</sup> |
| Physical Function<br>Nine hole peg test                  | The mean nine hole peg test score in the control groups was 96.3 (SD=66.2)                            | The mean 9 hole<br>peg test score in<br>the intervention<br>groups was<br>3.90 lower(86.56<br>lower to 78.76<br>higher) | -                           | 12<br>(1 observational<br>study) | Very low <sup>1,2</sup> |
| Health related quality of life- not reported             | -   | -   | -                           | -                                | -                       |
| Independence-<br>not reported                            | -   | -   | -                           | -                                | -                       |
| Fatigue- not reported                                    | -   | -   | -                           | -                                | -                       |
| Frequency of falls- not reported                         | -   | -   | -                           | -                                | -                       |
| Complications of treatment- not reported                 | -   | -   | -                           | -                                | -                       |
| Adherence- not reported                                  | -   | -   | -                           | -                                | -                       |

CI: confidence interval; GRADE: grading of recommendations assessment development and evaluation; SD: standard deviation; SMD: standardized mean difference

- 1. Downgraded for serious risk of bias due to self-reporting of outcomes
- 2. Downgraded for very serious imprecision as the confidence interval included both MID thresholds

Table 8: Summary clinical evidence profile: Comparison 6: Orthopaedic surgery, preversus post-operative outcomes

| voicus post operative cateomics  |  |   |  |                                    |                           |
|--|--|---|--|------------------------------------|---------------------------|
|  | Anticipated abso   | lute effects* (95% CI)  | Relative No of Qual  |                                    | Quality of the            |
| Outcomes   | Preoperative   | After Orthopaedic surgery   | effect<br>(95% CI)   | Participants<br>(studies)          | evidence<br>(GRADE)       |
| Participation Participants Walking without aids Follow-up: mean 10 years             | Not estimable  | Not estimable   | RR ranged<br>from 1.25<br>(0.42 to 3.70)<br>to 5.50 (2.09<br>to 14.49) | 53<br>(2 observational<br>studies) | Very low <sup>1,2,3</sup> |
| Physical function- Harris hip score  | The mean Harris<br>hip score before<br>surgery was<br>36 (SD=11.2) | The mean Harris hip<br>score after surgery<br>was<br>42 higher (36.92 to<br>47.08 higher) | -  | 39<br>(1 observational<br>study)   | Very low <sup>3</sup>     |
| Health related quality of life- not reported   | -  | -   | -  | -                                  | -                         |
| Independence Participants conducting their own hygiene care Follow-up: mean 10 years | 357 per 1000   | 429 more per 1000<br>(11 to 1000 more)  | RR 2.20<br>(1.03 to 4.68)  | 14<br>(1 observational<br>study)   | Very low <sup>1</sup>     |
| Fatigue- not reported  | -  | -   | -  | -                                  | -                         |
| Frequency of falls- not reported   | -  | -   | -  | -                                  | -                         |
| Complications of treatment- not reported   | -  | -   | -  | -                                  | -                         |

CI: confidence interval; GRADE: grading of recommendations assessment development and evaluation; RR: Risk ratio; SD: standard deviation

- 1. Downgraded for very serious risk of bias due to selection bias and outcome assessment bias
- 2. Downgraded for serious inconsistency: one of the studies showed a clinically significant benefit with orthopaedic surgery whereas the other did not
- 3. Downgraded for serious risk of bias due to retrospective collection of data

See appendix F for the full GRADE tables.

#### **Economic evidence**

#### Included studies

A systematic review of the economic literature was conducted but no studies were identified which were applicable to this review question.

#### **Excluded studies**

No studies were identified which were applicable to this review question.

#### Summary of studies included in the economic evidence review

No economic evaluations were included in this review.

#### Economic model

This question was not prioritised for economic modelling. Given the legislation in place around the provision of powered mobility aids the committee did not believe that any recommendation would lead to a significant resource impact.

#### Resource impact

No unit costs were presented to the committee as these were not prioritised for decision-making purposes.

#### Evidence statements

#### Comparison 1: Physical activity intervention, before versus after outcomes

#### Critical outcomes

#### Participation incorporating mobility

 Very low quality evidence from 1 before-and-after study including 10 people indicated that a physical activity intervention did not improve participation as measured by walking efficiency (gait energy expenditure index).

#### **Physical function**

 Very low quality evidence from 1 before-and-after study including 10 people indicated that a physical activity intervention did not improve physical function as measured by the Gross Motor Function Measure (GMFM).

#### Health related quality of life & psychological wellbeing

• No evidence was found for this outcome.

#### Important outcomes

#### Independence

No evidence was found for this outcome.

#### **Fatigue**

• No evidence was found for this outcome.

#### Frequency of falls

No evidence was found for this outcome.

#### **Complications of treatment**

No evidence was found for this outcome.

#### **Adherence**

No evidence was found for this outcome.

#### Comparison 2: physical activity interventions versus standard care

#### Critical outcomes

#### Participation incorporating mobility

 Low quality evidence from 1 randomised controlled trial including 32 people with spastic cerebral palsy, indicated physical activity intervention was associated with a clinically significant improvement in participation (as measured by change in maximal gait speed) compared to standard care.

#### **Physical function**

 Low quality evidence from 1 randomised controlled trial including 26 adults with cerebral palsy, indicated physical activity intervention was associated with a clinically significant improvement in physical function (as measured by the total international classification of functioning score) compared to standard care. Interventions that improve or maintain physical function and participation for adults over 25 with cerebral palsy.

#### Health related quality of life & psychological wellbeing

· No evidence was found for this outcome.

#### Important outcomes

#### Independence

 Low quality evidence from 1 randomised controlled trial including 26 adults with cerebral palsy, indicated physical activity intervention was associated with a clinically significant improvement in independence compared to standard care.

#### **Fatigue**

No evidence was found for this outcome.

#### Frequency of falls

No evidence was found for this outcome.

#### **Complications of treatment**

No evidence was found for this outcome.

#### **Adherence**

No evidence was found for this outcome.

#### Comparison 3: strengthening or training programmes versus standard care

#### Critical outcomes

#### Participation incorporating mobility

Low quality evidence from 1 randomised controlled trial including 15 people with cerebral
palsy indicated that a strengthening/training programme did not result in a clinically
significant change in participation (as measured by a change from baseline in 2 min walk
test) compared to standard care.

#### **Physical function**

- Low quality evidence from 2 randomised controlled trials including 60 people with cerebral
  palsy indicated that a strengthening/training programme did not bring clinically significant
  change in physical function (as measured by the change from baseline in 6 min walk test)
  compared to standard care.
- Low quality evidence from1 randomised controlled trial including 12 people with cerebral
  palsy indicated that a strengthening/training programme did not bring clinically significant
  change in physical function (as measured by a change from baseline in stair climbing)
  compared to standard care.
- Low quality evidence from1 randomised controlled trial including 48 people with cerebral
  palsy indicated that a strengthening/training programme did not bring clinically significant
  change in physical function (as measured by a change from baseline in gross motor
  function measure 66) compared to standard care.

#### Health related quality of life & psychological wellbeing

 Very low quality evidence from 1 randomised controlled trial including 15 people with cerebral palsy indicated that a strengthening/training programme did not bring clinically significant improvement in health related quality of life compared to standard care.

#### Important outcomes

#### Independence

No evidence was found for this outcome.

#### **Fatigue**

 Very low quality evidence from 1 randomised controlled trial including 15 people with cerebral palsy indicated that a strengthening/training programme did not bring clinically significant change in fatigue (as measured by the change from baseline on the fatigue severity scale) compared to standard care.

#### Frequency of falls

Low quality evidence from 1 randomised controlled trial including 15 people with cerebral
palsy indicated that a strengthening/training programme did not bring clinically significant
improvement in falls (as measured by the change from baseline on the falls efficacy scale)
compared to standard care.

#### **Complications of treatment**

Low quality evidence from 1 randomised controlled trial including 16 people with cerebral
palsy indicated that a strengthening/training programme led to a clinically significant
increase in treatment related adverse effects (as in the numbers of participants reporting
soreness) compared to standard care.

#### **Adherence**

 Low quality evidence from 1 randomised controlled trial including 15 people with cerebral palsy indicated a similar adherence to a strengthening/training programme (measured in number of sessions attended) as there was to standard care.

#### Comparison 4: task-oriented upper limb training versus standard care

#### Critical outcomes

#### Participation incorporating mobility

Very low quality evidence from 1 non randomised controlled study including 17 people
with cerebral palsy indicated that a task oriented upper limb programme did not bring
clinically significant change in participation (as measured by the change from baseline on
Jebsen Hand Function Test).

#### **Physical function**

Very low quality evidence from 1 non randomised controlled study including 17 people
with cerebral palsy indicated that a task oriented upper limb programme did not bring
clinically significant change in physical function (as measured by the change from
baseline on the nine hole peg test).

#### Health related quality of life & psychological wellbeing

No evidence was found for this outcome.

#### Important outcomes

#### Independence

Very low quality evidence from 1 non randomised controlled study including 17 people
with cerebral palsy indicated that a task oriented upper limb programme did not bring
clinically significant change in independence (as measured by the change from baseline
on the Barthel index).

#### **Fatigue**

No evidence was found for this outcome.

#### Frequency of falls

No evidence was found for this outcome.

#### **Complications of treatment**

No evidence was found for this outcome.

#### **Adherence**

No evidence was found for this outcome.

#### Comparison 5: Task oriented upper limb training, before versus after outcomes

#### Critical outcomes

#### Participation incorporating mobility

 Very low quality evidence from one before-and-after study including 12 people with cerebral palsy with predominantly unilateral involvement of the upper limb indicated that task oriented upper limb programme did not bring clinically significant change in participation (as measured by the motor activity log).

#### **Physical function**

 Very low quality evidence from one before-and-after study including 12 people with cerebral palsy with predominantly unilateral involvement of the upper limb indicated that task oriented upper limb programme did not bring clinically significant change in physical function (as measured by the nine hole peg test).

#### Health related quality of life & psychological wellbeing

No evidence was found for this outcome.

#### Important outcomes

#### Independence

No evidence was found for this outcome.

#### **Fatigue**

No evidence was found for this outcome.

#### Frequency of falls

No evidence was found for this outcome.

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#### **Complications of treatment**

No evidence was found for this outcome.

#### **Adherence**

No evidence was found for this outcome.

#### Comparison 6: Orthopaedic surgery, pre-versus post-operative outcomes

#### Critical outcomes

#### Participation incorporating mobility

Very low quality evidence from 2 before-and-after study including 53 ambulatory adults
with cerebral palsy with severely limited functional ability indicated that hip arthroplasty did
not result in a clinically significant change in participation (as measured by the number of
participants walking without aids).

#### **Physical function**

• Very low quality evidence from 1 before-and-after studies including 39 adults with cerebral palsy indicated that hip arthroplasty resulted in a clinically significant improvement in physical function (as measured by the Harris hip score).

#### Health related quality of life & psychological wellbeing

No evidence was found for this outcome.

#### Important outcomes

#### Independence

Very low quality evidence from 1 before-and-after study including 14 ambulatory people
with cerebral palsy with severely limited functional ability indicated that hip arthroplasty
brought clinically significant improved independence (as measured by the number of
participants able to conduct their own hygiene care).

#### **Fatigue**

No evidence was found for this outcome.

#### Frequency of falls

No evidence was found for this outcome.

#### **Complications of treatment**

No evidence was found for this outcome.

#### **Adherence**

No evidence was found for this outcome.

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#### Ballaz 2011

Ballaz L, Plamondon S, Lemay M. Group aquatic training improves gait efficiency in adolescents with cerebral palsy. Disabil Rehabil. 2011;33(17-18):1616-24. doi: 10.3109/09638288.2010.541544.

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#### **Brown 2010**

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#### Houdek 2017

Houdek, M. T., Watts, C. D., Wyles, C. C., Trousdale, R. T., Milbrandt, T. A., Taunton, M. J., Total Hip Arthroplasty in Patients with Cerebral Palsy: A Cohort Study Matched to Patients with Osteoarthritis, The Journal of bone and joint surgery, American volume. 99, 488-493, 2017

#### **Hutzler 2013**

Hutzler, Y., Rodriguez, B. L., Laiz, N. M., Diez, I., Barak, S., The effects of an exercise training program on hand and wrist strength, and function, and activities of daily living, in adults with severe Cerebral Palsy, Research in Developmental Disabilities, 34, 4343-4354, 2013

#### Lorentzen 2017

Lorentzen, J., Kirk, H., Fernandez-Lago, H., Frisk, R., Jensen, P., Nielsen, J. B., Randomised controlled clinical trial of the effect of gait training on muscle function and gait kinematics in adults with cerebral palsy, Developmental Medicine and Child Neurology, 58, 44, 2016

#### Maeland 2009

Maeland, S., Jahnsen, R., Opheim, A., Froslie, K.F., Moe-Nilssen, R., Stanghelle, J.K., No effect on gait function of progressive resistance exercise in adults with cerebral palsy A single-blind randomized controlled trial, Advances in Physiotherapy, 11, 227-233, 2009

#### Morgan 2015

Morgan, P., Murphy, A., Opheim, A., Pogrebnoy, D., Kravtsov, S., McGinley, J., The safety and feasibility of an intervention to improve balance dysfunction in ambulant adults with cerebral palsy: a pilot randomized controlled trial, Clinical Rehabilitation, 29, 907-19, 2015

#### Schroeder 2010

Schroeder K, Hauck C, Wiedenhöfer B, Braatz F, Aldinger PR. Long-term results of hip arthroplasty in ambulatory patients with cerebral palsy. Int Orthop. 2010 ;34(3):335-9

#### Taylor 2013

Taylor, N. F., Dodd, K. J., Baker, R. J., Willoughby, K., Thomason, P., Graham, H. K., Progressive resistance training and mobility-related function in young people with cerebral palsy: A randomized controlled trial, Developmental Medicine and Child Neurology, 55, 806-812, 2013

#### Teixeira-Machado 2017

Teixeira-Machado, L., Azevedo-Santos, I., DeSantana, J. M., Dance Improves Functionality and Psychosocial Adjustment in Cerebral Palsy: A Randomized Controlled Clinical Trial, American journal of physical medicine & rehabilitation, 96, 424-429, 2017

#### The committee's discussion of the evidence

#### Interpreting the evidence

#### The outcomes that matter most

The critical outcomes were participation, physical function and health related quality of life because interventions to maintain physical function are primarily aimed at improving these outcomes. Important outcomes were independence, fatigue, frequency of falls, complications and adherence to the intervention programme.

#### The quality of the evidence

Evidence for outcomes related to participation and physical function following physical activity interventions was very low to low using GRADE. This was because of imprecision in evidence from one before-and-after study and risk of bias and imprecision in two randomized controlled trials in 1 randomised controlled trial. The low quality of the evidence meant that strong recommendation for physical activity interventions could not be made. For this comparison the number of reported outcomes was limited to: walking efficiency, gross motor function, independence and change in maximal gait speed.

The evidence to assess the effectiveness of strengthening/training programmes came from three randomised controlled trials. The evidence was low to very low using GRADE due to imprecision and risk of bias due to lack of blinding.

The evidence for task oriented upper limb training programmes for outcomes related to participation, physical function and independence was very low quality using GRADE. The evidence came from one before-and-after study and one non randomised controlled trial and was downgraded for imprecision, risk of due to selective reporting and assessment of outcomes.

The evidence for outcomes related to participation, physical function, independence following orthopaedic surgery was very low quality using GRADE. There were several limitations to this evidence including inconsistency, imprecision and high risk of selection and outcome assessment bias.

The committee discussed the practicality of the interventions in the randomised controlled trials and agreed that these interventions were not generalisable due to access to these specific services.

#### Benefits and harms

Low quality evidence from one randomised controlled trial showed that physical activity intervention can improve physical function and independence. Based on their knowledge and experience committee members agreed that physical activity helps in maintaining general fitness and healthy weight in all people, including adults who have physical disability. Hence, there should be discussions with adults with cerebral palsy about appropriate physical activities that could help in maintaining general fitness, range of movement and healthy weight. The committee agreed that information about local services should be provided in order to raise awareness and encourage the uptake of physical activities.

Based on their knowledge and expertise, the committee discussed that referral to a physiotherapist or an occupational therapist may be appropriate to suggest or initiate physical activities which would help in maintaining general fitness, range of movement, healthy weight, muscle strength and flexibility of joints. They acknowledged that this was consistent with NHS guidance on <a href="choosing mobility equipment">choosing mobility equipment</a>, wheelchairs and scooters which states that assessing the need for such equipment would be carried out by a multidisciplinary team which may include occupational therapists or physiotherapists, and

rehabilitation engineers within a seating service. Even though there was no specific evidence identified the committee also noted, based on their experience and expertise that orthotic and functional electronic stimulation (FES) services can also provide help people participate in physical activities (including sport) and tasks of daily living. These are used in conjunction with other interventions to optimise treatment. If there is local service provision then referral to these services could also be considered.

The evidence showed that there were no serious adverse events associated with strengthening training interventions to maintain physical function (in other words there were no clear differences between intervention and control for frequency of falls, fatigue and soreness). This was an important finding because assumptions may be made that there are more risks associated with physical activities for adults with cerebral palsy compared to the general population. The committee agreed that access to mobility aids, including wheelchairs, is fundamental to participation in work, social and leisure activities and therefore made a recommendation that adults can be referred to rehabilitation engineering services that would provide such aids.

The committee also discussed the reported benefit of surgical interventions and the limited availability of surgeons with expertise in cerebral palsy. The committee noted that the evidence for orthopaedic surgery was very low quality with uncertainty around the outcomes. For this reason, the committee did not make a strong recommendation for orthopaedic surgery, instead they recommended considering referral to a specialist orthopaedic surgeon with experience and expertise in managing musculoskeletal pain in adults with cerebral palsy, if participation in physical activities is limited by pain or joint problems resistant to other measures. The committee noted that there is currently limited access to orthopaedic surgeons with expertise in cerebral palsy. Based on their knowledge and experience the committee agreed that a general orthopaedic surgeon may refer adults with cerebral palsy onwards to others with specific technical expertise (for example hip arthroplasty) within regional networks, but the referring surgeon would usually look after the rehabilitation aspects.

The committee discussed that there was a lot of variation in how orthoses were used in current practice. There was a lack of evidence in relation to this and the committee decided to make a research recommendation. They agreed that this was important because cerebral palsy is a condition that affects an individual over the course of their life and as a consequence there are different disorders of motor control that may occur. There are treatments aimed at improving posture and function in the upper limbs that result from these issues which include postural interventions (stretching or exercise), systemic pharmacological treatments (drugs) and focal pharmacological treatments (botulinum toxin or nerve blocks). Orthotic treatment includes the application of a rigid or flexible device to facilitate a positional change and function. It can be used in conjunction with these interventions or as a separate treatment. It is not known which types, intensities or durations of orthotic interventions applied either alone or as part of a multi-modal treatment strategy are effective in improving and maintaining posture or functional abilities in the upper limb. Therefore further research would provide important new information to guide practice in this area.

#### Cost effectiveness and resource use

No economic evaluations were identified for this topic.

Adults with cerebral palsy are encouraged to participate in activity and exercise that is available to the general population and usually not funded by the NHS, leading to no additional use of NHS resources. The committee noted that there may be individuals who would benefit from tailored physical activities and specialist advice. For example, when strength and resistance training is performed, supervision is key to ensure the exercise is performed correctly to reduce injuries and increase adherence. Furthermore, if specialist

advice is needed, referrals to physiotherapy or occupational therapy teams that have experience in dealing with neurological impairments should be considered as their expertise will help individuals to overcome (physical or emotional) barriers cerebral palsy can put up.

The committee agreed the initial costs of specialist advice would be negligible compared to the potential downstream cost savings from avoided injuries or inactivity. It was noted that recommending a healthcare professional to provide advice without experience dealing with neurological impairments, whilst less costly, may not provide any additional benefits.

The committee agreed it would not be appropriate or necessary to offer physiotherapy and occupational therapy services to all adults with cerebral palsy (this would also not be cost effective) and made a recommendation to consider a referral to those that need help overcoming barriers to physical activities or functional tasks.

No comparative evidence was identified on orthotics and wheelchairs which limited the committee's ability to make strong recommendation on relatively expensive interventions. However, given that existing NHS commissioning policies are in place for those interventions, the committee agreed it was likely cost effective to offer a referral so their needs can be assessed. The committee noted that a recommendation to offer referrals would increase the overall number given that practice is currently variable across England. However, this would be offset by the improved quality of life that greater independence will bring.

The committee also added that manual wheelchairs and powered wheelchairs will differ in their cost effectiveness and iterated the importance of weighing up their potential harms and benefits on an individual basis. For example, manual wheelchairs will be cheaper to purchase and maintain, but may have negative effects if they cause harm by being too heavy to operate or increase shoulder or back pain and can also limit participation.

Referrals for orthopaedic surgery are usually considered by a neurodisability specialist when other less invasive and less costly methods such as tone management are no longer effective. To reflect this, the committee's recommendations followed the stepwise approach taken in current practice. The committee referred to the single study on hip surgery that was included and agreed that other joints such as the elbow can also be targeted, adding that the cost of surgery will depend on the joint that is targeted. To prevent considerations of hip surgery alone, the committee did not specify the type of orthopaedic surgery in their recommendation as this should be individualised to the person's need.

#### Other factors the committee took into account

The committee also discussed access to wheelchairs (manual or powered). Regarding the use of wheelchairs, the committee highlighted that even though no evidence was identified there is legislation, which informed this. This is covered by the UN <u>Convention on disability rights</u> which has been agreed by the UK to protect and promote the rights of disabled people and <u>Article 20</u> which asks nations 'to ensure personal mobility with the greatest possible independence for persons with disabilities'.

# **Appendices**

# Appendix A – Review protocols

Review protocol for review question D2: Which interventions are effective for maintaining physical function and mobility in adults with cerebral palsy?

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

Table 9: Review protocol for interventions for maintaining physical function

| Field (based on PRISMA-P)  | Content  |
|--|--|
| Review question  | D2 Which interventions are effective for maintaining physical function and mobility in adults with cerebral palsy, for example:                            |
|  | physical activity  |
|  | strengthening programmes or training   |
|  | • orthotics  |
|  | task-oriented upper limb training  |
|  | • orthopaedic surgery (including tendon lengthening and orthopaedic bony procedures in adulthood)  |
|  | powered mobility aids and wheelchairs  |
| Type of review question  | Intervention   |
| Objective of the review  | This review aimed to compare the effectiveness of interventions for maintaining or improving physical function and mobility in adults with cerebral palsy. |
| Eligibility criteria – population/disease/condition/issue/domain | Adults aged 16 and over with cerebral palsy  |
| Eligibility criteria –   | <ul> <li>physical activity (exercise, sport, community leisure)</li> </ul>   |
| intervention(s)/exposure(s)/prognostic factor(s)                 | strengthening programmes or training   |
|  | <ul> <li>orthotics (FES – related guidance)</li> </ul>   |

| Field (based on PRISMA-P)   | Content   |
|---|---|
|   | <ul> <li>task-oriented upper limb training</li> <li>orthopaedic surgery (including tendon lengthening, wrist fixation, long finger flexor release, hip surgery for dislocation, adductor tendon release, hamstring release, and orthopaedic bony procedures in adulthood)</li> <li>Powered Mobility aids and wheelchairs</li> </ul>   |
| Eligibility criteria – comparator(s)/control or reference (gold) standard | Each other     Usual care   |
| Outcomes and prioritisation   | <ul> <li>Critical outcomes</li> <li>Participation (incorporating mobility)</li> <li>Physical function</li> <li>Health related quality of life &amp; psychological wellbeing</li> <li>Important outcomes</li> <li>Independence</li> <li>Fatigue</li> <li>Frequency of falls [in a subset]</li> <li>Complications of treatment</li> <li>Adherence</li> <li>Minimally important differences:</li> <li>For this review protocol there were a number of published minimally important differences. For a description of these is provided in the methods in supplementary document C.</li> </ul> |
| Eligibility criteria – <b>study design</b>                                | Only published full text papers – conference abstracts will not be considered.  • Systematic reviews of RCTs  • RCTs - are cross over RCTs appropriate for this question?  • Comparative cohort studies (only if RCTs unavailable or limited data to inform decision making)  |
| Other inclusion exclusion criteria  | None  |
| Proposed sensitivity/ <b>sub-group analysis</b> , or meta-regression      | In the presence of heterogeneity, the following subgroups will be considered for sensitivity analysis:  • Population subgroups  • GMFCS level I to II   |

| Field (based on PRISMA-P)                                  | Content   |
|--|---|
|  | <ul> <li>GMFCS III to IV</li> <li>GMFCS V</li> <li>Different patterns of motor disorder</li> <li>Proportion with cerebral palsy (studies including other non-progressive causes of neuro-disability should involve at least 50% people with cerebral palsy)</li> <li>Intervention subgroups (e.g. route of administration, drugs within drug classes, high/low dose):</li> <li>Type of physical activity</li> <li>Type of orthopaedic surgery</li> <li>Initiation, duration and frequency of intervention (the timing of when someone receives a wheelchair or mobility aid is an important consideration)</li> </ul> |
|  | Age and GMFCS level will be also considered important confounders which ideally should be adjusted for in any included comparative observational studies. Indicate any modifiers of treatment effect/confounders that will be used to try to explain heterogeneity.   |
| Selection process – duplicate screening/selection/analysis | A random sample of the references identified in the search will be sifted by a second reviewer. This sample size will be 10% of the total, or 100 studies if the search identifies fewer than 1000 studies. All disagreements in study inclusion will be discussed and resolved between the two reviewers. The senior systematic reviewer or guideline lead will be involved if discrepancies cannot be resolved between the two reviewers.   |
| Data management (software)                                 | Pairwise meta-analyses were performed using Cochrane Review Manager (RevMan5).<br>'GRADEpro' was used to assess the quality of evidence for each outcome.   |
| Information sources – databases and dates                  | Embase 1974 to 2018 March 22, Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) 1946 to Present Last searched on 22/03/2018  |
| Identify if an update                                      | Not an update   |
| Author contacts  | For details please see the guideline in development web site.   |
| Highlight if amendment to previous protocol                | For details please see section 4.5 of <u>Developing NICE guidelines: the manual 2014</u>  |
| Search strategy – for one database                         | For details please see appendix B.  |
| Data collection process – forms/duplicate                  | A standardised evidence table format will be used, and published as appendix D (clinical evidence tables) or H (economic evidence tables).  |

FINAL Interventions that improve or maintain physical function and participation for adults over 25 with cerebral palsy.

| Field (based on PRISMA-P)   | Content   |
|---|---|
| Data items – define all variables to be collected                                   | For details please see evidence tables in appendix D (clinical evidence tables) or H (economic evidence tables).  |
| Methods for assessing bias at outcome/study level                                   | Standard study checklists were used to critically appraise individual studies. For details please see section 6.2 of <a href="Developing NICE guidelines: the manual 2014">Developing NICE guidelines: the manual 2014</a>  |
|   | The risk of bias across all available evidence was evaluated for each outcome using an adaptation of the 'Grading of Recommendations Assessment, Development and Evaluation (GRADE) toolbox' developed by the international GRADE working group <a href="http://www.gradeworkinggroup.org/">http://www.gradeworkinggroup.org/</a> . |
| Criteria for quantitative synthesis   | For details please see section 6.4 of <u>Developing NICE guidelines: the manual 2014</u>  |
| Methods for quantitative analysis – combining studies and exploring (in)consistency | For details please see supplementary document C for a description of the methods used for the quantitative analysis.  |
| Meta-bias assessment – publication bias, selective reporting bias                   | For details please see section 6.2 of <u>Developing NICE guidelines: the manual 2014</u> .  |
| Confidence in cumulative evidence   | For details please see sections 6.4 and 9.1 of Developing NICE guidelines: the manual.  |
| Rationale/context – what is known   | For details please see the introduction to the evidence review.   |
| Describe contributions of authors and guarantor                                     | A multidisciplinary committee developed the evidence review. The committee was convened by the National Guideline Alliance (NGA) and chaired by Dr Paul Eunson in line with section 3 of <a href="Developing NICE guidelines: the manual 2014">Developing NICE guidelines: the manual 2014</a> .                                    |
|   | Staff from the NGA undertook systematic literature searches, appraised the evidence, conducted meta-analysis and cost effectiveness analysis where appropriate, and drafted the guideline in collaboration with the committee. For details please see the methods in supplementary document C.                                      |
| Sources of funding/support  | The NGA is funded by NICE and hosted by the Royal College of Obstetricians and Gynaecologists.  |
| Name of sponsor   | The National Guideline Alliance is funded by NICE and hosted by the Royal College of Obstetricians and Gynaecologists   |
| Roles of sponsor  | NICE funds NGA to develop guidelines for those working in the NHS, public health and social care in England   |
| PROSPERO registration number  | Not applicable  |

GRADE: Grading of Recommendations Assessment, Development and Evaluation; GMFCS, gross motor function classification system; ICF: International Classification of Functioning, Disability and Health; MID: minimally important difference; NGA: National Guideline Alliance; NHS: National Health Service; NICE: National Institute for Health and Care Excellence; RCT: randomised controlled trial; RoB: risk of bias; SD: standard deviation.

## Appendix B – Literature search strategies

Literature search strategies for review question D2: Which interventions are effective for maintaining physical function and mobility in adults with cerebral palsy?

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

This appendix is a combined search strategy and will be the same for all the evidence reviews for the D review questions as listed below:

D1: Which interventions (for example, vocational and independent living skills training) promote participation in adults with cerebral palsy?

D2: Which interventions are effective for maintaining physical function and mobility in adults with cerebral palsy?

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

D3: What is the effectiveness of electronic assistive technology in promoting independence in adults with cerebral palsy?

D4: Which interventions (for example augmentative and alternative communication systems) are effective in promoting communication for adults with cerebral palsy who have communication difficulties?

#### **Database: Medline & Embase (Multifile)**

Database(s): Embase 1974 to 2018 March 22, Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) 1946 to Present

Table 10: Last searched on 22 March 2018

| # | Searches   |
|---|--|
| 1 | exp Cerebral Palsy/ use prmz   |
| 2 | exp cerebral palsy/ use oemezd   |
| 3 | ((cerebral or brain or central) adj2 (pal* or paralys#s or pares#s)).tw.             |
| 4 | cerebral palsy.ti,ab.  |
| 5 | little? disease.tw.  |
| 6 | ((hemipleg* or dipleg* or tripleg* or quadripleg* or unilateral*) adj5 spastic*).tw. |

| #  | Searches   |
|----|--|
| 7  | ((hemipleg* or dipleg* or tripleg* or quadripleg* or unilateral*) adj3 ataxi*).tw.   |
| 8  | or/1-7   |
| 9  | limit 8 to english language  |
| 10 | limit 9 to (adult <18 to 64 years> or aged <65+ years>) use oemezd [Limit not valid in Ovid  |
|    | MEDLINE(R),Ovid MEDLINE(R) In-Process; records were retained]  |
| 11 | limit 9 to "all adult (19 plus years)" [Limit not valid in Embase; records were retained]  |
| 12 | 11 use prmz  |
| 13 | or/10,12   |
| 14 | exp Community Participation/ or exp Social Participation/ or exp "Activities of Daily Living"/ or exp Independent Living/ or exp Vocational Education/ or exp "Quality of Life"/ or exp Hearing Aids/ or exp Wheelchairs/ or exp Needs Assessment/ or exp Disability Evaluation/ or exp Self-Help Devices/ or exp Sickness Impact Profile/ or exp Sensory Aids/ or exp "Prostheses and Implants"/ or exp Orthotic Devices/ or exp Equipment Design/ or exp User-Computer Interface/ or exp communication aids for disabled/ or exp speech disorder/rh or exp Exercise/ or exp Rehabilitation/mt or exp Sports/ or exp Exercise Therapy/ or exp Orthopedic Procedures/ or exp Physical Therapy Modalities/  |
| 15 | 14 use prmz  |
| 16 | social behavior/ or exp social adaptation/ or exp social participation/ or exp social interaction/ or exp community integration/ or exp community living/ or exp daily life activity/ or exp independent living/ or exp vocational education/ or exp "quality of life"/ or exp hearing aid/ or exp wheelchair/ or exp needs assessment/ or exp disability/ or exp self help device/ or exp Sickness Impact Profile/ or exp sensory aid/ or exp "prostheses and orthoses"/ or exp orthosis/ or exp implant/ or exp equipment design/ or exp computer interface/ or exp exercise/ or exp rehabilitation/ or exp self help/ or exp assistive technology/ or exp vocational guidance/ or exp communication aid/ or exp facilitated communication/ or exp eye tracking/ or exp sport/ or exp kinesiotherapy/ or exp orthopedic surgery/ or exp physiotherapy/   |
| 17 | 16 use oemezd  |
| 18 | (participat* or (daily adj activit*) or (independen* adj5 liv*) or age* or aging or gender or motivat* or preference* or limitation* or restriction* or capacit* or performance* or (handl* adj5 object*) or assistive technolog* or (social adj5 interaction*) or employ* or vocation* or occupat* or educat* or profession* or isolat* or leisure activit* or mobil* or communicat* or eat* or dining or drink* or dress* or interact* or ((assistive or adaptive) adj5 (technolog* or device* or system*)) or home or school or work* or communit* or play* or eye tracking or sporting activit* or swim* or aqua* or upper limb training or bony procedure* or (neurodevelopmental adj (treatment* or therap* or training)) or NDT or (muscle adj (tissue or tone)) or ((strength* or endurance) adj5 (program* or training*)) or ((tendon* or muscle*) adj (length* or stretch*)) or treadmill* or weight*).tw. |
| 19 | (augmentative or alternative communication or AAC or voice synthesizer* or accommodation* or sign language or gestur* or manual language board* or high?tech or touch screen* or speech?generating* or electronic keyboard* or phone* or iPad* or laptop* or computer* or modificat* or modify* or adapt* or custom* or tailor* or assist* or ((walking or hearing) adj aid*) or (communication adj (device* or system* or board*))).ti,ab.  |
| 20 | 15 or 17 or 18 or 19   |
| 21 | 13 and 20  |
| 22 | conference abstract.pt. use oemezd   |
| 23 | letter.pt. or LETTER/ use oemezd   |
| 24 | Letter/ use prmz   |
| 25 | EDITORIAL/ use prmz  |

| #  | Searches                                |
|----|---|
| 26 | editorial.pt. use oemezd                |
| 27 | NEWS/ use prmz                          |
| 28 | exp HISTORICAL ARTICLE/ use prmz        |
| 29 | note.pt. use oemezd                     |
| 30 | ANECDOTES AS TOPIC/ use prmz            |
| 31 | COMMENT/ use prmz                       |
| 32 | CASE REPORT/ use prmz                   |
| 33 | CASE REPORT/ use oemezd                 |
| 34 | CASE STUDY/ use oemezd                  |
| 35 | (letter or comment* or abstracts).ti.   |
| 36 | or/22-35                                |
| 37 | RANDOMIZED CONTROLLED TRIAL/ use prmz   |
| 38 | RANDOMIZED CONTROLLED TRIAL/ use oemezd |
| 39 | random*.ti,ab.                          |
| 40 | or/37-39                                |
| 41 | 36 not 40                               |
| 42 | ANIMALS/ not HUMANS/ use prmz           |
| 43 | ANIMAL/ not HUMAN/ use oemezd           |
| 44 | exp ANIMALS, LABORATORY/ use prmz       |
| 45 | exp ANIMAL EXPERIMENTATION/ use prmz    |
| 46 | exp MODELS, ANIMAL/ use prmz            |
| 47 | exp RODENTIA/ use prmz                  |
| 48 | NONHUMAN/ use oemezd                    |
| 49 | exp ANIMAL EXPERIMENT/ use oemezd       |
| 50 | exp EXPERIMENTAL ANIMAL/ use oemezd     |
| 51 | ANIMAL MODEL/ use oemezd                |
| 52 | exp RODENT/ use oemezd                  |
| 53 | (rat or rats or mouse or mice).ti.      |
| 54 | or/41-53                                |
| 55 | 21 not 54                               |

## **Database: Cochrane Library**

Table 11: Last searched on 22 March 2018

| Hits | Search   |
|------|--|
| #1   | MeSH descriptor: [Cerebral Palsy] explode all trees and with qualifier(s): [Physiopathology - PP, Rehabilitation - RH] |
| #2   | ((cerebral or brain or central) N2 (pal* or paralys?s or pare?s))  |
| #3   | ((hemipleg* or dipleg* or tripleg* or quadripleg* or unilateral*) N5 spastic*)   |
| #4   | ((hemipleg* or dipleg* or tripleg* or quadripleg* or unilateral*) N3 ataxi*)   |
| #5   | #1 or #2 or #3 or #4   |

| Hits | Search   |
|------|--|
| #6   | MeSH descriptor: [Social Behavior] explode all trees   |
| #7   | MeSH descriptor: [Social Participation] explode all trees  |
| #8   | MeSH descriptor: [Interpersonal Relations] explode all trees   |
| #9   | MeSH descriptor: [Community Integration] explode all trees   |
| #10  | MeSH descriptor: [Independent Living] explode all trees  |
| #11  | MeSH descriptor: [Activities of Daily Living] explode all trees  |
| #12  | MeSH descriptor: [Vocational Education] explode all trees  |
| #13  | MeSH descriptor: [Quality of Life] explode all trees   |
| #14  | MeSH descriptor: [Hearing Aids] explode all trees  |
| #15  | MeSH descriptor: [Wheelchairs] explode all trees   |
| #16  | MeSH descriptor: [Needs Assessment] explode all trees  |
| #17  | MeSH descriptor: [Disability Evaluation] explode all trees   |
| #18  | MeSH descriptor: [Self-Help Devices] explode all trees   |
| #19  | MeSH descriptor: [Sickness Impact Profile] explode all trees   |
| #20  | MeSH descriptor: [Sensory Aids] explode all trees  |
| #21  | MeSH descriptor: [Prostheses and Implants] explode all trees   |
| #22  | MeSH descriptor: [Orthotic Devices] explode all trees  |
| #23  | MeSH descriptor: [Equipment Design] explode all trees  |
| #24  | MeSH descriptor: [User-Computer Interface] explode all trees   |
| #25  | MeSH descriptor: [Exercise] explode all trees  |
| #26  | MeSH descriptor: [Rehabilitation] explode all trees  |
| #27  | MeSH descriptor: [Vocational Guidance] explode all trees   |
| #28  | MeSH descriptor: [Communication Aids for Disabled] explode all trees   |
| #29  | MeSH descriptor: [Eye Movements] explode all trees   |
| #30  | MeSH descriptor: [Sports] explode all trees  |
| #31  | MeSH descriptor: [Exercise Therapy] explode all trees  |
| #32  | MeSH descriptor: [Orthopedic Procedures] explode all trees   |
| #33  | MeSH descriptor: [Physical Therapy Modalities] explode all trees   |
| #34  | sporting activit* or swim* or aqua* or upper limb training or bony procedures or Neuro-developmental near (Treatment* or therap* or training) or NDT or muscle tissue or muscle tone or strength* or endurance or length* or stretch* or treadmill* or weight*   |
| #35  | participat* or independent liv* or age or aging or limitation* or restriction* or capacit* or performance* or Assistive technolog* or augmentative communication or alternative communication or AAC or employ* or vocation* or occupat* or educat* or profession* or leisure activit* or interaction* or home or school or work* or communit* or play* or accommodation* or sign language or gestur* or manual language board* or high?tech or touch screen* or speech?generating* or electronic keyboard* or phone* or iPad* or laptop* or computer or eye tracking or modif* or adapt* or custom* or tailor* or assist* or walking aid* or hearing aid* |
| #36  | {or #6-#35}  |
| #37  | #5 and #36   |

**Database: Web of Science** 

Table 12: Last searched on 22 March 2018

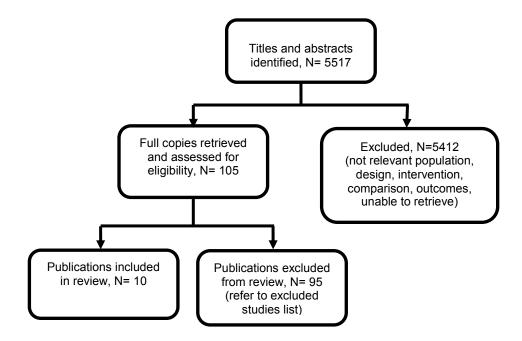
| IUDIC | 12. Last searched on 22 March 2010   |
|-------|--|
| #3    | #2 AND #1 AND LANGUAGE: (English)  |
| #2    | ts=Social Behavior or ts=Social Participation or ts=Interpersonal Relations or ts=Community Integration or ts=Independent Living or ts=Activities of Daily Living or ts=Vocational Education or ts=Quality of Life or ts=Hearing Aid* or ts=Wheelchair* or ts=Disability Evaluation or ts=Needs Assessment or ts=Self-Help Device* or ts=Sensory Aid* or ts=Prostheses or ts=Implant* or ts=Orthotic Device* or ts=Equipment Design or ts=User-Computer Interface or ts=Exercise* or ts=Rehabilitation or ts=Vocational Guidance or ts=Sport* or ts=Exercise Therap* or ts=Orthopedic Surgery or ts=Physiotherapy OR TS=Assistive technolog* or TS=augmentative communication or TS=alternative communication or TS=AAC OR TS=manual language board* or TS=high?tech or TS=touch screen* or TS=speech?generating* or TS=electronic keyboard* or TS=phone* or TS=iPad* or TS=laptop* or TS=eye tracking |
| #1    | ts=Cerebral Palsy  |

# Appendix C - Clinical evidence study selection

Clinical evidence study selection for review question D2: Which interventions are effective for maintaining physical function and mobility in adults with cerebral palsy?

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

Figure 1: Flow diagram of clinical article selection for interventions for physical function review



# **Appendix D – Clinical evidence tables**

Clinical evidence tables for review question D2: Which interventions are effective for maintaining physical function and mobility in adults with cerebral palsy?

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

Table 13: Studies included in the evidence review for interventions for maintaining physical function in adults with cerebral palsy

| Study details  | Participants  | Interventions   | Methods   | Outcomes and<br>Results   | Comments   |
|--|---|---|---|---------------------------|--|
| Full citation  Ballaz,L., Plamondon,S., Lemay,M., Group aquatic training improves gait efficiency in adolescents with cerebral palsy, Disability and Rehabilitation, 33, 1616-1624, 2011  Ref Id | Characteristics 12 adolescents.  Average age: 17. 25 yrs (14-21 yrs)  GMFCS I = 2, II=4, III=4, IV=2.  Inclusion criteria | Interventions  Aquatic training programme that focused mainly on swimming. It included 20 group training sessions supervised by physical therapists and sports teacher (45 min/twice a week).  Session Duration = Warm Up + 15 min race relay + 5 min cool down + 15 min water polo/volley ball | Details  Three physical therapists and a sports teacher supervised the training sessions.  Participants wore a heart rate monitor to assess sessions' intensity and a floatation device as appropriate. The primary outcome measure was gait efficiency as measured | Results  See Forest Plots | Limitations  1) Single group study  2) Small sample size  Other information  Limitations  EPOC Quality criteria for interrupted time |
| 132595   | 1) Ability to follow simple verbal instructions   |   | by the gait energy<br>expenditure index<br>(EEI).2 participants   |                           | series (ITS)   |

FINAL Interventions that improve or maintain physical function and participation for adults over 25 with cerebral palsy.

| Study details  | Participants   | Interventions | Methods                | Outcomes and Results | Comments  |
|--|--|---------------|------------------------|----------------------|---|
| Country/ies where the study was carried out Canada Study type Single group prepost design Aim of the study To evaluate the effect and feasibility of a 10-week group aquatic training programme in adolescents with cerebral palsy (CP). Study dates not reported Source of funding Not reported | 2) Independent in walking (with or without assistive devices) for at least 5 min  Exclusion criteria  1) Any known cardiovascular disease 2) Surgical intervention or Botulinum toxin A injection in the lower extremities |               | dropped out at week 5. |                      | Protection against secular changes - done  Data were analysed appropriately - not done  Sample size calculation performed - not done  Shape of the intervention effect was specified - not clear  Protection against detection bias: Intervention unlikely to affect data collection - done  Protection against detection bias: Blinded assessment of primary outcome(s) - not done |
| Full citation  | Sample size  | Interventions | Details                | Results              | Limitations   |

FINAL Interventions that improve or maintain physical function and participation for adults over 25 with cerebral palsy.

| Study details  | Participants   | Interventions   | Methods   | Outcomes and Results | Comments  |
|--|--|---|---|----------------------|---|
| Brown, S. H., Lewis, C. A., McCarthy, J. M., Doyle, S. T., Hurvitz, E. A., The effects of Internet-based home training on upper limb function in adults with cerebral palsy, Neurorehabilitation and neural repair, 24, 575-83, 2010  Ref Id  416064  Country/ies where the study was carried out United States  Study type  Uncontrolled Before-and-after study  Aim of the study  The purpose of this study was to examine the | Characteristics  Age: 21 to 57 years  (mean age: 33 years) | Intervention Equipment: An upper limb training system consisting of a laptop, webcam, target light board, and hand manipulation/ discrimination devices .  Intervention Task: unilateral and bilateral reach movements as well as a series of hand sensorimotor tasks such as card turning, stereognosis, and tactile discrimination.  Site of intervention: Home Intensity/Duration: 40 min/day, 5 days/wk for 8 wks | Data generated during each session were transmitted to the laboratory via the Internet. Main outcome measures were movement time, interlimb delay time, and performance on hand sensorimotor tasks. |                      | 1) No control group 2) small sample size Other information Limitations Risk of Bias Using New Castle Ottawa Checklist for non randomised studies Selection:4/4 1) Representativeness of the exposed cohort: Somewhat representative* 2) Selection of the non exposed cohort: drawn from the same community as cohort* 3) Ascertainment of exposure: webcams * 4) Demonstration that outcome of interest was not |

FINAL Interventions that improve or maintain physical function and participation for adults over 25 with cerebral palsy.

| Study details  | Participants                                      | Interventions     | Methods | Outcomes and Results | Comments  |
|--|---|-------------------|---------|----------------------|---|
| effectiveness of a home and Internet-                                  | involvement of upper limb                         |                   |         |                      | present at the start of study: yes*                 |
| based upper limb training program for                                  | 2) Independent community dwellers                 |                   |         |                      | Comparability:1/2                                   |
| adults with hemiplegic CP  | 3) Able to extend                                 |                   |         |                      | 1) Comparability of cohorts on the basis            |
| Study dates  | each finger of the affected hand by at least 10°. | ach finger of the |         |                      | of the design or analysis: *                        |
| Not mentioned  |   |                   |         |                      | Outcome:1/3   |
| Source of funding  | Exclusion criteria                                |                   |         |                      | 1) Assessment of                                    |
| , , ,  | Receiving medical treatment related to            |                   |         |                      | outcome: Not blind assessment                       |
| initiated grant<br>awarded to SHB<br>from the National<br>Institute on | upper limb function.                              |                   |         |                      | 2) Was follow-up enough for outcomes to occur: yes* |
| Disability and<br>Rehabilitation<br>Research<br>(H133G050151) and      |   |                   |         |                      | 3) Adequacy of follow up of cohorts: 2 dropped      |
| research fellowships<br>awarded to CAL<br>from the Office of           |   |                   |         |                      | out   |
| Special Education and Rehabilitative                                   |   |                   |         |                      |   |
| Services Leadership Training Program                                   |   |                   |         |                      |   |
| (H325D020028) and the University of                                    |   |                   |         |                      |   |
| Michigan Medical<br>Rehabilitation NIH                                 |   |                   |         |                      |   |

| Study details  | Participants   | Interventions   | Methods  | Outcomes and Results   | Comments  |
|--|--|---|--|--|---|
| Training Program (HD007422-15).  |  |   |  |  |   |
| Full citation  | Sample size  | Interventions   | Details  | Results  | Limitations   |
| Hutzler, Y., Rodriguez, B. L., Laiz, N. M., Diez, I., Barak, S., The effects of an exercise training program on hand and wrist strength, and function, and activities of daily living, in adults with severe Cerebral Palsy, Research in Developmental Disabilities, 34, 4343-4354, 2013  Ref Id 416051  Country/ies where the study was carried out Spain  Study type | Characteristics Intervention group: 10 participants (six males and four females) with a mean age of 46.80, SD=11.35 years. Functional classification GMFCS levels II (n = 2), III (n = 5) and IV (n = 3).  Control group: 7 participants (four males and three females) with a mean age of 39.85, SD=14.43 years and GMFCS levels III (n = 3) and IV (n = 4). All participants were Caucasian.  Inclusion criteria | Total duration: 3 months  First 4 weeks: Familiarizing participants with equipment & exercises  Next 8 weeks:  Main training period:  3 training sessions each (totalling 24 sessions) lasted a net time of 90 min within a two and a-half hour total time.  Each session included four parts:  (a) 10 min of warm-up and flexibility training of the upper extremity and trunk joints;  (b) main specific training of the major muscle groups (biceps brachii, triceps brachii, pectoralis major and deltoid) during a 40–50 min duration; | prospective time series design for the experimental group was completed, including a pre-test, a post-test after a 12-week intervention period, and a follow-up in the experimental group after an additional 10- week period. | wrist and hand<br>dynamometry;<br>dominant hand<br>upper-extremity<br>function<br>measures<br>(Jebsen Hand<br>Function Test =<br>JHFT, Minnesota<br>Manual Dexterity<br>Test = MMDT, | There was no random allocation of participants to experimental & control groups, thus there is a high risk for selection bias.  Other information  Risk of Bias:  Risk of Bias Assessment Using New Castle Ottawa Scale  Selection:2/4  1)  Representativeness: Institution based  2)Selection of non-exposed: From same group as exposed * |

FINAL Interventions that improve or maintain physical function and participation for adults over 25 with cerebral palsy.

| Study details   | Participants   | Interventions   | Methods | Outcomes and Results | Comments  |
|---|--|---|---------|----------------------|---|
| Control group design with pre test post test for experimental group  Aim of the study  The purpose of the current study was to establish measurement reliability in adults with Cerebral Palsy (CP), and to examine the feasibility and outcomes of an upper extremity strength training program (three times per week for 90 min each time).  Study dates  Not mentioned  Source of funding  Not mentioned | comparison groups<br>were: (a) scores of<br>less than 45 out of<br>100 points in the | (c) a stretching period of the major muscle groups for 10 min; and  (d) after about an hour's rest, a second training period of the major muscle groups was performed lasting 30 min. |         |                      | 3)Ascertainment of exposure: Fidelity not measured 4) Demonstration that outcome of interest was not present at the start of study Baseline scores mentioned* Comparability 2/2 ** Controls for important factor, baseline characteristics comparable Outcome 3/3 *** 1) Blind/self-report Blinded evaluators 2) Was follow up enough Yes 3) Follow-up of Cohort: * |
| Full citation   | Sample size  | Interventions   | Details | Results              | Limitations   |

FINAL Interventions that improve or maintain physical function and participation for adults over 25 with cerebral palsy.

| Study details   | Participants  | Interventions   | Methods   | Outcomes and Results | Comments   |
|---|---|---|---|----------------------|--|
| Lorentzen, J., Kirk, H., Fernandez-Lago, H., Frisk, R., Jensen, P., Nielsen, J. B., Randomized controlled clinical trial of the effect of gait training on muscle function and gait kinematics in adults with cerebral palsy, Developmental Medicine and Child Neurology, 58, 44, 2016  Ref Id 587088  Country/ies where the study was carried out Denmark  Study type  Randomised controlled trial  Aim of the study | Characteristics Thirty-two adults diagnosed with CP (age 38.1 years SD 12, range 19–59 years; 14 men, 18 women) Training Group (n=16, Female=62.5%, Age: 37.4(2.6) 25% Hemiplegia, 62.5% Diplegia, 12.5% Quadriplegia, most affected leg Rt (44%), GMFCS 1=37.5%, 2=12.5%,3=50%) Surgical procedure: 2.3 +/- 2.9 Control Group: (n=16, Female=50%, Age: 38.5(12.5), Hemiplegia 12.5%, Diplegia 81.3%, Quadriplegia :6.2%, Most affected leg: 44% (?Rt), GMFCS | The training intervention consisted of 30 min daily uphill gait training for 6 weeks on a treadmill. Individualised training program +follow up visits by physiotherapists+maintainance of training log | After inclusion all participant were randomised to either the training group or intervention group. Block randomization was used to assure an equal amount of participants in each group. Sixteen participants were accordingly assigned to a training group and 16 participants to a non-training control group. | See Forest Plots     | No information on inclusion/exclusion criteria  Other information  Risk of Bias Assessment:  1) Selection bias a) Random sequence generation: Unclear risk b) Allocation concealment: Unclear risk 2) Performance bias: Low risk 3) Detection bias: Low risk 4) Attrition bias: Low risk 5) Reporting bias: Unclear risk |

FINAL Interventions that improve or maintain physical function and participation for adults over 25 with cerebral palsy.

| Study details  | Participants   | Interventions   | Methods | Outcomes and Results     | Comments  |
|--|--|---|---------|--------------------------|---|
| To investigate if 30min of daily treadmill training with an incline for 6 weeks would reduce ankle joint stiffness and improve active range of movement in adults with cerebral palsy (CP).  Study dates  Not mentioned  Source of funding  None mentioned | 1=18.8%, 2=37.5%,3=43.7%, ), Surgical procedure: 2.0=/-1.8  Both groups: Antispastic medication: 12.5%  Inclusion criteria  Not described  Exclusion criteria  Not described |   |         |                          | 6) Other bias: No mention of dropouts Overall: High Risk  |
| Full citation  Maeland,S., Jahnsen,R., Opheim,A., Froslie,K.F., Moe- Nilssen,R., Stanghelle,J.K., No effect on gait function of progressive resistance exercise in adults with   | Sample size  12 (PRE group=6, Control group=6)  Characteristics  Training group, Males-2, Females-4, Age=32-69 yrs, GMFCS 2- 4,GMFCS 3-2                                     | Interventions  PRE programme consisting of a 10-min warm-up, followed by SLP 1215 repetitions maximum (RM) in 4 sets, 3 days a week, for the first 2 weeks, progressing to 6RM in 4 sets, 3 days a week, for the following 6 weeks. |         | Results See Forest Plots | Limitations  Baseline differences in outcome measures between groups.  Other information  Risk of Bias Assessment:  1) Selection bias |

FINAL Interventions that improve or maintain physical function and participation for adults over 25 with cerebral palsy.

| Study details  | Participants  | Interventions | Methods  | Outcomes and Results | Comments  |
|--|---|---------------|--|----------------------|---|
| cerebral palsy A<br>single-blind<br>randomised<br>controlled trial,<br>Advances in<br>Physiotherapy, 11,<br>227-233, 2009  | Control group, Males-2, Females-4, Age=27-65 yrs; GMFCS 2- 3,GMFCS 3-3  |               | information about the treatment were prepared by the statistician. |                      | a) Random sequence generation: Low risk b) Allocation concealment: Low risk   |
| <b>Ref Id</b> 76077  | 1) above 18 years of age,   |               |  |                      | 2) Performance bias:<br>Low risk  |
| Country/ies where the study was carried out  | 2) spastic diplegic CP<br>3) GMFCS level II or<br>III   |               |  |                      | 3) Detection bias:<br>Low risk  |
| Norway  Study type  Single-blind randomised controlled trial   | 4)experiencing difficulties with walking, but able to walk for 6 min without or with minimal support from one person                                  |               |  |                      | <ul><li>4) Attrition bias: Low risk</li><li>5) Reporting bias: Unclear risk</li><li>6) Other bias: Low Risk</li></ul> |
| Aim of the study  To examine the effects of a progressive resistance exercise (PRE) programme of seated leg press (SLP) on gait function in adults with spastic diplegic | 5) being motivated for PRE.  Exclusion criteria  1) having taken part in a specific strength training regime for the lower limbs during the past year |               |  |                      | Overall : Low Risk  |

FINAL Interventions that improve or maintain physical function and participation for adults over 25 with cerebral palsy.

| Study details  | Participants   | Interventions   | Methods  | Outcomes and Results | Comments   |
|--|--|---|--|----------------------|--|
| CP, Gross Motor<br>Function<br>Classification<br>System (GMFCS)<br>level II and III, who<br>experience reduced<br>walking ability.                 | 2) having severe cognitive disorders   |   |  |                      |  |
| Study dates  |  |   |  |                      |  |
| Not mentioned  |  |   |  |                      |  |
| Source of funding  |  |   |  |                      |  |
| Helse-Ost RHF<br>(Eastern Norway<br>Regional Health<br>Authority)  |  |   |  |                      |  |
| Full citation  | Sample size  | Interventions   | Details  | Results              | Limitations  |
| Morgan, P., Murphy,  | 17   | In both groups, participants  | Following enrolment  | See Forest Plots     | 1) Small sample size   |
| A., Opheim, A.,<br>Pogrebnoy, D.,  | Characteristics  | attended an out-patient programme in small groups of  | and baseline assessment,   |                      | 2) Only high   |
| Kravtsov, S., McGinley, J., The safety and feasibility of an intervention to improve balance dysfunction in ambulant adults with cerebral palsy: a | 17 participants (ten males, mean age 37 years, SD 11.3, range 19–53 years)  Inclusion criteria | three, on a Saturday afternoon, once weekly, for 1.5 hour sessions over an eight-week intervention period. An individualised structured home practice session (once a week, 30–60 minutes) was also prescribed for those in the | participants were randomised in blocks of six to either the intervention or control group. To conceal randomization, consecutively numbered sealed |                      | functioning young/middle aged adults with cerebral palsy  3) Control group might have benefited from seated yoga |

FINAL Interventions that improve or maintain physical function and participation for adults over 25 with cerebral palsy.

| Study details   | Participants  | Interventions  | Methods  | Outcomes and Results | Comments   |
|---|---|--|--|----------------------|--|
| pilot randomised controlled trial, Clinical Rehabilitation, 29, 907-19, 2015  Ref Id  433649  Country/ies where the study was carried out  Australia  Study type  assessor-blinded randomised controlled trial.  Aim of the study  To investigate the safety, feasibility and potential efficacy of balance training in adults with cerebral palsy  Study dates  Screening: January to October 2013 | Inclusion criteria were: (i) a diagnosis of cerebral palsy (any subtype); (ii) aged ≥18 years; (iii) Gross Motor Function Classification System – Extended and Revised (GMFCS- E&R) Level I, II, or III (that is: able to walk independently or with an aid);17 (iv) able and willing to attend an eight- week therapy programme; and (v) medically permitted to participate in a balance training programme. In addition, in order to be able to provide informed consent, and actively participate within the programmes, eligible participants needed to have functional English language skills, and be classified as Level I | performance, as indicated by the Balance Evaluation Systems test.  The balance training included practice of anticipatory and reactive dynamic balance strategies in standing and stepping, and dynamic gait activities, tailored to improve walking ability and safety.  Progressive resistance strengthening exercises were incorporated into the balance training programme and targeted major muscle groups of the lower limbs involved in balance control, such as ankle dorsiflexors and plantarflexors, knee extensors, hip extensors, and abductors, all carried out in functional training positions.  The control group programme included seated activities, such | envelopes were prepared in advance and opened in sequence by an independent advisor not involved in recruitment. A maximum of three participants were enrolled at a time in either balance or control groups in order to optimize the individual tailoring of the training programme and provision of close supervision. Four experienced physiotherapists and two allied health assistants (exercise physiologists) were trained to deliver the interventions. Clinical outcome measures were evaluated at baseline (Week 0), following intervention (Week 8), and 4 months after programme completion (Week 24). |                      | Other information Risk of Bias Assessment:  1) Selection bias  a) Random sequence generation: Low risk  b) Allocation concealment: Low risk  2) Performance bias: High risk  3) Detection bias: Low risk  4) Attrition bias: Low risk  5) Reporting bias: Unclear risk  Overall: High Risk |

| Study details  | Participants  | Interventions  | Methods   | Outcomes and Results   | Comments  |
|--|---|--|---|--|---|
| Source of funding This study has been funded by a 2013 Lions John Cockayne Memorial Trust Fund.  | or II on the<br>Communication<br>Function System for<br>individuals with<br>cerebral palsy<br>Exclusion criteria  | mindfulness and seated yoga, and Tai Chi. No activities relating to walking or standing balance were included in the programme for the control group.        | Assessments were completed in an outpatient department by an experienced physiotherapist blinded to group allocation.   |  |   |
| Full citation  | Sample size   | Interventions  | Details   | Results  | Limitations   |
| Schroeder,K., Hauck,C., Wiedenhofer,B., Braatz,F., Aldinger,P.R., Long- term results of hip arthroplasty in ambulatory patients with cerebral palsy, International Orthopaedics, 34, 335-339, 2010  Ref Id 133935  Country/ies where the study was carried out Germany | Characteristics Total number=16, Age: 42±8 years (range 32–58) Male=6, Female=10 Spastic Quadriplegia=8, Hemiplegia=3, Diplegia=4, Unclassified=1 Inclusion criteria Painful osteoarthritis with severely limited functional ability. | Hip replacement using different combination of implants (cemented/uncemented)+ Soft tissue releases(in case of contracture)/Brace(if needed) + Physiotherapy | Lost to follow up=2, 1 patient died.  Analysis of 13 patients for most outcomes.  Follow-up of 10±6 years (range 2–18 years).  Patients were either interviewed themselves (n=5) or questions were answered by carers (family or nurses) n=8).Immediately after operation anteriorposterior radiographs | Participation: Walking: Free walking pre & post op=2, walking aids pre and post op=7, non ambulatory preop, free walking post op=3, free walking preop, walking preop, walking aids post op=2  Independence: Improvement in hygiene care | 1) Small sample Size 2) Telephonic interview 3) Lack of uniformity in implants  Other information  Risk of Bias assessment using Checklist for Interrupted times series  Protection against secular changes - done  Data were analysed appropriately - not done |

FINAL Interventions that improve or maintain physical function and participation for adults over 25 with cerebral palsy.

| Study details  | Participants   | Interventions  | Methods   | Outcomes and Results  | Comments  |
|--|--|--|---|---|---|
| Study type  Before-and-after Single group  Aim of the study  To study the long- term results of hip arthroplasty in ambulatory patients with cerebral palsy  Study dates  1988-2004  Source of funding  Not reported | Others not described  Exclusion criteria  Not described  |  | of the hip joint were taken and evaluated.  | postpopratively= 7, No problems preop and postop=4, No improvement in hygiene care =2 Problems with hygiene care postop=1 | Sample size calculation performed - not done Shape of the intervention effect was specified - not done Protection against detection bias: Intervention unlikely to affect data collection - done Protection against detection bias: Blinded assessment of primary outcome(s) - not done |
| Full citation  Taylor, N. F., Dodd, K. J., Baker, R. J., Willoughby, K., Thomason, P., Graham, H. K., Progressive resistance training  | Sample size  48  Characteristics  Number = 48, Diagnosis=Spastic diplegic CP, Gender: 26 males, 22 | Interventions Intervention Duration & Frequency: Twice a week for 12 weeks Intervention Description: Progressive resistance training programme in a community gymnasium on weights | Details  Separate randomization procedure for each stratum (GMFCS levels II and III) was done using permuted blocks. An | See Forest Plots  | Limitations  1) Amount of other physical activity done by the subjects was not measured  2) Target sample size not achieved   |

FINAL Interventions that improve or maintain physical function and participation for adults over 25 with cerebral palsy.

| Study details  | Participants   | Interventions  | Methods   | Outcomes and Results | Comments  |
|--|--|--|---|----------------------|---|
| and mobility-related function in young people with cerebral palsy: A randomised controlled trial, Developmental Medicine and Child Neurology, 55, 806-812, 2013  Ref Id 587561  Country/ies where the study was carried out Australia  Study type  Randomised controlled trial  Aim of the study  To investigate whether individualized resistance training improves the physical mobility of young people with cerebral palsy (CP). | 18y 1mo, SD= 1y 11mo, Classification: level II or III on the Gross Motor Function Classification Inclusion criteria  1) spastic diplegic CP 2) Aged between 14 years and 22 years 3) Classified as level II or III on the Gross Motor Function | machines either singly or in pairs under the supervision of a physiotherapist.  10 to 12 repetitions of each exercise, with a 2-minute break between each set.  Participants were instructed that they should feel as though they had worked 'hard', scoring at least a 5 on the 0 to 10 category of the Borg Perceived Exertion Scale, which was evaluated at the end of each session. Each participant had a logbook detailing each exercise, the weight lifted, the number of repetitions, the number of sets completed, and the details of any injuries. | independent researcher generated a block allocation sequence for each stratum by drawing pieces of paper from a sealed container and then sealing assignments in sequentially numbered opaque envelopes. The research coordinator allocated participants after enrolment and baseline testing. Participants allocated to the experimental group completed a twice-weekly, 12-week progressive resistance training programme in a community gymnasium close to home. Outcome measures were evaluated at baseline, after the intervention (week 12), and after a further 12 weeks (week 24). Assessments were completed in a hospital |                      | Other information Risk of Bias Assessment:  1) Selection Bias a) Random sequence generation (selection bias): Low risk b) Allocation concealment (selection bias): Low risk  2) Blinding of participants and personnel (performance bias): Low risk  3) Blinding of outcome assessment (detection bias): High risk  4) Incomplete outcome data (attrition bias): Low risk |

FINAL Interventions that improve or maintain physical function and participation for adults over 25 with cerebral palsy.

| Study details   | Participants   | Interventions  | Methods  | Outcomes and Results | Comments   |
|---|--|--|--|----------------------|--|
| Study dates Not reported Source of funding This trial was supported financially by a grant from the National Health and Medical Research Council of Australia (ID 487321).  | 2) Undergone single event multi-level orthopaedic surgery in the previous 2 years, or 3) Contractures of more than 20° at the hip and knees  |  | gait laboratory by an assessor blinded to group allocation   |                      | 5) Selective reporting (reporting bias): Unclear risk 6) Other bias: None Overall: High risk   |
| Full citation   | Sample size  | Interventions  | Details  | Results              | Limitations  |
| Houdek, M. T., Watts, C. D., Wyles, C. C., Trousdale, R. T., Milbrandt, T. A., Taunton, M. J., Total Hip Arthroplasty in Patients with Cerebral Palsy: A Cohort Study Matched to Patients with Osteoarthritis, The Journal of bone and joint surgery, | Characteristics  No. of participants with CP group= 39, Number of participants in osteoarthritis group= 78; Mean age= 49 (Range: 21 to 74 years); Total males: 26 in CP group, 52 in osteoarthritis group; Total females: 13 in CP group, 26 | Total hip arthroplasty surgery: The surgical procedures were performed by high volume adult reconstruction subspeciality surgeons by their preferred surgical approach. Surgeries were augmented with a tendon release (n=7), or psoas(n=2), acetabular constraint(dual mobility, n=5) or lipped liner (n=2) and acetabular structural support (femoral head augmentation ,n=4). | Patients with cerebral palsy were matched randomly in 1: 2 ratio to a group of patients undergoing total hip arthroplasty for osteoarthritis over the same time period. All patients were followed longitudinally to the time of implant revision or death. Mean follow up: 7 years (range, 2 to 20 years) | See forest plots     | 1) Retrospective collection of data 2) Small sample size 3) Use of Harris hip scores for people with cerebral palsy is not validated Other information Risk of Bias: Risk of Bias Assessment Using |

FINAL Interventions that improve or maintain physical function and participation for adults over 25 with cerebral palsy.

| Study details   | Participants   | Interventions | Methods | Outcomes and Results | Comments   |
|---|--|---------------|---------|----------------------|--|
| American volume. 99, 488-493, 2017  Ref Id 635779  Country/ies where the study was carried out United States  Study type  Retrospective cohort study with control group  Aim of the study  To compare the outcomes of total hip arthroplasty in patients with cerebral palsy to matched patients with a diagnosis of osteoarthritis  Study dates 1990 to 2013 | in osteoarthritis group at the time of surgical procedure  Inclusion criteria  Those undergoing primary total hip arthroplasty for : radiographic evidence of hip osteoarthritis, failure of non operative treatment for hip pain, the ability to walk either independently or with use of gait aids, and correctable hip contractures  Exclusion criteria  Not obtained 2 years of clinical follow-up | Interventions | Wethods |                      | New Castle Ottawa Scale Selection:2/4  1) Representativeness: Institution based 2)Selection of non exposed: From same institution as exposed *  3)Ascertainment of exposure: Fidelity not measured  4) Demonstration that outcome of interest was not present at the start of study Baseline scores mentioned*  Comparability 2/2  ** Controls for important factor, baseline characteristics comparable |
| Source of funding   |  |               |         |                      | Outcome 2/3 **   |

FINAL Interventions that improve or maintain physical function and participation for adults over 25 with cerebral palsy.

| Study details   | Participants  | Interventions   | Methods  | Outcomes and Results | Comments   |
|---|---|---|--|----------------------|--|
| None Full citation  | Sample size   | Interventions   | Details  | Results              | 1) Blind/self report: Blinding not possible 2) Was follow up enough Yes 3) Follow up of Cohort: Yes  Limitations   |
| Teixeira-Machado, L., Azevedo-Santos, I., DeSantana, J. M., Dance Improves Functionality and Psychosocial Adjustment in Cerebral Palsy: A Randomised Controlled Clinical Trial, American journal of physical medicine & rehabilitation, 96, 424-429, 2017  Ref Id  675601 | Characteristics Dance group (n=13), Mean age: 18 (3.46), Male=6, Female=7; Kinesiotherapy group (n=13), Mean age: 17.07(2.36), Male=5, Female=8; Inclusion criteria 1) Having a diagnosis of cerebral palsy 2) Age between 15 to 29 years | Dance class based on<br>Feldenkrais, Horton, Graham<br>and Laban/Bartenieff concepts, | The control group performed traditional kinesiotherapy | See forest plots     | Small sample size  Other information  Risk of Bias Assessment:  1) Selection Bias  a) Random sequence generation (selection bias) :Low risk  b) Allocation concealment (selection bias) :Unclear risk  2) Blinding of participants and personnel |

FINAL Interventions that improve or maintain physical function and participation for adults over 25 with cerebral palsy.

| Study details   | Participants  | Interventions | Methods | Outcomes and Results | Comments   |
|---|---|---------------|---------|----------------------|--|
| Country/ies where the study was carried out Brazil Study type Randomised controlled trial Aim of the study To study the effect of dance on functionality and psychosocial adjustment of young subjects with cerebral palsy (CP) Study dates Not mentioned Source of funding Not mentioned | 3) increased muscle tone 4) No physical activity during the duration of study 5) No cardiopathy or neoplasy  Exclusion criteria  Cognitive & psychiatric disturbances |               |         |                      | (performance bias):Low risk  3) Blinding of outcome assessment (detection bias): High risk  4) Incomplete outcome data (attrition bias):Low risk  5) Selective reporting (reporting bias): Unclear risk  6) Other bias: None  Overall: High risk |

### Appendix E - Forest plots

Forest plots for review question D2: Which interventions are effective for maintaining physical function and mobility in adults with cerebral palsy?

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

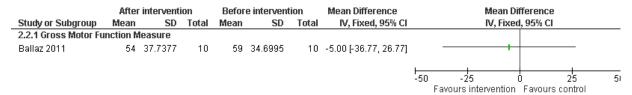
### Comparison 1: Physical activity intervention, before versus after

Figure 2: Participation (walking efficiency) at post-test following physical activity intervention versus before

|                       | tion     | Before intervention Mean Difference |        |            |     | Mean Difference |                     |             |                   |            |             |             |
|-----------------------|----------|-------------------------------------|--------|------------|-----|-----------------|---------------------|-------------|-------------------|------------|-------------|-------------|
| Study or Subgroup     | Mean     | SD                                  | Total  | Mean       | SD  | Total           | IV, Fixed, 95% CI   |             | IV,               | Fixed, 95% | CI          |             |
| 2.1.1 Walking Efficie | ncy(Gait | energy                              | expend | iture inde | x)  |                 |                     |             |                   |            |             |             |
| Ballaz 2011           | 1.53     | 1.22                                | 10     | 1.77       | 1.3 | 10              | -0.24 [-1.34, 0.86] |             | _                 |            |             |             |
|                       |          |                                     |        |            |     |                 |                     | <u> </u>    |                   |            | +           | <del></del> |
|                       |          |                                     |        |            |     |                 |                     | -4<br>Favou | -2<br>rs interver | ntion Favo | urs control | 4           |

CI: Confidence interval; IV: Inverse variance; SD: Standard deviation

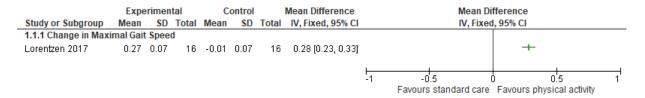
Figure 3: Physical function (Gross Motor Function Measure) at post-test following physical activity intervention versus before



CI: Confidence interval; IV: Inverse variance; SD: Standard deviation

### Comparison 2: Physical activity interventions versus standard care

Figure 4: Participation (maximal gait speed) at post-test following physical activity intervention versus standard care



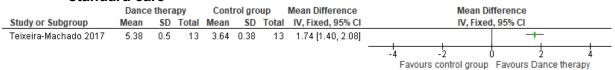
CI: Confidence interval; IV: Inverse variance; SD: Standard deviation

Figure 5: Physical function at post-test following physical activity intervention versus standard care

|                       | Dance therapy          |    |       | C    | ontrol |       | Mean Difference         |           | Mean Di      | fference     |       |
|-----------------------|------------------------|----|-------|------|--------|-------|-------------------------|-----------|--------------|--------------|-------|
| Study or Subgroup     | Mean                   | SD | Total | Mean | SD     | Total | IV, Fixed, 95% CI       |           | IV, Fixed    | I, 95% CI    |       |
| Teixeira-Machado 2017 | 39.9 5.8 13 69.55 4.39 |    |       |      | 4.39   | 13    | -29.65 [-33.60, -25.70] |           | +            |              |       |
|                       |                        |    |       |      |        |       |                         | -100      | 50 (         | 5            | 0 100 |
|                       |                        |    |       |      |        |       |                         | Favours d | ance therapy | Favours cont | trol  |

CI: Confidence interval; IV: Inverse variance; SD: Standard deviation

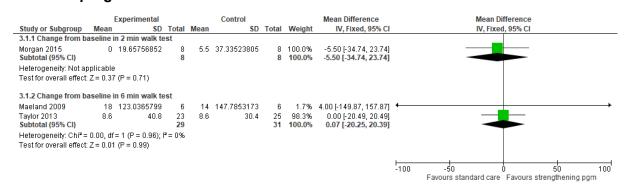
Figure 6: Independence at post-test following physical activity intervention versus standard care



CI: Confidence interval; IV: Inverse variance; SD: Standard deviation

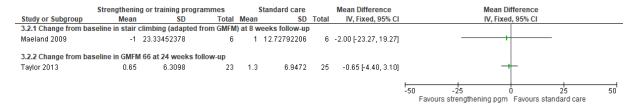
#### Comparison 3: Strengthening or training programmes versus standard care

Figure 7: Participation at 8 to 12 weeks follow-up after strengthening or training programmes versus standard care



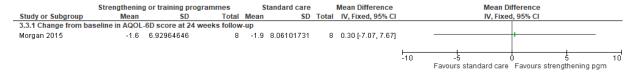
CI: Confidence interval; IV: Inverse variance; pgm: programme; SD: Standard deviation

Figure 8: Physical function at 8 to 12 weeks follow-up after strengthening or training programmes versus standard care



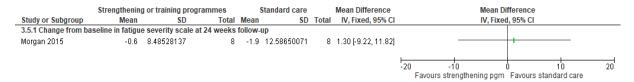
CI: Confidence interval; GMFM: Gross motor function measure; IV: Inverse variance; pgm: programme, SD: Standard deviation

Figure 9: Health related quality of life at 24 weeks follow-up after strengthening or training programmes versus standard care



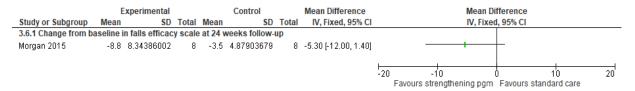
AQOL-6D: Assessment of Quality of life instrument 6D; CI: Confidence interval; GMFM: Gross motor function measure; IV: Inverse variance; pgm: programme; SD: Standard deviation

Figure 10: Fatigue at 24 weeks follow-up after strengthening or training programmes versus standard care



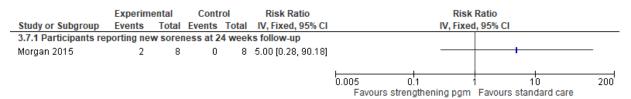
CI: Confidence interval; IV: Inverse variance; pgm: programme; SD: Standard deviation

Figure 11: Frequency of falls at 24 weeks follow-up after strengthening or training programmes versus standard care



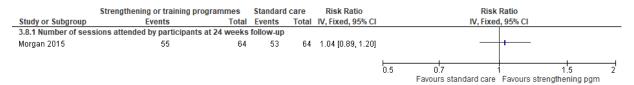
CI: Confidence interval; IV: Inverse variance; pgm: programme; SD: Standard deviation

Figure 12: Complications of treatment at 24 weeks follow-up after strengthening or training programmes versus standard care



CI: Confidence interval; IV: Inverse variance; pgm: programme;SD: Standard deviation

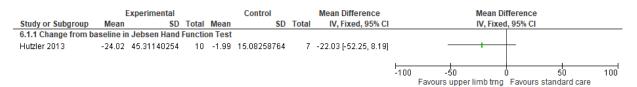
Figure 13: Adherence to treatment at 24 weeks follow-up after strengthening or training programmes versus standard care



CI: Confidence interval; IV: Inverse variance; pgm: programme; SD: Standard deviation

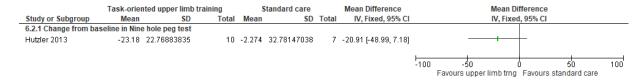
#### Comparison 4: Task oriented upper limb training versus standard care

Figure 14: Participation at post-test following task oriented upper limb training versus standard care



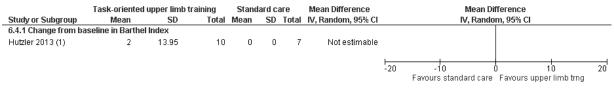
CI: Confidence interval; IV: Inverse variance; pgm: programme; SD: Standard deviation

Figure 15: Physical function at post-test following task oriented upper limb training versus standard care



CI: Confidence interval; IV: Inverse variance; pgm: programme; SD: Standard deviation

Figure 16: Independence at post-test following task oriented upper limb training versus standard care



Footnotes

CI: Confidence interval; IV: Inverse variance; pgm: programme; SD: Standard deviation

### Comparison 5: Task oriented upper limb training, before versus after

Figure 17: Participation at post-test following task oriented upper limb training versus before

|                        | After    |        |         | Before |     |       | Mean Difference    |          | Me              | e                |               |   |
|------------------------|----------|--------|---------|--------|-----|-------|--------------------|----------|-----------------|------------------|---------------|---|
| Study or Subgroup      | Mean     | SD     | Total   | Mean   | SD  | Total | IV, Fixed, 95% CI  |          | IV,             | Fixed, 95% (     | CI            |   |
| 9.1.1 Motor Activity L | .og (amo | ount ( | of use) |        |     |       |                    |          |                 |                  |               |   |
| Brown 2010             | 1.6      | 0.9    | 6       | 1.4    | 0.8 | 6     | 0.20 [-0.76, 1.16] |          |                 | +                |               |   |
|                        |          |        |         |        |     |       |                    | <u> </u> | <del></del>     |                  |               |   |
|                        |          |        |         |        |     |       |                    | -2       | -1<br>Favours b | 0<br>efore Favou | 1<br>rs after | 2 |

CI: Confidence interval; IV: Inverse variance; SD: Standard deviation

Figure 18: Physical function at post-test following task oriented upper limb training versus before

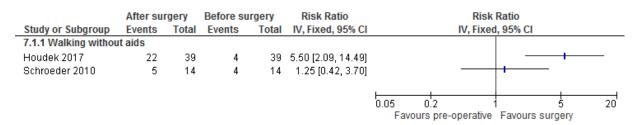
|                       | After |    |                        | Before |                       |         | Mean Difference   |      |               |           |    |     |
|-----------------------|-------|----|------------------------|--------|-----------------------|---------|-------------------|------|---------------|-----------|----|-----|
| Study or Subgroup     | Mean  | SD | Total                  | Mean   | SD                    | ) Total | IV, Fixed, 95% CI |      | IV, Fixe      | d, 95% CI |    |     |
| 9.2.1 9 hole peg test |       |    |                        |        |                       |         |                   |      |               |           |    |     |
| Brown 2010            |       |    | 96.3 66.2 6 -3.90 [-86 |        | -3.90 [-86.56, 78.76] | +       |                   |      |               | _         |    |     |
|                       |       |    |                        |        |                       |         |                   | -100 | -50           | <u> </u>  | 50 | 100 |
|                       |       |    |                        |        |                       |         |                   | -100 | Favours after | Favours b |    | 100 |

CI: Confidence interval; IV: Inverse variance; SD: Standard deviation

<sup>(1)</sup> Mean & SD in the standard care group were identical before & after the intervention.

#### Comparison 6: Orthopaedic surgery, pre versus post-operative

Figure 19: Participation following orthopaedic surgery, pre versus post-operative outcomes



CI: Confidence interval; IV: Inverse variance; SD: Standard deviation

Figure 20: Physical function following orthopaedic surgery, pre versus post-operative outcomes

|                   | After surgery |      | Befor | e surg | егу  | Mean Difference |                      | Mean | Difference        |             |         |    |
|-------------------|---------------|------|-------|--------|------|-----------------|----------------------|------|-------------------|-------------|---------|----|
| Study or Subgroup | Mean          | SD   | Total | Mean   | SD   | Total           | IV, Fixed, 95% CI    |      | IV, Fix           | ced, 95% CI |         |    |
| Houdek 2017       | 78            | 11.7 | 39    | 36     | 11.2 | 39              | 42.00 [36.92, 47.08] |      |                   |             |         | +  |
|                   |               |      |       |        |      |                 |                      |      |                   |             |         |    |
|                   |               |      |       |        |      |                 |                      | -50  | -25               | Ó           | 25      | 50 |
|                   |               |      |       |        |      |                 |                      | Fav  | vours pre-operati | ve Favours  | suraerv |    |

CI: Confidence interval; IV: Inverse variance; SD: Standard deviation

Figure 21: Independence following orthopaedic surgery, pre versus post-operative outcomes



CI: Confidence interval; IV: Inverse variance; SD: Standard deviation

## **Appendix F – GRADE tables**

GRADE tables for review question D2: Which interventions are effective for maintaining physical function and mobility in adults with cerebral palsy?

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

Table 14: Clinical evidence profile: Comparison 1: Physical activity intervention, before versus after outcomes

| Quality       | assessment            |                      |                          | Inconsistency Indirectness Im |                      |                        | No of patients                             |                 | Effect                  |   |             |               |
|---------------|-----------------------|----------------------|--------------------------|-------------------------------|----------------------|------------------------|--|-----------------|-------------------------|---|-------------|---------------|
| No of studies | Design                | Risk of bias         | Inconsistency            | Indirectness                  | Imprecision          | Other considerations   | After Physical<br>Activity<br>intervention | Before          | Relative<br>(95%<br>CI) | Absolute  | Quality     | Importance    |
| Participa     | tion (measured w      | vith: Walking eff    | iciency(Gait energy      | expenditure index             | ; Better indicate    | ed by lower values)1   |  |                 |                         |   |             |               |
| 1             | observational studies | Serious <sup>2</sup> | No serious inconsistency | No serious indirectness       | Serious <sup>3</sup> | None                   | 10 <sup>5</sup>                            | 10 <sup>5</sup> | -                       | MD 0.24<br>lower (1.3<br>lower to<br>0.82 higher)       | VERY<br>LOW | CRITICAL      |
| Physical      | function (measur      | ed with: Gross       | Motor Function Mea       | asure (GMFM) D &              | E; Better indica     | ited by lower values)4 |  |                 |                         |   |             |               |
| 1             | observational studies | Serious <sup>2</sup> | No serious inconsistency | No serious indirectness       | Serious <sup>3</sup> | None                   | 10⁵  | 10⁵             | -                       | MD 5.00<br>lower (35.31<br>lower to<br>25.31<br>higher) | VERY<br>LOW | CRITICAL      |
| Health re     | elated quality of lif | e - not reported     | t                        |                               |                      |                        |  |                 |                         |   |             |               |
| -             | -                     | -                    | -                        | -                             | -                    | -                      | -  | -               | -                       | -   | -           | CRITICAL      |
| Independ      | dence - not report    | ed                   |                          |                               |                      |                        |  |                 |                         |   |             |               |
| -             | -                     | -                    | -                        | -                             | -                    | -                      | -  | -               | -                       | -   | -           | IMPORTA<br>NT |
| Fatigue-      | not reported          |                      |                          |                               |                      |                        |  |                 |                         |   |             |               |
| -             | -                     | -                    | -                        | -                             | -                    | -                      | -  | -               | -                       | -   | -           | IMPORTA<br>NT |
| Frequen       | cy of falls- not rep  | orted                |                          |                               |                      |                        |  |                 |                         |   |             |               |
| -             | -                     | -                    | -                        | -                             | -                    | -                      | -  | -               | -                       | -   | -           | IMPORTA<br>NT |

|               | assessment            |              |               |              |             |                      | No of patients                             |        | Effect                  |          |         |               |
|---------------|-----------------------|--------------|---------------|--------------|-------------|----------------------|--|--------|-------------------------|----------|---------|---------------|
| No of studies | Design                | Risk of bias | Inconsistency | Indirectness | Imprecision | Other considerations | After Physical<br>Activity<br>intervention | Before | Relative<br>(95%<br>CI) | Absolute | Quality | Importance    |
| -<br>Adheren  | -<br>ce- not reported | -            | -             | -            | -           | -                    | -  | -      | -                       | -        | -       | IMPORTA<br>NT |
| -             | -                     | -            | -             | -            | -           | -                    | -  | -      | -                       | -        | -       | IMPORTA<br>NT |

CI: confidence interval; GRADE: grading of recommendations assessment development and evaluation; GMFM: gross motor function measure; MD: Mean difference; SD: standard deviation;

- 1. Gait energy expenditure index: Lower values indicate better gait efficiency
- 2. Downgraded for serious risk of bias due to lack of blinding during assessment
- 3. Downgraded for serious imprecision as confidence interval includes one MID threshold
- 4. Higher GMFM scores indicate better motor function
- 5 10/12 participants completed the training intervention

Table 15: Clinical evidence profile: Comparison 2: Physical activity interventions versus standard care

|                        | ssessment            |                      |                          |                         |                      |                        | No of patients                  |               | Effect                  |  |             |               |
|------------------------|----------------------|----------------------|--------------------------|-------------------------|----------------------|------------------------|---------------------------------|---------------|-------------------------|--|-------------|---------------|
| No of studies          | Design               | Risk of bias         | Inconsistency            | Indirectness            | Imprecision          | Other considerations   | Physical activity interventions | Standard care | Relative<br>(95%<br>CI) | Absolute   | Qualit<br>y | Importance    |
| Participa <sup>a</sup> | tion (Follow-up: F   | Post-test at 3       | months; measured         | with: Change in n       |                      | d; Better indicated b  |                                 |               |                         |  |             |               |
| 1                      | randomised<br>trials | Serious <sup>2</sup> | No serious inconsistency | No serious indirectness | Serious <sup>3</sup> | None                   | 16                              | 16            | -                       | MD 3.90<br>higher<br>(2.67 to<br>5.13<br>higher) | LOW         | CRITICAL      |
|                        |                      |                      |                          |                         |                      | dicated by lower value |                                 |               |                         |  |             |               |
| 1                      | randomised<br>trials | Serious <sup>4</sup> | No serious inconsistency | No serious indirectness | Serious <sup>3</sup> | None                   | 13                              | 13            | -                       | MD 29.65<br>lower (33.6<br>to 25.7<br>lower)     | LOW         | CRITICAL      |
| Health re              | lated quality of lif | e- not report        |                          |                         |                      |                        |                                 |               |                         |  |             |               |
| -                      | -                    | -                    | -                        | -                       | -                    | -                      | -                               | -             | -                       | -  | -           | CRITICAL      |
|                        |                      |                      | 3 months; measure        |                         |                      |                        |                                 |               |                         |  |             |               |
| 1                      | randomised<br>trials | Serious <sup>4</sup> | No serious inconsistency | No serious indirectness | Serious <sup>3</sup> | None                   | 13                              | 13            | -                       | MD 1.74<br>higher (1.4<br>to 2.08<br>higher)     | LOW         | IMPORTAI<br>T |
| -atigue-               | not reported         | 1                    |                          |                         | <u> </u>             | •                      |                                 |               | 1                       |  |             |               |
| •                      | -                    | -                    | -                        | -                       | -                    | -                      | -                               | -             | -                       | -  | -           | IMPORTA<br>T  |
| requenc                | cy of falls- not rep | orted                |                          |                         |                      |                        |                                 |               |                         |  |             |               |
|                        | -                    | -                    | -                        | -                       | -                    | -                      | -                               | -             | -                       | -  | -           | IMPORTA<br>T  |
| Complica               | ations of treatmer   | nt- not report       | ed                       |                         |                      |                        |                                 |               |                         |  |             |               |
|                        | -                    | -                    | -                        | -                       | -                    | -                      | -                               | -             | -                       | -  | -           | IMPORTA<br>T  |
| dheren                 | ce- not reported     |                      |                          |                         |                      |                        |                                 |               |                         |  |             |               |
|                        |                      |                      | _                        | _                       |                      | _                      |                                 |               |                         |  | _           | IMPORTA       |

CI: confidence interval; FIM: Functional independence measure; GRADE: grading of recommendations assessment development and evaluation; ICF: International classification of functioning; NGA: National Guideline Alliance; MD: Mean difference; RCT: randomised controlled trial; SD: standard deviation

- 1. Higher mean change in maximal gait speed indicates better participation; change in maximal gait speed calculated by NGA team
- 2. Downgraded for serious risk of bias as information on withdrawal/dropouts is not reported for control group
- 3. Downgraded for serious imprecision as number of participants <400
- 4. Downgraded for serious risk of bias due to lack of blinding of assessors

Table 16: Clinical evidence profile: Comparison 3: Strengthening or training programmes versus standard care

| Quality a     | ssessment            |                                  |                          |                         |                              |                               | No of patients                       |               | Effect               |   |             |                |
|---------------|----------------------|----------------------------------|--------------------------|-------------------------|------------------------------|-------------------------------|--------------------------------------|---------------|----------------------|---|-------------|----------------|
| No of studies | Design               | Risk of<br>bias                  | Inconsistency            | Indirectness            | Imprecision                  | Other considerations          | Strengthening or training programmes | Standard care | Relative<br>(95% CI) | Absolute  | Quality     | Importan<br>ce |
|               | ion - Change fro     |                                  | to 24 weeks in 2 m       | nin walk test (Bett     | er indicated by h            | higher values) <sup>1</sup>   |                                      |               |                      |   |             |                |
| 1             | randomised<br>trials | No<br>serious<br>risk of<br>bias | No serious inconsistency | No serious indirectness | Very<br>serious <sup>3</sup> | None                          | 7 <sup>12</sup>                      | 8             | -                    | MD 5.5<br>lower<br>(34.74<br>lower to<br>23.74<br>higher)   | LOW         | CRITICAL       |
|               | _ `                  |                                  | e in baseline in 6 m     |                         |                              | ·                             |                                      |               |                      |   |             |                |
| 2             | randomised<br>trials | No<br>serious<br>risk of<br>bias | No serious inconsistency | No serious indirectness | Very<br>serious <sup>3</sup> | None                          | 29                                   | 31            |                      | MD 0.07<br>higher<br>(20.25<br>lower to<br>20.39<br>higher) | LOW         | CRITICAL       |
| Physical 1    | function (measu      | red with: Ch                     | ange from baseline       | in Stair Climbing       | (adapted from                | GMFM); Better indic           | cated by lower values                |               |                      |   |             |                |
| 1             | randomised<br>trials | No<br>serious<br>risk of<br>bias | No serious inconsistency | No serious indirectness | Very<br>serious <sup>3</sup> | None                          | 6                                    | 6             | -                    | MD 2.00<br>lower<br>(23.27<br>lower to<br>19.27<br>higher)  | LOW         | CRITICAL       |
| Physical t    | function (measu      | red with: Ch                     | ange from Baseline       | e in GMFM 66; Be        | etter indicated by           | y higher values) <sup>6</sup> |                                      |               |                      |   |             |                |
| 1             | randomised<br>trials | No<br>serious<br>risk of<br>bias | No serious inconsistency | No serious indirectness | Very<br>serious <sup>3</sup> | None                          | 23                                   | 25            | -                    | MD 0.65<br>lower (4.4<br>lower to 3.1<br>higher)            | LOW         | CRITICAL       |
|               |                      |                                  |                          |                         |                              |                               | ument-6D); Better inc                |               | ner values)          |   |             |                |
| 1             | randomised<br>trials | Serious <sup>8</sup>             | No serious inconsistency | No serious indirectness | Very<br>serious <sup>3</sup> | None                          | 7 <sup>12</sup>                      | 8             | -                    | MD 0.30<br>higher (7.07<br>lower to<br>7.67 higher)         | VERY<br>LOW | CRITICAL       |
| Independ      | ence - not repor     | ted                              |                          |                         |                              |                               |                                      |               |                      |   |             |                |
| -             | -                    | -                                | -                        | -                       | -                            | -                             | -                                    | -             | -                    | -   | -           | IMPORTA        |

| Quality a     | ssessment            |                                  |                          |                         |                              |                      | No of patients                       |                  | Effect                        |   |             |                |
|---------------|----------------------|----------------------------------|--------------------------|-------------------------|------------------------------|----------------------|--------------------------------------|------------------|-------------------------------|---|-------------|----------------|
| No of studies | Design               | Risk of<br>bias                  | Inconsistency            | Indirectness            | Imprecision                  | Other considerations | Strengthening or training programmes | Standard care    | Relative<br>(95% CI)          | Absolute  | Quality     | Importan<br>ce |
| 1             | randomised<br>trials | Serious <sup>8</sup>             | No serious inconsistency | No serious indirectness | Very<br>serious <sup>3</sup> | None                 | 712                                  | 8                | -                             | MD 1.30<br>higher (9.22<br>lower to<br>11.82<br>higher)   | VERY<br>LOW | IMPORTA<br>NT  |
| Falls (me     | asured with: Ch      | ange from b                      | aseline to 24 week       | s in Falls Efficac      | y Scale; Better ir           | ndicated by lower va |                                      |                  |                               |   |             |                |
| 1             | randomised<br>trials | No<br>serious<br>risk of<br>bias | No serious inconsistency | No serious indirectness | Very<br>serious <sup>3</sup> | None                 | 7 <sup>12</sup>                      | 8                | -                             | MD 5.3<br>lower (12<br>lower to 1.4<br>higher)            | VERY<br>LOW | IMPORTA<br>NT  |
| Complica      | ations of treatme    | nt (measure                      | d with: Participants     | reporting new so        | reness; Better ii            | ndicated by lower va | alues) <sup>11</sup>                 |                  |                               |   |             |                |
| 1             | randomised<br>trials | No<br>serious<br>risk of<br>bias | No serious inconsistency | No serious indirectness | Very<br>serious <sup>3</sup> | None                 | 2/8<br>(25%)                         | 0/8<br>(0%)      | RR 5.00<br>(0.28 to<br>90.18) | -   | LOW         | IMPORTA<br>NT  |
| Adherend      | ce to treatment (    | measured w                       | ith: Number of sess      | sions attended)         |                              |                      |                                      |                  |                               |   |             |                |
| 1             | randomised<br>trials | Serious <sup>2</sup>             | No serious inconsistency | No serious indirectness | Serious <sup>11</sup>        | None                 | 55/64<br>(85.9%)                     | 53/64<br>(82.8%) | RR 1.04<br>(0.89 to<br>1.20)  | 31 more per<br>1000 (from<br>126 fewer<br>to 113<br>more) | LOW         | IMPORTA<br>NT  |

AQOL-6D: Assessment of Quality of Life Instrument-6D; CI: confidence interval; GMFM: gross motor function measure; GRADE: grading of recommendations assessment development and evaluation; HrQOL: health related quality of life; MD: mean difference; RR: risk ratio; NGA: National Guideline Alliance; RCT: randomised controlled trial; SD: standard deviation

- 1. Higher change from baseline in 2 minute walk test indicates better participation; change from baseline scores calculated by NGA team
- 2. Downgraded for serious risk of bias due to unit of analysis issues there were 8 observations for this outcome from each participant which are likely to be correlated
- 3. Downgraded for very serious imprecision due as confidence interval includes both MID thresholds
- 4. Change from baseline in 6 minute walk test: Higher value indicates better participation
- 5. Change from baseline in stair climbing: Higher value indicates better motor function
- 6. Change from baseline in GMFM 66: higher value indicates better motor function
- 7. Change in baseline in HrQOL: higher value indicates better health related quality of life
- 8. Downgraded for serious risk of bias due to lack of blinding in this subjective outcome
- 9. Change from baseline in fatigue severity scale: Lower value indicates better outcome
- 10. Change from baseline in falls efficacy scale: lower value indicates better outcome
- 11. Downgraded for serious imprecision due to number of events < 300
- 12. Outcome data at week 24 were available for 15/17 participants.1 participant was lost to follow-up and 1 withdrew (both in the intervention group)

Table 17: Clinical evidence profile: Comparison 4: Task-oriented upper limb training versus standard care

| Quality a     | assessment               |                      |                             |                         |                           |                        | No of patients                    |                   | Effect                  |  |             |               |
|---------------|--------------------------|----------------------|-----------------------------|-------------------------|---------------------------|------------------------|-----------------------------------|-------------------|-------------------------|--|-------------|---------------|
| No of studies | Design                   | Risk of bias         | Inconsistency               | Indirectness            | Imprecision               | Other considerations   | Task-oriented upper limb training | Standa<br>rd care | Relative<br>(95%<br>CI) | Absolute   | Quality     | Importar<br>e |
| Participa     | tion (measured with      | n: Change fro        | m baseline in Jebse         | n Hand Function 1       | Γest; Better indica       | ted by lower values)   |                                   |                   |                         |  |             |               |
| 1             | observational studies    | Serious <sup>2</sup> | no serious<br>inconsistency | no serious indirectness | Very serious <sup>6</sup> | none                   | 10                                | 7                 | -                       | MD 22.03<br>lower (52.25<br>lower to 8.19<br>higher) | VERY<br>LOW | CRITICA       |
| Physical      |                          |                      | e from baseline in N        |                         |                           | y lower values)4       |                                   |                   |                         |  |             |               |
| 1             | observational<br>studies | Serious <sup>2</sup> | no serious<br>inconsistency | no serious indirectness | Serious <sup>3</sup>      | none                   | 10                                | 7                 | -                       | MD 20.91<br>lower (48.99<br>lower to 7.18<br>higher) | VERY<br>LOW | CRITICA       |
| HrQOL -       | not reported             |                      |                             |                         |                           |                        |                                   |                   |                         |  |             |               |
| -             | -                        | -                    | -                           | -                       | -                         | -                      | -                                 | -                 | -                       | -  | -           | CRITICA       |
| Independ      | dence (measured w        | ith: Change f        | rom baseline in Bar         | thel Index; Better in   | ndicated by highe         | r values) <sup>5</sup> |                                   |                   |                         |  |             |               |
| 1             | observational studies    | Serious <sup>2</sup> | no serious<br>inconsistency | no serious indirectness | Very serious <sup>7</sup> | none                   | 10                                | 7                 | -                       | Not estimable <sup>7</sup>                           | VERY<br>LOW | IMPORT.<br>NT |
| Fatigue-      | not reported             |                      |                             |                         |                           |                        |                                   |                   |                         |  |             |               |
| -             | -                        | -                    | -                           | -                       | -                         | -                      | -                                 | -                 | -                       | -  | -           | IMPORT.<br>NT |
| Frequence     | cy of falls- not repor   | ted                  |                             |                         |                           |                        |                                   |                   |                         |  |             |               |
| -             | -                        | -                    | -                           | -                       | -                         | -                      | -                                 | -                 | -                       | -  | -           | IMPORT.       |
| Complica      | ations of treatment-     | not reported         |                             |                         |                           |                        |                                   |                   |                         |  |             |               |
| _             | -                        | -                    | -                           | -                       | -                         | -                      | -                                 | -                 | -                       | -  | -           | IMPORT<br>NT  |
|               |                          |                      |                             |                         |                           |                        |                                   |                   |                         |  |             |               |
| Adheren       | ce- not reported         |                      |                             |                         |                           |                        |                                   |                   |                         |  |             |               |

CI: confidence interval; GRADE: grading of recommendations assessment development and evaluation; MD: mean difference; SD: standard deviation

<sup>1.</sup> Jebsen hand function test: Lower score indicates greater function. Change from baseline values calculated by NGA team

<sup>2.</sup> Downgraded for serious risk of selection bias, as the baseline characteristics of intervention and control groups are not reported (and no adjustments were made for confounders) and it is unclear how they were selected

<sup>3.</sup> Downgraded for serious imprecision as confidence interval includes one MID threshold

<sup>4.</sup> Nine hole peg test: lower scores indicate better function. Change from baseline values calculated by NGA team.

- 5. Barthel Index: Higher scores indicate more independence. Change from baseline values calculated by NGA team.
- 6. Downgraded for very serious imprecision as confidence interval includes both MID thresholds.
- 7. Mean and standard deviation of change from baseline in the standard care group were both zero, so mean difference could not be estimated.

Table 18: Clinical evidence profile: Comparison 5: Task-oriented upper limb training, before versus after outcomes

|                        | ssessment                |                      |                             |                            |                              |                             | No of pati                         |                                     | Effect               |  |             |                |
|------------------------|--------------------------|----------------------|-----------------------------|----------------------------|------------------------------|-----------------------------|------------------------------------|-------------------------------------|----------------------|--|-------------|----------------|
| No of<br>studies       | Design                   | Risk of bias         | Inconsistency               | Indirectness               | Imprecision                  | Other considerations        | After<br>Upper<br>limb<br>training | Before<br>Upper<br>limb<br>training | Relative<br>(95% CI) | Absolute   | Quality     | Importanc<br>e |
| Participa <sup>a</sup> | tion - Motor Activity    | y Log (amount o      | of use) (Better indica      | ated by higher valu        | ues)                         |                             |                                    |                                     |                      |  |             |                |
| 1                      | observational<br>studies | Serious <sup>1</sup> | no serious<br>inconsistency | no serious<br>indirectness | Very<br>serious <sup>2</sup> | none                        | 6                                  | 6                                   | -                    | MD 0.20<br>higher<br>(0.76<br>lower to<br>1.16<br>higher)  | VERY<br>LOW | CRITICAL       |
| -                      |                          |                      | eg test; Better indic       |                            |                              |                             |                                    |                                     |                      |  |             |                |
| 1                      | observational<br>studies | Serious <sup>1</sup> | no serious<br>inconsistency | no serious<br>indirectness | Very<br>serious <sup>2</sup> | none                        | 6                                  | 6                                   | -                    | MD 3.90<br>lower<br>(86.56<br>lower to<br>78.76<br>higher) | VERY<br>LOW | CRITICAL       |
| HrQOL -                | not reported             |                      |                             |                            |                              |                             |                                    |                                     |                      |  |             | ODITION        |
| -<br>Independ          | -<br>lence (measured v   |                      | m baseline in Barth         |                            |                              | -<br>r values) <sup>5</sup> | -                                  | -                                   | -                    | -  | -           | CRITICAL       |
| -                      | -                        |                      | in baseline in bartin       |                            | -                            | -                           | -                                  | -                                   | -                    | -  | -           | IMPORTA<br>NT  |
| Fatigue-               | not reported             |                      |                             |                            |                              |                             |                                    |                                     |                      |  |             |                |
| -                      | -                        |                      |                             | •                          | -                            | -                           | -                                  | -                                   | -                    | -  | -           | IMPORTA<br>NT  |
| Frequenc               | cy of falls- not repo    |                      |                             |                            |                              |                             |                                    |                                     |                      |  |             |                |
| -                      | -                        |                      |                             | •                          | -                            | -                           | -                                  | -                                   | -                    | -  | -           | IMPORTA<br>NT  |
| Complica               | tions of treatment       | - not reported       |                             |                            |                              |                             |                                    |                                     |                      |  |             |                |
| -                      | -                        |                      |                             |                            | -                            | -                           | -                                  | -                                   | -                    | -  | -           | IMPORTA<br>NT  |
| Adheren                | ce- not reported         |                      |                             |                            |                              |                             |                                    |                                     |                      |  |             |                |
| -                      | -                        |                      |                             | -                          | -                            | -                           | -                                  | -                                   | -                    | -  | -           | IMPORTA<br>NT  |

Cl: confidence interval; GRADE: grading of recommendations assessment development and evaluation; MD: mean difference; SD: standard deviation

- 1. Downgraded for serious risk of bias due to self-reporting of outcomes
- 2. Downgraded for very serious imprecision as the confidence interval included both MID thresholds

Table 19: Clinical evidence profile: Comparison 6: Orthopaedic surgery, pre- versus post-operative outcomes

| Quality a        | assessment               |                                |                          |                         |                        |                      | No of pati                 | ents                                 | Effect   |          |             |                |
|------------------|--------------------------|--------------------------------|--------------------------|-------------------------|------------------------|----------------------|----------------------------|--------------------------------------|--|----------|-------------|----------------|
| No of<br>studies | Design                   | Risk of bias                   | Inconsistency            | Indirectness            | Imprecision            | Other considerations | After orthopa edic surgery | Before<br>orthopa<br>edic<br>surgery | Relative<br>(95% CI)   | Absolute | Quality     | Importanc<br>e |
| Participa        | ation (Follow-up:        | mean 7 to 10 yea               | ars; measured with       | :participants wal       | king without aid       | s; Better indicated  | by higher va               | lues)                                |  |          |             |                |
| 2                | observational<br>studies | Very<br>serious <sup>1,3</sup> | Serious <sup>2</sup>     | No serious indirectness | No serious imprecision | None                 | 53                         | 53                                   | RR<br>ranged<br>from 1.25<br>(0.42 to<br>3.70) to<br>5.50 (2.09<br>to 14.49) | -        | VERY<br>LOW | CRITICAL       |
| <b>Physical</b>  | function (Follow         | -up: mean 7 yea                | rs; measured with        | Harris hip score;       | Better indicated       | by higher values)    |                            |                                      |  |          |             |                |
| 1                | observational studies    | Serious <sup>3</sup>           | No serious inconsistency | No serious indirectness | No serious imprecision | None                 | 39                         | 39                                   | MD 42.0<br>(36.92 to<br>47.08<br>higher)                                     | -        | VERY<br>LOW | CRITICAL       |
| Health re        | elated quality of li     | fe- not reported               |                          |                         |                        |                      |                            |                                      |  |          |             |                |
| -                | -                        | -                              | -                        | -                       | -                      | -                    | -                          | -                                    | -  | -        | -           | CRITICAL       |
| ndepen           | dence(Follow-up:         |                                | measured with: pa        | rticipants with hy      | giene care; Bett       | er indicated by higl | ner values)                |                                      |  |          |             |                |
| 1                | observational studies    | Very serious <sup>1</sup>      | No serious inconsistency | No serious indirectness | No serious imprecision | None                 | 14                         | 14                                   | RR 2.20<br>(1.03 to<br>4.68)   | -        | VERY<br>LOW | IMPORTA<br>NT  |
| Fatigue-         | not reported             |                                |                          |                         |                        |                      |                            |                                      |  |          |             |                |
| -                | -                        | -                              | -                        | -                       | -                      | -                    | -                          | -                                    | -  | -        | -           | IMPORTA<br>NT  |
| Frequen          | cy of falls- not re      | ported                         |                          |                         |                        |                      |                            |                                      |  |          |             |                |
| -                | -                        | -                              | -                        | -                       | -                      | -                    | -                          | -                                    | -  | -        | -           | IMPORTA<br>NT  |
| Complic          | ations of treatme        | nt- not reported               |                          |                         |                        |                      |                            |                                      |  |          |             |                |
| -                | -                        | -                              | -                        | -                       | -                      | -                    | -                          | -                                    | -  | -        | -           | IMPORTA<br>NT  |
| Complic          | ations of treatme        |                                | -                        | -                       | -                      | -                    | -                          | -                                    | -  | -        | -           |                |
| n                | ce- not reported         |                                |                          |                         |                        |                      |                            |                                      |  |          |             |                |
|                  | -                        | -                              | -                        | -                       | -                      | -                    | -                          | -                                    | -  | -        | -           | IMPORT<br>NT   |

#### FINAL

Interventions that improve or maintain physical function and participation for adults over 25 with cerebral palsy.

SD: standard deviation; CI: confidence interval; GRADE: grading of recommendations assessment development and evaluation; RR: Risk ratio

- Downgraded for very serious risk of bias due to selection bias and outcome assessment bias
   Downgraded for serious inconsistency: one of the studies showed a clinically significant benefit with orthopaedic surgery whereas the other did not
- 3. Downgraded for serious risk of bias due to retrospective collection of data

## Appendix G – Economic evidence study selection

Economic evidence study selection for review question D2: Which interventions are effective for maintaining physical function and mobility in adults with cerebral palsy?

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

## **Appendix H – Economic evidence tables**

Economic evidence tables for review question D2: Which interventions are effective for maintaining physical function and mobility in adults with cerebral palsy?

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

## Appendix I – Health economic evidence profiles

Health economic evidence profiles for review question D2: Which interventions are effective for maintaining physical function and mobility in adults with cerebral palsy?

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

# Appendix J – Health economic analysis

Health economic analysis for review question D2: Which interventions are effective for maintaining physical function and mobility in adults with cerebral palsy?

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

No economic analysis was included in this review.

## Appendix K – Excluded studies

Clinical and economic lists of excluded studies for review question D2: Which interventions are effective for maintaining physical function and mobility in adults with cerebral palsy?

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

#### **Clinical studies**

#### Table 20: Excluded clinical studies for interventions for maintaining physical function

Excluded studies – D2: Which interventions are effective for maintaining physical function and mobility in adults with cerebral palsy?

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

| Study  | Reason for Exclusion   |
|--|--|
| Abel, M.F., Damiano, D.L., Pannunzio, M., Bush, J., Muscle-tendon surgery in diplegic cerebral palsy: functional and mechanical changes, Journal of Pediatric Orthopedics, 19, 366-375, 1999   | The mean age at surgery was 8.7 years                                      |
| Ahmed, G. S., Flexor carpi ulnaris transfer to improve function and cosmesis of hand in patients with cerebral palsy, Pakistan Journal of Medical Sciences, 23, 242-244, 2007  | Age group of participants is 7.5 years                                     |
| Bania, T, Dodd, Kj, Taylor, N, Habitual physical activity can be increased in people with cerebral palsy: a systematic review (Provisional abstract), Clinical Rehabilitation, 25, 303-15, 2011  | RCTs for paediatric age  |
| Bania, Ta, Dodd, Kj, Baker, Rj, Graham, Hk, Taylor, Nf, The effects of progressive resistance training on daily physical activity in young people with cerebral palsy: a randomised controlled trial, Disability and Rehabilitation, 38, 620-6, 2016 | This evidence has already<br>been used in Spasticity<br>Under 19 Guideline |
| Boldingh, E. J. K., Jacobs-Van Der Bruggen, M. A. M., Bos, C. F. A., Lankhorst, G. J., Bouter, L. M., Radiographic hip disorders and associated complications in severe cerebral palsy, Journal of Pediatric Orthopaedics Part B, 16, 31-34, 2007    | Cross sectional study  |
| Boldingh, E. J., Bouwhuis, C. B., van der Heijden-Maessen, H. C., Bos, C. F., Lankhorst, G. J., Palliative hip surgery in severe cerebral palsy: a systematic review, Journal of Pediatric Orthopaedics, Part B, 23, 86-92, 2014                     | Outcomes mentioned in protocol not reported                                |
| Boyd, R. N., Mitchell, L. E., James, S. T., Ziviani, J., Sakzewski, L., Smith, A., Rose, S., Cunnington, R., Whittingham, K., Ware, R. S., Comans, T. A., Scuffham, P. A., Move it to improve it (Mitii): Study                                      | Protocol   |

| protocol of a randomised controlled trial of a novel web-based multimodal training program for children and adolescents with cerebral palsy, BMJ Open, 3, 2013   |   |
|--|---|
| Brunton, L. K., Bartlett, D. J., Description of Exercise Participation of Adolescents With Cerebral Palsy Across a 4-Year Period, Pediatric Physical Therapy, 22, 180-187, 2010  | Mean age was 14.7 years   |
| Bulman, W. A., Dormans, J. P., Ecker, M. L., Drummond, D. S., Posterior spinal fusion for scoliosis in patients with cerebral palsy: a comparison of Luque rod and Unit Rod instrumentation, Journal of Pediatric Orthopedics, 16, 314-23, 1996  | Mean age 14.5 years   |
| Buly, R. L., Huo, M., Root, L., Binzer, T., Wilson Jr, P. D., Total hip arthroplasty in cerebral palsy: Long-term follow-up results, Clinical Orthopaedics and Related Research, 148-153, 1993   | No comparison group   |
| Carlon, S. L., Taylor, N. F., Dodd, K. J., Shields, N., Differences in habitual physical activity levels of young people with cerebral palsy and their typically developing peers: a systematic review, Disability and rehabilitation, 35, 647-655, 2013   | Mean age group in all studies: 5- 18 years  |
| Cassidy,C., Craig,C.L., Perry,A., Karlin,L.I., Goldberg,M.J., A reassessment of spinal stabilization in severe cerebral palsy, Journal of Pediatric Orthopaedics, 14, 731-739, 1994  | Borderline age group. Main outcome measure is pain, pulmonary medication utilization, which is not included in protocol |
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| Kobayashi, N., Kishigami, H., Sato, M., Evaluating the relationships between the postural adaptation of patients with profound cerebral palsy and the configuration of the Seating Buggy's seating support surface, Journal of Physiological Anthropology, 26, 217-224, 2007  Hergenroder, H., Blank, R., Subjective well-being and satisfaction with life in adults with spastic cerebral palsy: a pilot study of a randomized sample, Developmental Medicine and Child Neurology, 51, 389-396, 2009  Hinderer, S. R., Gupta, S., Functional outcome measures to assess interventions for spasticity, Archives of Physical Medicine and Rehabilitation, 77, 1083-1089, 1996  Hombergen, S. P., Huisstede, B. M., Streur, M. F., Stam, H. J., Slaman, J., Bussmann, J. B., van den Berg-Emons, R. J., Impact of cerebral palsy on health-related physical fitness in adults: systematic review, Archives of Physical Medicine & Rehabilitation, 93, 871-81, 2012  Horsman, M., Suto, M., Dudgeon, B., Harris, S. R., Growing older with cerebral palsy: insiders' perspectives, Pediatric Physical Therapy, 22, 296-303, 2010  Hundertmark, L. H., Evaluating the adult with cerebral palsy for  Single case report  | cerebral palsy: a problem-based approach to assessment and management, British Journal of Occupational Therapy, 75, 252-252,  |                             |
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| Slaman, J., Bussmann, J. B., van den Berg-Emons, R. J., Impact of cerebral palsy on health-related physical fitness in adults: systematic review, Archives of Physical Medicine & Rehabilitation, 93, 871-81, 2012  Horsman, M., Suto, M., Dudgeon, B., Harris, S. R., Growing older with cerebral palsy: insiders' perspectives, Pediatric Physical Therapy, 22, 296-303, 2010  Hundertmark, L. H., Evaluating the adult with cerebral palsy for  Single case report  | interventions for spasticity, Archives of Physical Medicine and   | No intervention             |
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| Not related to intervention efficiency but clinimetric properties of aerobic and anaeroobic capacity measures |
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| Full text Article not in English  |
| Review with mixed population and outcomes. Study related to intervention in adults included                   |
| No intervention   |
| Not physical activity intervention  |
| Validity of scale, not effectiveness of intervention  |
| Age below 16 years  |
| RCTs available for this question  |
| Age below 16 years  |
| Article not in English language   |
| Average age: 6 years  |
| Outcomes of interest not reported   |
| No physical function outcomes   |
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| training on mobility in adults with cerebral palsy: A systematic review, Disability and Health Journal, 9, 375-384, 2016 Ryan, J. M., Cassidy, E. E., Noorduyn, S. G., O'Connell, N. E., Exercise interventions for cerebral palsy, Cochrane Database of Systematic ReviewsCochrane Database Syst Rev, 6, CD011660, 2017 Ryan, J.M., Crowley, V.E., Hensey, O., Broderick, J.M., McGahey, A., Gormley, J., Habitual physical activity and cardiometabolic risk factors in adults with cerebral palsy, Research in Developmental Disabilities, 35, 1995-2002, 2014 Sahlin, K. B., Lexell, J., Impact of Organized Sports on Activity, Participation, and Quality of Life in People With Neurologic Disabilities, PM and R, 7, 1081-1088, 2015 Sakzewski, L., Ziviani, J., Boyd, R. N., Efficacy of upper limb therapies for unilateral cerebral palsy: a meta-analysis, Pediatrics, 133, e175-e204, 2014 Samilson, R. L., Orthopedic-Surgery of the Hips and Spine in Retarded Cerebral-Palsy Patients, Orthopedic Clinics of North America, 12, 83-90, 1981 Schiariti, V., Fayed, N., Cieza, A., Klassen, A., O'Donnell, M., Content Comparison of Health Related Quality of Life Measures for Cerebral Palsy Based on the International Classification of Functioning (Icf-Cy), Acta PaediatricaActa Paediatric, 98, 228-228, 2009 Schiariti, V., Fayed, N., Cieza, A., Klassen, A., O'donnell, M., Content comparison of health-related quality of life measures for cerebral palsy based on the International Classification of Functioning, Disability and Rehabilitation, 33, 1330-1339, 2011 Schopp, L. H., Clark, M. J., Hagglund, K. J., Mokelke, E. K., Stout, B. J., Mazurek, M. O., Evaluation of a consumer-personal assistant training project, Disability and Rehabilitation, 32, 403-410, 2007 Schweizer, K., Brunner, R., Romkes, J., Upper body movements in children with hemiplegic cerebral palsy walking with and without an ankle-foot orthosis, Clinical Biomechanics, 29, 387-394, 2014 Scianni, A., Butler, J. M., Ada, L., Teixeira-Salmela, L. F., Muscle strengthening is not effective in childre | with cerebral palsy, Journal of Bone and Joint Surgery - American   | Mean age less than 16 yrs                              |
| Exercise interventions for cerebral palsy, Cochrane Database of Systematic ReviewsCochrane Database Syst Rev, 6, CD011660, 2017  Ryan,J.M., Crowley,V.E., Hensey,O., Broderick,J.M., McGahey,A., Gormley,J., Habitual physical activity and cardiometabolic risk factors in our review.  No intervention  Review focuses on spinal cord injuries cases  Review focuses on spinal cord injuries cases  Disabilities, PM and R, 7, 1081-1088, 2015  Sakzewski,L., Ziviani,J., Boyd,R.N., Efficacy of upper limb therapies for unilateral cerebral palsy. a meta-analysis, Pediatrics, 133, e175-e204, 2014  Samilson, R. L., Orthopedic-Surgery of the Hips and Spine in Retarded Cerebral-Palsy Patients, Orthopedic Clinics of North America, 12, 83-90, 1981  Schiariti, V., Fayed, N., Cieza, A., Klassen, A., O'Donnell, M., Content Comparison of Health Related Quality of Life Measures for Cerebral Palsy Based on the International Classification of Functioning (Icf-Cy), Acta PaediatricaActa Paediatr, 93, 228-228, 2009  Schiariti, V., Fayed, N., Cieza, A., Klassen, A., O'donnell, M., Content comparison of health-related quality of life measures for cerebral palsy based on the International Classification of Functioning, Disability and Rehabilitation, 33, 1330-1339, 2011  Schopp, L. H., Clark, M. J., Hagglund, K. J., Mokelke, E. K., Stout, B. J., Mazurek, M. O., Evaluation of a consumer-personal assistant training project, Disability and Rehabilitation, 29, 403-410, 2007  Schweizer, K., Brunner, R., Romkes, J., Upper body movements in children with hemiplegic cerebral palsy walking with and without an ankle-foot orthosis, Clinical Biomechanics, 29, 387-394, 2014  Scianni, A., Butler, J. M., Ada, L., Teixeira-Salmela, L. F., Muscle strengthening is not effective in children and adolescents with cerebral palsy: a systematic review. Australian Journal of Physiotherapy, 55, 81-7, 2009  Senft, K. E., Pueschel, S. M., Robison, N. A., Kiessling, L. S., Level of function of young adults with cerebral palsy, Physical atrain of walking relates to activity lev | training on mobility in adults with cerebral palsy: A systematic review,  | Individual studies included                            |
| Gormley, J., Habitual physical activity and cardiometabolic risk factors in adults with cerebral palsy, Research in Developmental Disabilities, 35, 1995-2002, 2014  Sahlin, K. B., Lexell, J., Impact of Organized Sports on Activity, Participation, and Quality of Life in People With Neurologic Disabilities, PM and R, 7, 1081-1088, 2015  Sakzewski, L., Ziviani, J., Boyd, R.N., Efficacy of upper limb therapies for unilateral cerebral palsy: a meta-analysis, Pediatrics, 133, e175-e204, 2014  Samilson, R. L., Orthopedic-Surgery of the Hips and Spine in Retarded Cerebral-Palsy Patients, Orthopedic Clinics of North America, 12, 83-90, 1981  Schiariti, V., Fayed, N., Cieza, A., Klassen, A., O'Donnell, M., Content Comparison of Health Related Quality of Life Measures for Cerebral Palsy Based on the International Classification of Functioning (Icf-Cy), Acta PaediatricaActa Paediatr, 98, 228-228, 2009  Schiariti, V., Fayed, N., Cieza, A., Klassen, A., O'donnell, M., Content comparison of health-related quality of life measures for cerebral palsy based on the International Classification of Functioning, Disability and Rehabilitation, 33, 1330-1339, 2011  Schopp, L. H., Clark, M. J., Hagglund, K. J., Mokelke, E. K., Stout, B. J., Mazurek, M. O., Evaluation of a consumer-personal assistant training project, Disability and Rehabilitation, 29, 403-410, 2007  Schweizer, K., Brunner, R., Romkes, J., Upper body movements in children with hemiplegic cerebral palsy walking with and without an ankle-foot orthosis, Clinical Biomechanics, 29, 387-394, 2014  Scianni, A., Butler, J. M., Ada, L., Teixeira-Salmela, L. F., Muscle strengthening is not effective in children and adolescents with cerebral palsy: a systematic review, Australian Journal of Physiotherapy, 55, 81-7, 2009  Senft, K. E., Pueschel, S. M., Robison, N. A., Kiessling, L. S., Level of function of young adults with cerebral palsy, Physical and Occupational Therapy in Pediatrics, 10, 19-25, 1990  Slaman, J., Bussmann, J., Van Den Berg-Emons, R. J., Physical strain of walkin | Exercise interventions for cerebral palsy, Cochrane Database of Systematic ReviewsCochrane Database Syst Rev, 6, CD011660,                      | included in this systematic review is already included |
| Participation, and Quality of Life in People With Neurologic Disabilities, PM and R, 7, 1081-1088, 2015  Sakzewski, L., Ziviani, J., Boyd, R.N., Efficacy of upper limb therapies for unilateral cerebral palsy: a meta-analysis, Pediatrics, 133, e175-e204, 2014  Samilson, R. L., Orthopedic-Surgery of the Hips and Spine in Retarded Cerebral-Palsy Patients, Orthopedic Clinics of North America, 12, 83-90, 1981  Schiariti, V., Fayed, N., Cieza, A., Klassen, A., O'Donnell, M., Content Comparison of Health Related Quality of Life Measures for Cerebral Palsy Based on the International Classification of Functioning (Icf-Cy), Acta PaediatricaActa Paediatr, 98, 228-228, 2009  Schiariti, V., Fayed, N., Cieza, A., Klassen, A., O'donnell, M., Content comparison of health-related quality of life measures for cerebral palsy based on the International Classification of Functioning, Disability and Rehabilitation, 33, 1330-1339, 2011  Schopp, L. H., Clark, M. J., Hagglund, K. J., Mokelke, E. K., Stout, B. J., Mazurek, M. O., Evaluation of a consumer-personal assistant training project, Disability and Rehabilitation, 29, 403-410, 2007  Schweizer, K., Brunner, R., Romkes, J., Upper body movements in children with hemiplegic cerebral palsy walking with and without an ankle-foot orthosis, Clinical Biomechanics, 29, 387-394, 2014  Scianni, A., Butler, J. M., Ada, L., Teixeira-Salmela, L. F., Muscle strengthening is not effective in children and adolescents with cerebral palsy: a systematic review, Australian Journal of Physiotherapy, 55, 81-7, 2009  Senft, K. E., Pueschel, S. M., Robison, N. A., Kiessling, L. S., Level of function of young adults with cerebral palsy, Physical and Occupational Therapy in Pediatrics, 10, 19-25, 1990  Slaman, J., Bussmann, J., Van Der Slot, W. M., Stam, H. J., Roebroeck, M. E., Van Den Berg-Emons, R. J., Physical strain of walking relates to activity level in adults with cerebral palsy, Archives  | Gormley, J., Habitual physical activity and cardiometabolic risk factors in adults with cerebral palsy, Research in Developmental Disabilities, | No intervention  |
| for unilateral cerebral palsy: a meta-analysis, Pediatrics, 133, e175-e204, 2014  Samilson, R. L., Orthopedic-Surgery of the Hips and Spine in Retarded Cerebral-Palsy Patients, Orthopedic Clinics of North America, 12, 83-90, 1981  Schiariti, V., Fayed, N., Cieza, A., Klassen, A., O'Donnell, M., Content Comparison of Health Related Quality of Life Measures for Cerebral Palsy Based on the International Classification of Functioning (Icf-Cy), Acta PaediatricaActa Paediatr, 98, 228-228, 2009  Schiariti, V., Fayed, N., Cieza, A., Klassen, A., O'donnell, M., Content comparison of health-related quality of life measures for cerebral palsy based on the International Classification of Functioning, Disability and Rehabilitation, 33, 1330-1339, 2011  Schopp, L. H., Clark, M. J., Hagglund, K. J., Mokelke, E. K., Stout, B. J., Mazurek, M. O., Evaluation of a consumer-personal assistant training project, Disability and Rehabilitation, 29, 403-410, 2007  Schweizer, K., Brunner, R., Romkes, J., Upper body movements in children with hemiplegic cerebral palsy walking with and without an ankle-foot orthosis, Clinical Biomechanics, 29, 387-394, 2014  Scianni, A., Butler, J. M., Ada, L., Teixeira-Salmela, L. F., Muscle strengthening is not effective in children and adolescents with cerebral palsy: a systematic review, Australian Journal of Physiotherapy, 55, 81-7, 2009  Senft, K. E., Pueschel, S. M., Robison, N. A., Kiessling, L. S., Level of function of young adults with cerebral palsy, Physical and Occupational Therapy in Pediatrics, 10, 19-25, 1990  Slaman, J., Bussmann, J., Van Der Slot, W. M., Stam, H. J., Roebroeck, M. E., Van Den Berg-Emons, R. J., Physical strain of walking relates to activity level in adults with cerebral palsy, Archives  | Participation, and Quality of Life in People With Neurologic  |  |
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| Comparison of Health Related Quality of Life Measures for Cerebral Palsy Based on the International Classification of Functioning (Icf-Cy), Acta PaediatricaActa Paediatr, 98, 228-228, 2009  Schiariti, V., Fayed, N., Cieza, A., Klassen, A., O'donnell, M., Content comparison of health-related quality of life measures for cerebral palsy based on the International Classification of Functioning, Disability and Rehabilitation, 33, 1330-1339, 2011  Schopp, L. H., Clark, M. J., Hagglund, K. J., Mokelke, E. K., Stout, B. J., Mazurek, M. O., Evaluation of a consumer-personal assistant training project, Disability and Rehabilitation, 29, 403-410, 2007  Schweizer, K., Brunner, R., Romkes, J., Upper body movements in children with hemiplegic cerebral palsy walking with and without an ankle-foot orthosis, Clinical Biomechanics, 29, 387-394, 2014  Scianni, A., Butler, J. M., Ada, L., Teixeira-Salmela, L. F., Muscle strengthening is not effective in children and adolescents with cerebral palsy: a systematic review, Australian Journal of Physiotherapy, 55, 81-7, 2009  Senft, K. E., Pueschel, S. M., Robison, N. A., Kiessling, L. S., Level of function of young adults with cerebral palsy, Physical and Occupational Therapy in Pediatrics, 10, 19-25, 1990  Slaman, J., Bussmann, J., Van Der Slot, W. M., Stam, H. J., Roebroeck, M. E., Van Den Berg-Emons, R. J., Physical strain of walking relates to activity level in adults with cerebral palsy, Archives  | Retarded Cerebral-Palsy Patients, Orthopedic Clinics of North   | Opinion piece  |
| comparison of health-related quality of life measures for cerebral palsy based on the International Classification of Functioning, Disability and Rehabilitation, 33, 1330-1339, 2011  Schopp, L. H., Clark, M. J., Hagglund, K. J., Mokelke, E. K., Stout, B. J., Mazurek, M. O., Evaluation of a consumer-personal assistant training project, Disability and Rehabilitation, 29, 403-410, 2007  Schweizer, K., Brunner, R., Romkes, J., Upper body movements in children with hemiplegic cerebral palsy walking with and without an ankle-foot orthosis, Clinical Biomechanics, 29, 387-394, 2014  Scianni, A., Butler, J. M., Ada, L., Teixeira-Salmela, L. F., Muscle strengthening is not effective in children and adolescents with cerebral palsy: a systematic review, Australian Journal of Physiotherapy, 55, 81-7, 2009  Senft, K. E., Pueschel, S. M., Robison, N. A., Kiessling, L. S., Level of function of young adults with cerebral palsy, Physical and Occupational Therapy in Pediatrics, 10, 19-25, 1990  Slaman, J., Bussmann, J., Van Der Slot, W. M., Stam, H. J., Roebroeck, M. E., Van Den Berg-Emons, R. J., Physical strain of walking relates to activity level in adults with cerebral palsy, Archives   | Comparison of Health Related Quality of Life Measures for Cerebral Palsy Based on the International Classification of Functioning (Icf-Cy),     | No intervention  |
| J., Mazurek, M. O., Evaluation of a consumer-personal assistant training project, Disability and Rehabilitation, 29, 403-410, 2007  Schweizer, K., Brunner, R., Romkes, J., Upper body movements in children with hemiplegic cerebral palsy walking with and without an ankle-foot orthosis, Clinical Biomechanics, 29, 387-394, 2014  Scianni, A., Butler, J. M., Ada, L., Teixeira-Salmela, L. F., Muscle strengthening is not effective in children and adolescents with cerebral palsy: a systematic review, Australian Journal of Physiotherapy, 55, 81-7, 2009  Senft, K. E., Pueschel, S. M., Robison, N. A., Kiessling, L. S., Level of function of young adults with cerebral palsy, Physical and Occupational Therapy in Pediatrics, 10, 19-25, 1990  Slaman, J., Bussmann, J., Van Der Slot, W. M., Stam, H. J., Roebroeck, M. E., Van Den Berg-Emons, R. J., Physical strain of walking relates to activity level in adults with cerebral palsy, Archives  | comparison of health-related quality of life measures for cerebral palsy based on the International Classification of Functioning,              | No intervention  |
| children with hemiplegic cerebral palsy walking with and without an ankle-foot orthosis, Clinical Biomechanics, 29, 387-394, 2014  Scianni, A., Butler, J. M., Ada, L., Teixeira-Salmela, L. F., Muscle strengthening is not effective in children and adolescents with cerebral palsy: a systematic review, Australian Journal of Physiotherapy, 55, 81-7, 2009  Senft, K. E., Pueschel, S. M., Robison, N. A., Kiessling, L. S., Level of function of young adults with cerebral palsy, Physical and Occupational Therapy in Pediatrics, 10, 19-25, 1990  Slaman, J., Bussmann, J., Van Der Slot, W. M., Stam, H. J., Roebroeck, M. E., Van Den Berg-Emons, R. J., Physical strain of walking relates to activity level in adults with cerebral palsy, Archives  | J., Mazurek, M. O., Evaluation of a consumer-personal assistant   | participants have cerebral                             |
| strengthening is not effective in children and adolescents with cerebral palsy: a systematic review, Australian Journal of Physiotherapy, 55, 81-7, 2009  Senft, K. E., Pueschel, S. M., Robison, N. A., Kiessling, L. S., Level of function of young adults with cerebral palsy, Physical and Occupational Therapy in Pediatrics, 10, 19-25, 1990  Slaman, J., Bussmann, J., Van Der Slot, W. M., Stam, H. J., Roebroeck, M. E., Van Den Berg-Emons, R. J., Physical strain of walking relates to activity level in adults with cerebral palsy, Archives  | children with hemiplegic cerebral palsy walking with and without an   | Related to kinematics                                  |
| function of young adults with cerebral palsy, Physical and Occupational Therapy in Pediatrics, 10, 19-25, 1990  Slaman, J., Bussmann, J., Van Der Slot, W. M., Stam, H. J., Roebroeck, M. E., Van Den Berg-Emons, R. J., Physical strain of walking relates to activity level in adults with cerebral palsy, Archives  | strengthening is not effective in children and adolescents with cerebral palsy: a systematic review, Australian Journal of                      | Age less than 16 years                                 |
| Roebroeck, M. E., Van Den Berg-Emons, R. J., Physical strain of walking relates to activity level in adults with cerebral palsy, Archives  | function of young adults with cerebral palsy, Physical and  | No intervention  |
| of a hydrodical wild remaining of , 500 001, 2010  | Roebroeck, M. E., Van Den Berg-Emons, R. J., Physical strain of   | No intervention  |

| Slaman, J., Roebroeck, M., Dallmijer, A., Twisk, J., Stam, H., Van Den Berg-Emons, R., Can a lifestyle intervention programme improve physical behaviour among adolescents and young adults with spastic cerebral palsy? A randomized controlled trial, Developmental medicine and child neurology, 57, 159-166, 2015                                 | This evidence has already<br>been used in Spasticity<br>Under 19 Guideline |
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| Slaman, J., Roebroeck, M., van der Slot, W., Twisk, J., Wensink, A., Stam, H., van den Berg-Emons, R., Learn Move Research Group, Can a lifestyle intervention improve physical fitness in adolescents and young adults with spastic cerebral palsy? A randomized controlled trial, Archives of Physical Medicine & Rehabilitation, 95, 1646-55, 2014 | Outcomes not related to physical function                                  |
| Slaman, J., Roebroek, M., Stam, H., Van Den Berg-Emons, H., Effectiveness of a lifestyle program on daily physical activity and fitness in adolescents and young adults with cerebral palsy: A randomized controlled trial, Developmental medicine and child neurology, 55, 30-1, 2013  | conference abstract  |
| Takken, T., Helders, P., Description of Exercise Participation of Adolescents With Cerebral Palsy Across a 4-Year Period, Pediatric Physical Therapy, 22, 188-188, 2010   | Not primary study- Clinical Bottom Line                                    |
| Taneja, S., Narang, S., Midha, T., Drop Outs from a Cerebral Palsy Physiotherapy Program : A Clinical Appraisal, European Journal of Pediatrics, 175, 1689-1690, 2016   | Age group less than 16 years   |
| Taylor, N. F., Dodd, K. J., Larkin, H., Adults with cerebral palsy benefit from participating in a strength training programme at a community gymnasium, Disability & Rehabilitation, 26, 1128-34, 2004   | Single group study   |
| Thorpe, D., The role of fitness in health and disease: status of adults with cerebral palsy, Developmental Medicine & Child Neurology, 51 Suppl 4, 52-8, 2009   | Abstract of Conference   |
| Thorpe, D. E., McMurray, R., Henderson, R., Turk, M. A., Adults with cerebral palsy training to increase overall wellness: Project act now, Developmental Medicine and Child Neurology, 53, 53-54, 2011   | Conference abstract  |
| Thyberg, M., Gerdle, B., Samuelsson, K., Larsson, H., Wheelchair seating intervention. Results from a client-centred approach, Disability and Rehabilitation, 23, 677-682, 2001   | Results not analyzed separately for 4 subjects with CP                     |
| Unger,M., Faure,M., Frieg,A., Strength training in adolescent learners with cerebral palsy: a randomized controlled trial, Clinical Rehabilitation, 20, 469-477, 2006   | This evidence has already been used in Spasticity Under 19 Guideline       |
| Usuba, K., Oddson, B., Gauthier, A., Young, N. L., Leisure-Time<br>Physical Activity in adults with Cerebral Palsy, Disability and Health<br>Journal, 8, 611-618, 2015  | No intervention  |
| van der Dussen, L., Niewstraten, W., Roebroeck, M., Stam, H. J., Functional level of young adults with cerebral palsy, Clinical Rehabilitation, 15, 84-91, 2001   | No intervention  |
| van der Slot Wilma, M. A., Roebroeck, M. E., Landkroon, A. P., Terburg, M., van den Berg-Emons, R. J. G., Stam, H. J., Everyday physical activity and community participation of adults with hemiplegic Cerebral Palsy, Disability and Rehabilitation, 29, 179-189, 2007  | No intervention  |
| van Hedel, H. J. A., Meyer-Heim, A., Rusch-Bohtz, C., Robot-assisted gait training might be beneficial for more severely affected children with cerebral palsy, Developmental neurorehabilitation, 19, 410-415, 2016  | Mean age of 11.2 years   |
|   |  |

| Van Heest, A. E., Ramachandran, V., Stout, J., Wervey, R., Garcia, L., Quantitative and qualitative functional evaluation of upper extremity tendon transfers in spastic hemiplegia caused by cerebral palsy, Journal of Pediatric Orthopaedics, 28, 679-683, 2008 | Mean age of 10.8 years   |
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| Verschuren, O., Ketelaar, M., Gorter, J. W., Helders, P. J. M., Takken, T., Relation between physical fitness and gross motor capacity in children and adolescents with cerebral palsy, Developmental Medicine and Child Neurology, 51, 866-871, 2009              | Mean age less than 16 years  |
| Verschuren, O., Peterson, M. D., Balemans, A. C. J., Hurvitz, E. A., Exercise and physical activity recommendations for people with cerebral palsy, Developmental Medicine and Child Neurology., 2016  | Guidance recommendation based on mixed population, mostly children |
| Vogtle, L. K., Malone, L. A., Azuero, A., Outcomes of an exercise program for pain and fatigue management in adults with cerebral palsy, Disability & Rehabilitation, 36, 818-25, 2014   | Repeated measures design   |
| Warms, C. A., Belza, B. L., Whitney, J. D., Correlates of physical activity in adults with mobility limitations, Family & Community Health, 30, S5-S16, 2007   | No intervention  |
| Wiart, L., Darrah, J., Cook, A., Hollis, V., May, L., Evaluation of powered mobility use in home and community environments, Physical and Occupational Therapy in Pediatrics, 23, 59-75, 2003  | Mean age of 15.2 years   |
| Wiart, L., Rosychuk, R. J., Wright, F. V., Evaluation of the effectiveness of robotic gait training and gait-focused physical therapy programs for children and youth with cerebral palsy: A mixed methods RCT, BMC Neurology, 16 (1) (no pagination), 2016        | Research Protocol  |

CP: cerebral palsy; RCT: randomised controlled trial

### **Economic studies**

# Appendix L – Research recommendations

Research recommendations for review question D2: Which interventions are effective for maintaining physical function and mobility in adults with cerebral palsy?

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

What is the optimum regime for orthoses applied to the upper limb in adults with cerebral palsy to improve or maintain posture or function?

Table 21: Research recommendation rationale

| Research question                          | What is the optimum regime for orthoses applied to the upper limb in adults with cerebral palsy to improve or maintain posture or function?  |
|--|--|
| Importance to 'patients' or the population | <ul> <li>Improved independence, for example:         <ul> <li>Wheelchair independence</li> <li>Increased gait efficiency nb. Endurance/ speed/reduced falls</li> <li>Access to technology, which may enable communication</li> <li>Self Care</li> <li>Desk top – school/employment</li> <li>Sporting</li> <li>Reduce pain/discomfort – enable rest</li> <li>Handwriting, feeding computer use</li> </ul> </li> <li>Reduce pain</li> <li>Reduce need for surgical intervention</li> <li>Allow ease of administration of care</li> </ul> |
| Relevance to NICE guidance                 | Ability to define the value of this treatment approach   |
| Relevance to the NHS                       | Reduce surgical or pharmacological costs Reduce health related issues secondary to fixed contractures Establish consistency in availability of most effective/cost effective orthosis  |
| National priorities                        | Reduce variation in treatment Improve participation for adults with Cerebral Palsy NCEPOD Chronic Neurodisability Study  |
| Current evidence base                      | Current evidence was not clear and was graded as very low quality with high rates of imprecision   |
| Equality                                   | Applies to all adults with cerebral palsy and upper limb problems related to spasticity or dystonia  |

NCEPOD: National Confidential Enquiry into Patient Outcome and Death; NHS: National Health Service; NICE: National Institute for Health and Care Excellence.

Table 22: Research recommendation modified PICO table

| Criterion              | Explanation  |
|------------------------|--|
| Population             | Adults (16 or over) with cerebral palsy who have dystonia or spasticity causing functional impairment or postural changes in the upper limbs   |
| Intervention           | Application of orthoses  |
| Comparator             | <ul><li>Treatment as usual</li><li>No treatment</li></ul>  |
| Outcome                | <ul> <li>Patient satisfaction</li> <li>Ease of care administration</li> <li>Treatment-related morbidity</li> <li>HRQoL</li> <li>In-hand hygiene and in-hand skin integrity</li> <li>Functional ability <ul> <li>GAS/ GAS lite</li> </ul> </li> <li>Self-reported measures such as the:</li> <li>VAS or NRS for pain</li> <li>DASH or TOMS for function/participation.</li> <li>ARM-A; ARM-B</li> </ul> <li>Measures can also be used to objectively determine performance for dexterity</li> <li>9-hole peg test; grip and pinch strength</li> |
| Study design           | Large Multicentre cohort study   |
| Timeframe              | 5 years  |
| Additional information | Need to stratify by: Type of motor abnormality: Dystonia Spasticity Consider additional / previous interventions Surgery Systemic treatments (muscle relaxants, dystonia medication)   |
|                        | Therapy input  |

DASH: disabilities of the Arm, Shoulder and Hand; FES: Functional electrical stimulation; GAS: goal attainment scaling; HRQoL, health-related quality of life; ITB: intrathecal baclofen; NRS: numerical rating scale; TOM: therapy outcome measure; TUG: timed up and go; VAS: visual analogue scale