

## Cerebral palsy in adults

**[B2] Assessing and monitoring complications and comorbidities: mental health problems**

*NICE guideline NG119*

*Evidence reviews*

*January 2019*

*Final*

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



## **Disclaimer**

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or service users. The recommendations in this guideline are not mandatory and the guideline does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

Local commissioners and/or providers have a responsibility to enable the guideline to be applied when individual health professionals and their patients or service users wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with compliance with those duties.

NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the [Welsh Government](#), [Scottish Government](#), and [Northern Ireland Executive](#). All NICE guidance is subject to regular review and may be updated or withdrawn.

## **Copyright**

© NICE, 2019. All rights reserved. Subject to [Notice of Rights](#).

ISBN: 978-1-4731-3223-8

# Contents

<b>Assessing and monitoring complications and comorbidities associated with cerebral palsy in adults aged 25 and over .....</b>	<b>5</b>
Review question .....	5
Introduction .....	5
PIRO table.....	5
Methods and process .....	6
Clinical evidence .....	6
Summary of clinical studies included in the evidence review .....	6
Quality assessment of clinical studies included in the evidence review .....	6
Economic evidence .....	6
Summary of studies included in the economic evidence review.....	6
Economic model.....	6
Resource impact .....	7
Evidence statements .....	7
The committee’s discussion of the evidence.....	7
References.....	9
<b>Appendices.....</b>	<b>10</b>
Appendix A – Review protocols .....	10
Appendix B – Literature search strategies .....	14
Appendix C – Clinical evidence study selection .....	20
Appendix D – Clinical evidence tables .....	21
Appendix E – Forest plots.....	22
Appendix F – GRADE tables .....	23
Appendix G – Economic evidence study selection.....	24
Appendix H – Economic evidence tables .....	25
Appendix I – Health economic evidence profiles.....	26
Appendix J – Health economic analysis.....	27
Appendix K – Excluded studies .....	28
Clinical studies .....	28
Economic studies .....	29
Appendix L – Research recommendations .....	30

# Assessing and monitoring complications and comorbidities associated with cerebral palsy in adults aged 25 and over

## Review question

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

## Introduction

Adults with cerebral palsy may experience mental health issues, such as anxiety and depression more frequently than the wider population. Learning and communication difficulties can also lead to specific emotions and behaviours that require specialist understanding and input. As part of this they may also experience barriers to accessing support for their problems. This question reviews the evidence for the assessment and monitoring of these mental health problems.

## PIRO table

Please see

Table 1 for a summary of the Population, Index test, Reference standard and Outcome (PIRO) characteristics of this review.

**Table 1: Summary of the protocol (PIRO table)**

<b>Population</b>	Adults aged 25 and over with cerebral palsy and suspected mental health problems
<b>Index test</b>	Test for identification or assessment of mental health problems, for example: <ul style="list-style-type: none"> <li>• Whooley questions</li> <li>• GAD 2-2 from GAD-7</li> <li>• PHQ-9</li> <li>• CES-D</li> </ul>
<b>Reference standard</b>	<ul style="list-style-type: none"> <li>• Diagnosis from full psychiatric or psychological assessment</li> <li>• Each other</li> <li>• Other mental health assessment tools</li> </ul>
<b>Outcome</b>	<p><b>Critical</b></p> <ul style="list-style-type: none"> <li>• Test accuracy: <ul style="list-style-type: none"> <li>○ Sensitivity</li> <li>○ Specificity</li> <li>○ Positive/Negative likelihood ratio</li> </ul> </li> <li>• Validity and reliability</li> </ul> <p><b>Important</b></p> <ul style="list-style-type: none"> <li>• Patient satisfaction</li> </ul>

*CES-D: Center for Epidemiologic Studies Depression Scale; GAD: Generalised Anxiety Disorder Questionnaire; PHQ-9: Patient Health Questionnaire 9 question depression scale.*

For full details see review the protocol in appendix A.

## Methods and process

This evidence review was developed using the methods and process described in [Developing NICE guidelines: the manual 2014](#). Methods specific to this review question are described in the review protocol in appendix A and for a full description of the methods see supplementary document C.

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

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

See the literature search strategy in appendix B and study selection flow chart in appendix C.

### 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

No clinical studies were identified for this review.

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

No clinical studies were identified for this review.

## 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 topic was not prioritised for economic modelling because it was assumed that early recognition would lead to targeting of interventions at the correct indications and would therefore be cost neutral or cost saving.

## **Resource impact**

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

## **Evidence statements**

No relevant evidence was identified.

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

### **Interpreting the evidence**

#### ***The outcomes that matter most***

The committee agreed that the most relevant outcomes related to identification of mental health problems in adults with cerebral palsy would be accuracy measures related to tests, the validity and reliability of such tests. The committee classified patient satisfaction as an important outcome rather than a critical outcomes because the aim of the review is to identify mental health conditions and it may be possible that the most accurate tool is not the most satisfying for patients. This was because accurate identification of any mental health problems is critical to their successful management.

The review did not identify any evidence and therefore none of the outcomes were reported.

#### ***The quality of the evidence***

No evidence was identified for this review.

#### ***Benefits and harms***

Due to the lack of available evidence the committee based their recommendations on their experience and expertise.

The committee agreed that healthcare services for adults with cerebral palsy currently focus on physical impairments and that this can risk that a mental health problem may not be detected and treated. Therefore the committee decided to raise awareness that the detection of mental health problems and emotional difficulties can be as important as physical health problems. Early recognition can inform an individualised management plan that includes mental as well as physical functions. Assessment and recognition is particularly challenging in people who have communication difficulties or learning disabilities.

The committee discussed, based on their experience, that families and carers can have insights into the mental wellbeing of the adult with cerebral palsy and that they could also have a supporting role when problems are identified (where appropriate). Involving the people that are important to the adult with cerebral palsy was therefore important and the committee agreed to make a strong recommendation to encourage this to happen. This is also consistent with other guidance which highlights that social support has a positive impact on mental wellbeing (please see below).

The committee emphasised that asking the adult with cerebral palsy whether they have any concerns is an important part of individualised assessments and should be monitored at each review (defined as a planned clinical appointment). They did not want to specify the frequency of these reviews as it would depend on individual's needs and wishes. Based on their experience, the committee decided to include examples of the most common types of concerns that may indicate an emotional or mental health problem (for example the committee discussed that concerns about mood could indicate depressive or manic symptoms, or concerns about social interactions could indicate anxiety or social isolation).

Based on their knowledge the committee agreed that there are contributing factors that are more common in people with cerebral palsy and that these impact on the recognition and assessment of mental health problems. The committee noted that it is not always recognised that mental health medication can have an impact on motor function and vice versa medication used to manage motor function can also have an effect on mental health. If this is not taken into account then the adult may be given the wrong management when a medication change or dose adjustment would have been a more effective option. Other important factors that impact on mental health are communication difficulties because they can lead to frustration and feelings of isolation; comorbidities that can lead to higher levels of depression or distress (for instance pain or epilepsy); neuropsychological and executive function impairments (for example leading to problems with organising and planning day to day activities); and polypharmacy (which is a recognised risk factor for depression and other mental health problems). Early recognition of these would improve the treatment programme by providing care that is tailored to each adult with cerebral palsy who experiences mental health difficulties.

The committee acknowledged that there are some particular challenges related to their condition that are commonly experienced by adults with cerebral palsy which impact on their mental wellbeing. It was highlighted that communication difficulties or lack of stimulation (for instance it was noted that this can occur in residential care settings) can often lead to emotional distress or challenging behaviour. These factors should be taken into consideration when assessing the mental health of the person with cerebral palsy.

The committee discussed whether a research recommendation should be made given the lack of evidence. They decided not to prioritise this topic for further research because there are already established tools available that could be applied to people with cerebral palsy and that there is a wide range of mental health problems that may need to be assessed. The committee also agreed that

### **Cost effectiveness and resource use**

The committee noted that no relevant published economic evaluations had been identified for this topic.

The committee considered that the recommendations would lead to targeting of interventions at the correct indications through better identification of the cause of problems. If the wrong indication is targeted this will lead to an ineffective use of NHS resources; not only with regards to the intervention, but also downstream from adverse effects and reductions in quality of life.

Mental health problems and emotional difficulties can be as important as physical health problems and better prediction, identification and timely management could lead to the prevention of mental health problems in this population and potentially large resource savings.

### **Other factors the committee took into account**

The committee highlighted that there are many relevant published NICE guidelines related to mental health problems available and that these would need to be included in the pathway of the final guideline. They agreed to directly cross reference to the following guidelines for people with cerebral palsy because based on their knowledge and experience there are physical (such as reduced mobility), neurological (leading to learning disabilities) and social (lack of an advocate) factors that make adults with cerebral palsy more likely to develop these conditions:

- [attention deficit hyperactivity disorder](#)
- [autism spectrum disorder in adults](#)



- [challenging behaviour and learning disabilities](#)
- [depression in adults](#) and [depression in adults with a chronic physical health problem](#)
- [generalised anxiety disorder and panic disorder in adults](#)
- [mental health problems in people with learning disabilities.](#)

Familiarity with the relevant recommendation related to the recognition and assessment of the conditions that are cross-referenced is therefore an important step in the identification of mental health problems in adults with cerebral palsy.

## References

No studies were included in this review.

# Appendices

## Appendix A – Review protocols

Review protocol for review question B2: Which mental health assessment tools are clinically useful for adults with cerebral palsy?

**Table 2: Review protocol for monitoring and assessing mental health**

Field (based on <u>PRISMA-P</u> )	Content
Review question	B.2 Which mental health assessment tools are clinically useful for adults with cerebral palsy?
Type of review question	Diagnostic test accuracy
Objective of the review	The aim of this review is to compare the clinical utility of assessment tools in adults with cerebral palsy.
Eligibility criteria – <b>population</b> /disease/condition/issue/domain	Adults aged 25 and over with cerebral palsy and suspected mental health problems.
Eligibility criteria – <b>intervention(s)</b> /exposure(s)/prognostic factor(s)	Test for identification or assessment of mental health problems, for example: <ul style="list-style-type: none"> <li>• Whooley questions</li> <li>• GAD 2-2 from GAD-7</li> <li>• PHQ-9</li> <li>• CES-D (Center for Epidemiological studies depression scale)</li> </ul>
Eligibility criteria – <b>comparator(s)</b> /control or reference (gold) standard	<ul style="list-style-type: none"> <li>• Diagnosis from full psychiatric or psychological assessment</li> <li>• Each other</li> <li>• Other mental health assessment tools</li> </ul>
<b>Outcomes and prioritisation</b>	<p><b>Critical outcomes</b></p> <ul style="list-style-type: none"> <li>• Test accuracy: <ul style="list-style-type: none"> <li>◦ Sensitivity</li> <li>◦ Specificity</li> <li>◦ Positive/Negative likelihood ratio</li> </ul> </li> <li>• Validity and reliability</li> </ul> <p><b>Important outcomes</b></p> <ul style="list-style-type: none"> <li>• Patient satisfaction</li> </ul>

Field (based on <u>PRISMA-P</u> )	Content
	<p>The thresholds for clinical usefulness of tests:</p> <ul style="list-style-type: none"> <li>• Sensitivity and specificity (sensitivity will be prioritised as the tests in question will be used for screening rather than definitive diagnosis): <ul style="list-style-type: none"> <li>○ High &gt;90%</li> <li>○ Moderate 75-90%</li> <li>○ Low &lt;75%</li> </ul> </li> <li>• Positive likelihood ratio: <ul style="list-style-type: none"> <li>○ Very useful test &gt;10</li> <li>○ Moderately useful test 5-10</li> <li>○ Not a useful test &lt;5</li> </ul> </li> <li>• Negative likelihood ratio: <ul style="list-style-type: none"> <li>○ Very useful test &lt;0.1</li> <li>○ Moderately useful test 0.1 to 0.2</li> <li>○ Not a useful test &gt;0.2</li> </ul> </li> </ul>
Eligibility criteria – <b>study design</b>	<p>Only published full text papers -  Systematic reviews of cross sectional diagnostic accuracy studies  cross sectional diagnostic accuracy studies  Case control studies (only in the absence of cross sectional diagnostic accuracy studies)</p>
Other inclusion <b>exclusion criteria</b>	None
Proposed sensitivity/ <b>sub-group analysis</b> , or meta-regression	<p>In the presence of heterogeneity, the following subgroups will be considered for sensitivity analysis:</p> <ul style="list-style-type: none"> <li>• Population subgroups: <ul style="list-style-type: none"> <li>○ Presence of chronic pain</li> <li>○ Learning difficulties</li> <li>○ Communication difficulties</li> <li>○ Ambulant vs. non-ambulant</li> <li>○ People with limbic system damage</li> </ul> </li> <li>• Assessment subgroups per assessment tool where possible</li> <li>• Important confounders: <ul style="list-style-type: none"> <li>○ learning difficulties</li> <li>○ communication difficulties</li> </ul> </li> </ul>

Field (based on PRISMA-P)	Content
Selection process – duplicate screening/selection/analysis	A random sample of the references identified in the search was sifted by a second reviewer. This sample size was 10% of the total, or 100 studies if the search identifies fewer than 1000 studies. All disagreements in study inclusion were discussed and resolved between the two reviewers. The senior systematic reviewer or guideline lead was involved if discrepancies could not be resolved between the two reviewers.
Data management (software)	STAR was used to sift through the references identified by the search.
Information sources – databases and dates	Embase 1974 to present, Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) 1946 to Present, PsycINFO 1806 to present
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 <a href="#">Developing NICE guidelines: the manual 2014</a>
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) of the full guideline.
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</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 <a href="#">Developing NICE guidelines: the manual 2014</a>
Methods for quantitative analysis – combining studies and exploring (in)consistency	For details please see the methods see supplementary document C.
Meta-bias assessment – publication bias, selective reporting bias	For details please see section 6.2 of <a href="#">Developing NICE guidelines: the manual 2014</a>
Confidence in cumulative evidence	For details please see sections 6.4 and 9.1 of <a href="#">Developing NICE guidelines: the manual 2014</a>
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</a> .

Field (based on <u>PRISMA-P</u> )	Content
	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 NGA 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

*CDSR: Cochrane Database of Systematic Reviews; CENTRAL: Cochrane Central Register of Controlled Trials; CES-D: Center for Epidemiologic Studies Depression Scale; DARE: Database of Abstracts of Reviews of Effects; GAD: Generalised Anxiety Disorder Questionnaire; GMFCS, gross motor function classification system; GRADE: Grading of Recommendations Assessment, Development and Evaluation; HTA: Health Technology Assessment; MID: minimally important difference; NGA: National Guideline Alliance; NICE: National Institute for Health and Care Excellence; PHQ-9, Patient Health Questionnaire 9 question depression scale; RoB: risk of bias; SD: standard deviation*

## Appendix B – Literature search strategies

Literature search strategy for evidence review question B2: Which mental health assessment tools are clinically useful for adults with cerebral palsy?

### 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, PsycINFO 1806 to March Week 3 2018

**Table 3: Last searched on 22 March 2018**

#	Searches
1	exp Cerebral Palsy/ use prmz
2	exp cerebral palsy/ use oemezd
3	exp Cerebral Palsy/ use psyh
4	((cerebral or brain or central) adj2 (pal* or paralys#s or pares#s)).tw.
5	cerebral palsy.ti,ab.
6	little? disease.tw.
7	((hemipleg* or dipleg* or tripleg* or quadripleg* or unilateral*) adj5 spastic*).tw.
8	((hemipleg* or dipleg* or tripleg* or quadripleg* or unilateral*) adj3 ataxi*).tw.
9	or/1-8
10	limit 9 to english language
11	limit 10 to (adult <18 to 64 years> or aged <65+ years>) use oemezd [Limit not valid in Ovid MEDLINE(R),Ovid MEDLINE(R) In-Process,PsycINFO; records were retained]
12	limit 10 to "all adult (19 plus years)" [Limit not valid in Embase,PsycINFO; records were retained]
13	12 use prmz
14	limit 10 to adulthood <18+ years> [Limit not valid in Embase,Ovid MEDLINE(R),Ovid MEDLINE(R) In-Process; records were retained]
15	14 use psyh
16	or/11,13,15
17	exp mental health/ or exp mental disease/ or exp developmental disorder/ or intellectual impairment/ or exp mental deficiency/ or exp learning disorder/ or exp depression/ or exp Hamilton Depression Rating Scale/ or exp Depression Anxiety Stress Scale/ or exp Center for Epidemiological Studies Depression Scale/ or exp depression assessment/ or exp Edinburgh Postnatal Depression Scale/ or exp Calgary Depression Scale/ or exp "Hospital Anxiety and Depression Scale"/ or exp Montgomery Asberg Depression Rating Scale/ or exp Self-rating Depression Scale/ or exp depression inventory/ or exp "mixed anxiety and depression"/ or exp Beck Depression Inventory/ or exp experimental depression test/ or exp Zung Self Rating Depression Scale/ or exp generalized anxiety disorder/ or exp Social Interaction Anxiety Scale/ or exp State Trait Anxiety Inventory/ or exp Liebowitz Social Anxiety Scale/ or exp Anxiety Sensitivity Index/ or exp Hamilton Anxiety Scale/ or exp anxiety disorder/ or exp anxiety assessment/ or exp Beck Anxiety Inventory/ or exp anxiety/ or exp Depression Anxiety Stress Scale/ or exp mental stress/ or exp Depression Anxiety Stress Scale/ or exp Perceived Stress Scale/ or stress/ or exp stress assessment/ or exp Brief Pain Inventory/ or exp pain measurement/ or exp experimental pain test/ or exp experimental chronic pain test/ or exp Memorial Pain Assessment Card/ or exp chronic pain/ or exp pain parameters/ or exp pain assessment/ or exp pain/ or exp McGill Pain Questionnaire/ or exp experimental acute pain test/ or exp panic/ or exp mood disorder/ or exp personality disorder/ or exp health survey/ or exp health care survey/ or exp questionnaire/ or exp psychological rating scale/ or exp "sensitivity and specificity"/ or exp psychometry/ or exp diagnostic procedure/ or exp "Diagnostic and Statistical Manual of Mental Disorders"/ or exp "quality of

#	Searches
	life"/ or exp adaptive behavior/ or clinical assessment tool/ or exp diagnostic test/ or exp psychologic test/ or psychometry/ or rating scale/ or screening test/ or summated rating scale/ or exp cognitive therapy/ or exp behavior therapy/
18	17 use oemezd
19	exp Mental Disorders/ or exp Psychopathology/ or exp Mental Health/ or exp developmental disabilities/ or exp intellectual development disorder/ or "intellectual development disorder (attitudes toward)"/ or exp learning disabilities/ or exp recurrent depression/ or exp beck depression inventory/ or exp "depression (emotion)"/ or exp zungs self rating depression scale/ or exp emotional states/ or exp coping behavior/ or exp generalized anxiety disorder/ or exp anxiety disorders/ or exp anxiety/ or exp social anxiety/ or exp anxiety management/ or exp state trait anxiety inventory/ or exp anxiety sensitivity/ or exp acute stress disorder/ or exp psychological stress/ or exp "stress and coping measures"/ or exp chronic stress/ or exp stress/ or exp stress management/ or exp stress reactions/ or exp pain management/ or exp chronic pain/ or exp pain measurement/ or exp pain/ or exp panic/ or exp panic disorder/ or exp Emotional States/ or exp Personality Disorders/ or exp Affective Disorders/ or exp Psychometrics/ or exp Surveys/ or exp questionnaires/ or exp Psychological Assessment/ or exp Psychopathology/ or exp Rating Scales/ or exp Psychodiagnosis/ or exp Symptoms/ or exp Test Reliability/ or exp Screening/ or exp Medical Diagnosis/ or exp "Diagnostic and Statistical Manual"/ or exp "Quality of Life"/ or exp Adaptation/ or exp measurement/ or exp inventories/ or performance tests/ or exp personality measures/ or exp preference measures/ or exp reading measures/ or exp retention measures/ or exp screening tests/ or sociometric tests/ or "speech and hearing measures"/ or standardized tests/ or subtests/ or symptom checklists/ or exp testing/ or testing methods/ or exp test scores/ or verbal tests/ or exp cognitive therapy/ or exp behavior therapy/
20	19 use psyh
21	exp Mental Health/ or developmental disabilities/ or exp intellectual disability/ or exp learning disorders/ or mentally disabled persons/ or exp Depression/ or exp Depressive Disorder/ or exp Anxiety Disorders/ or exp Anxiety/ or exp Stress, Psychological/ or exp Pain/ or exp Chronic Pain/ or exp Panic Disorder/ or exp Panic/ or exp Mood Disorders/ or exp Personality Disorders/ or exp Psychiatric Status Rating Scales/ or exp "Surveys and Questionnaires"/ or exp "Sensitivity and Specificity"/ or exp Psychometrics/ or exp "Diagnostic Techniques and Procedures"/ or exp "Diagnostic and Statistical Manual of Mental Disorders"/ or exp Health Surveys/ or exp Test Anxiety Scale/ or exp "Quality of Life"/ or exp Adaptation, Psychological/ or exp Psychopathology/ or diagnostic tests, routine/ or "predictive value of tests"/ or exp psychiatric status rating scales/ or exp psychological tests/ or exp cognitive therapy/ or exp behavior therapy/
22	21 use prnz
23	((mental* or psychologic*) adj2 (health or disorder* or disease* or deficien* or illness or problem*)).ti,ab,sh.
24	((intellect* adj (deficien* or difficult* or disab* or disorder* or impair* or handicap* or incapacit* or handicap* or subnorm* or sub*1 average or sub*1 average or sub*1 norm*)) or (low*2 adj2 intellect*) or (learning adj (deficien* or difficult* or disab* or disorder* or handicap* or impair* or incapacit* or handicap* or subnorm* or sub*1 average or sub*1 average or sub*1 norm*)) or (mental* adj (disab* or handicap* or impair* or handicap* or incapacit* or retard* or subnorm* or sub*1 average or sub*1 average or sub*1 norm*))).ti,ab.
25	((development* or neurodevelopment*) adj (disab* or delay)).tw.
26	(education* adj5 subnorm*).tw.
27	(depres* or seasonal affective disorder* or dysthym* or melancholi*).ti,ab.
28	(depress* or nervous or anxious or edg* or afraid or grief* or griev* or pleasure* or joy or enjoy or worry* or worrie* or blue* or weary* or relax* or restless* or sit* still or fidget* or focus* or slow* or speak* or speech* or annoy* or irritable or panic* or dread* or anguish or anxiet* or post-traumatic stress* or stress* or appetite or sad* or happy* or unhappy* or bad* or dead* or hurt* or like myself or get* going or interest* or concentrat* or despond* or gloom* or despair* or low spirit* or hope* or miser* or tension* or turmoil* or asleep or sleep* or tired or overeas* or weight loss* or weight gain* or appetite* or feeling down or energy or

#	Searches
	mood* or chronic pain* or suicid* or pessimis* or failure* or self-reproach* or self-deprecat* or self-accusa* or guilt* or sin* or remorse* or self-report*).ti,ab.
29	(Beck Depression Inventory or BDI-21 or anxiety disorder scale* or Generalized Anxiety Disorder* or GAD or depression scale* or CES-D or Whooley questions).tw.
30	(health adj2 (survey* or questionnaire*)).tw.
31	((mental* or psychologic*) adj2 (rating scale* or assess* or monitor* or screen* or diagnos* or test* or symptom* or measure* or status)).tw.
32	(psychopatholog* or psychometric* or psychodiagnos* or adapt*).tw.
33	exp psychosis/ use oomezd or exp "schizophrenia and disorders with psychotic features"/ use prmz or exp psychosis/ use psyh or (borderline states or paranoid schizophrenia).sh.
34	(paranoi* or psychotic* or psychosis or psychoses or schizo*).ti,ab.
35	((assessment adj2 dual diagnosis) or behaviour checklist* or (clinical outcomes adj2 routine evaluation adj3 learning disabilities) or (diagnostic assessment adj3 severely handicapped) or (psychopathology checklist* adj2 adults with intellectual disability) or psychiatric assessment schedule for adults with developmental disabilities checklist* or (reiss screen for maladaptive adj behav*) or (strength adj2 difficulties questionnaire*) or (psychiatric assessment schedule adj2 adults adj3 developmental disability) or psychopathology instrument for mentally retarded adults or health of the nation outcome scales for people with learning disabilities).ti,ab.
36	((add*1 or cbcl or core-ld or coreld or dash or dash-ii or pac or p-aid or paid or pas-add*1 or pasadd or rsmb or sdq or pas-add*1 or pimra or honos-ld or honosld) adj3 (assessment* or checklist* or interview* or inventor* or questionnaire* or scale* or screen*)).ti,ab.
37	or/23-36
38	18 or 20 or 22 or 37
39	16 and 38
40	conference abstract.pt. use oomezd
41	letter.pt. or LETTER/ use oomezd
42	Letter/ use prmz
43	EDITORIAL/ use prmz
44	editorial.pt. use oomezd
45	NEWS/ use prmz
46	exp HISTORICAL ARTICLE/ use prmz
47	note.pt. use oomezd
48	ANECDOTES AS TOPIC/ use prmz
49	COMMENT/ use prmz
50	CASE REPORT/ use prmz
51	CASE REPORT/ use oomezd
52	CASE STUDY/ use oomezd
53	(letter or comment* or abstracts).ti.
54	or/40-53
55	RANDOMIZED CONTROLLED TRIAL/ use prmz
56	RANDOMIZED CONTROLLED TRIAL/ use oomezd
57	random*.ti,ab.
58	or/55-57
59	54 not 58
60	ANIMALS/ not HUMANS/ use prmz
61	ANIMAL/ not HUMAN/ use oomezd
62	exp ANIMALS, LABORATORY/ use prmz



#	Searches
63	exp ANIMAL EXPERIMENTATION/ use prmz
64	exp MODELS, ANIMAL/ use prmz
65	exp RODENTIA/ use prmz
66	NONHUMAN/ use oomezd
67	exp ANIMAL EXPERIMENT/ use oomezd
68	exp EXPERIMENTAL ANIMAL/ use oomezd
69	ANIMAL MODEL/ use oomezd
70	exp RODENT/ use oomezd
71	exp ANIMALS/ use psych
72	exp Animal Models/ use psych
73	exp Rodents/ or exp Mice/ or exp RATS/ use psych
74	(rat or rats or mouse or mice).ti.
75	or/59-74
76	39 not 75

### Database: Cochrane Library

**Table 4: Last searched on 22 March 2018**

ID	Search
#1	MeSH descriptor: [Cerebral Palsy] explode all trees
#2	((cerebral or brain or central) N2 (pal* or paraly?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
#6	MeSH descriptor: [Mental Health] explode all trees
#7	MeSH descriptor: [Developmental Disabilities] explode all trees
#8	MeSH descriptor: [Intellectual Disability] explode all trees
#9	MeSH descriptor: [Learning Disorders] explode all trees
#10	MeSH descriptor: [Mentally Disabled Persons] explode all trees
#11	MeSH descriptor: [Mental Disorders] explode all trees
#12	MeSH descriptor: [Mentally Ill Persons] explode all trees
#13	MeSH descriptor: [Anxiety] explode all trees
#14	MeSH descriptor: [Anxiety Disorders] explode all trees
#15	MeSH descriptor: [Panic] explode all trees
#16	MeSH descriptor: [Panic Disorder] explode all trees
#17	MeSH descriptor: [Stress, Psychological] explode all trees
#18	MeSH descriptor: [Depression] explode all trees
#19	MeSH descriptor: [Depressive Disorder] explode all trees
#20	MeSH descriptor: [Mood Disorders] explode all trees
#21	MeSH descriptor: [Personality Disorders] explode all trees
#22	MeSH descriptor: [Pain] explode all trees
#23	MeSH descriptor: [Chronic Pain] explode all trees
#24	MeSH descriptor: [Psychiatric Status Rating Scales] explode all trees
#25	MeSH descriptor: [Surveys and Questionnaires] explode all trees
#26	MeSH descriptor: [Sensitivity and Specificity] explode all trees
#27	MeSH descriptor: [Psychometrics] explode all trees

ID	Search
#28	MeSH descriptor: [Diagnostic Techniques and Procedures] explode all trees
#29	MeSH descriptor: [Diagnostic and Statistical Manual of Mental Disorders] explode all trees
#30	MeSH descriptor: [Health Surveys] explode all trees
#31	MeSH descriptor: [Test Anxiety Scale] explode all trees
#32	MeSH descriptor: [Quality of Life] explode all trees
#33	MeSH descriptor: [Adaptation, Psychological] explode all trees
#34	MeSH descriptor: [Psychopathology] explode all trees
#35	MeSH descriptor: [Diagnostic Tests, Routine] explode all trees
#36	MeSH descriptor: [Predictive Value of Tests] explode all trees
#37	MeSH descriptor: [Psychiatric Status Rating Scales] explode all trees
#38	MeSH descriptor: [Psychological Tests] explode all trees
#39	((mental* or psychologic*) near/2 (deficien* or disease* or disorder* or disturbance* or dysfunction* or health or illness* or problem*)):ti,ab,kw
#40	(intellect* near/1 (deficien* or difficult* or disab* or disorder* or impair* or handicap* or incapacit* or subnorm* or "sub* norm*" or subaverage or "sub* average")) or (low* near/2 intellect*) or (learning near/1 (deficien* or difficult* or disab* or disorder* or handicap* or impair* or incapacit* or handicap* or subnorm* or "sub* norm*" or subaverage or "sub* average")) or (mental* near/1 (deficien* or disab* or impair* or handicap* or incapacit* or delay* or retard* or subnorm* or subaverage or "sub* average" or "sub* norm*")) or ((subaverage or "sub* average" or subnormal or "sub* normal*") near/3 (adult* or cognit* or intel*)) or ((development* or neurodevelopment*) near/1 (disab* or delay*)) or (education* near/5 subnorm*)
#41	(special* near/2 (educat* or need*)):ti,ab,kw,ab,kw
#42	(anxiet* or anxious* or ((chronic* or excessiv* or intens* or (long* near/2 last*) or neuros* or neurotic* or ongoing or persist* or serious* or sever* or uncontrol* or "un control*" or unrelent* or "un relent*") near/2 worry or chronic near/1 pain)):ti,ab,kw
#43	depres* or seasonal affective disorder* or dysthym* or melancholi*
#44	(depress* or nervous or anxious or edg* or afraid or grief* or griev* or pleasure* or joy or enjoy or worry* or worrie* or blue* or weary* or relax* or restless* or sit* still or fidget* or focus* or slow* or speak* or speech* or annoy* or irritable or panic* or dread* or anguish or anxiet* or post-traumatic stress* or stress* or appetite or sad* or happy* or unhappy* or bad* or dead* or hurt* or like myself or get* going or interest* or concentrat* or despond* or gloom* or despair* or low spirit* or hope* or miser* or panic* or mood* or tension* or turmoil* or asleep or sleep* or tired or overeat* or weight loss* or weight gain* or appetite* or feeling down or energy or mood* or chronic pain* or suicid* or pessimis* or failure* or self-reproach* or self-deprecat* or self-accusa* or guilt* or sin* or remorse* or self-report*)
#45	Beck Depression Inventory or BDI-21 or anxiety disorder scale* or Generalized Anxiety Disorder* or GAD or depression scale* or CES-D or Whooley questions
#46	health near/2 (survey* or questionnaire*)
#47	((mental* or psychologic*) near/2 (rating scale* or assess* or monitor* or screen* or diagnos* or test* or symptom* or measure* or status))
#48	psychopatholog* or psychometric* or psychodiagnos* or adapt*
#49	((assessment near/22 dual diagnosis) or behaviour checklist* or (clinical outcomes near/2 routine evaluation near/3 learning disabilities) or (diagnostic assessment near/3 severely handicapped) or (psychopathology checklist* near/2 adults with intellectual disability) or psychiatric assessment schedule for adults with developmental disabilities checklist* or (reiss screen for maladaptive near behav*) or (strength near/2 difficulties questionnaire*) or (psychiatric assessment schedule near/2 adults near/3 developmental disability) or psychopathology instrument for mentally retarded adults or health of the nation outcome scales for people with learning disabilities)
#50	paranoi* or psychotic* or psychosis or psychoses or schizo*
#51	assessment* or checklist* or interview* or inventor* or questionnaire* or scale* or screen*

ID	Search
#52	#6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32 or #33 or #34 or #35 or #36 or #37 or #38 or #39 or #40 or #41 or #42 or #43 or #44 or #45 or #46 or #47 or #48 or #49 or #50 or #51
#53	#5 and #52

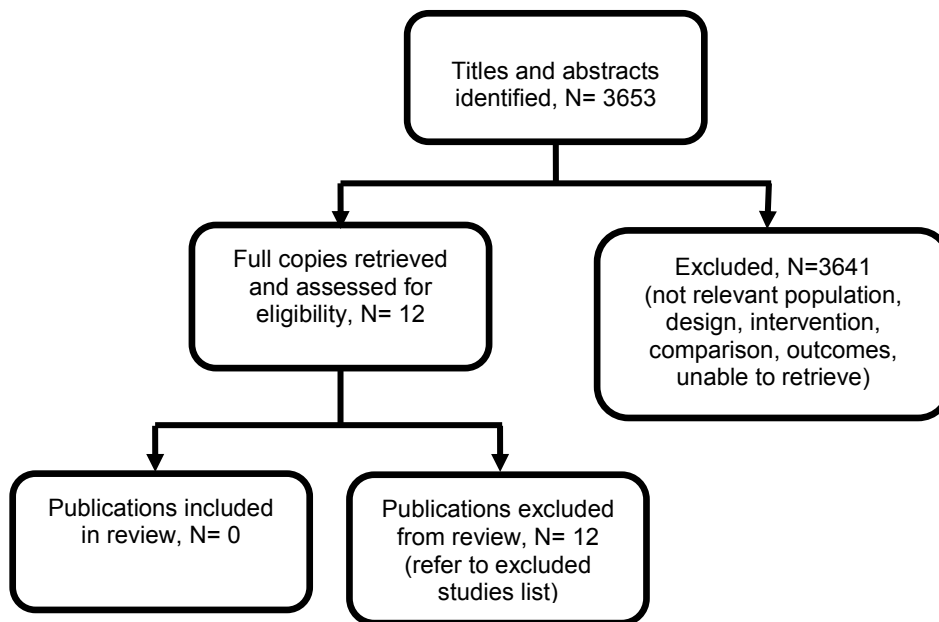
**Database: Web of Science****Table 5: Last searched on 22/03/2018**

Set	Search
#8	(#7) AND LANGUAGE: (English)
#7	#5 not #6
#6	ts=child* or ts=infant* or ts=p?ediat* or ts=preterm or ts=stroke* or ts=dementia
#5	#4 AND #1
#4	#3 OR #2
#3	ts=Developmental Disabilit* or ts=Intellectual Disabilit* or ts=Learning Disorder* or ts=Mentally Disabled Person* or ts=Mental Disorder* or ts=Mentally Ill Person* or ts=Anxiet* or ts=Depressive Disorder* or ts=Personality Disorder* or ts=depress* or ts=nervous or ts=anxious or ts=edg* or ts=afraid or ts=grief* or ts=griev* or ts=pleasure* or ts=joy or ts=enjoy or ts=worry* or ts=worrie* or ts=blue* or ts=weary* or ts=relax* or ts=restless* or ts=sit* still or ts=fidget* or ts=focus* or ts=slow* or ts=speak* or ts=speech* or ts=annoy* or ts=irritable or ts=panic* or ts=dread* or ts=anguish or ts=anxiet* or ts=post-traumatic stress* or ts=stress* or ts=appetite or ts=sad* or ts=happy* or ts=unhappy* or ts=bad* or ts=dead* or ts=hurt* or ts=like myself or ts=get* going or ts=interest* or ts=concentrat* or ts=despond* or ts=gloom* or ts=despair* or ts=low spirit* or ts=hope* or ts=miser* or ts=tension* or ts=turmoil* or ts=asleep or ts=sleep* or ts=tired or ts=overeat* or ts=weight loss* or ts=weight gain* or ts=appetite* or ts=feeling down or ts=energy or ts=mood* or ts=chronic pain* or ts=suicid* or ts=pessimis* or ts=failure* or ts=self-reproach* or ts=self-deprecat* or ts=self-accusa* or ts=guilt* or ts=sin* or ts=remorse* or ts=self-report*
#2	ts=Psychiatric Status Rating Scale* or ts=Survey* or ts=Questionnaire* or ts=Psychometric* or ts=Routine Diagnostic test* or ts=Health Survey* or ts=Test Anxiety Scale* or ts=Psychopathology or ts=Psychiatric Status Rating Scale* or ts=Psychological Test* or ts=Beck Depression Inventory or ts=BDI-21 or ts=anxiety disorder scale* or ts=Generalized Anxiety Disorder* or ts=GAD or ts=depression scale* or ts=CES-D or ts=Whooley questions or ts=(mental* (health or disorder* or disease* or deficien* or illness or problem* or rating scale* or assess* or monitor* or screen* or diagnos* or test* or symptom* or measure* or status)) or ts=(psychologic* (health or disorder* or disease* or deficien* or illness or problem* or rating scale* or assess* or monitor* or screen* or diagnos* or test* or symptom* or measure* or status)) or ts=behaviour checklist* or ts=routine evaluation* or ts=psychopathology checklist* or ts=psychiatric assessment
#1	ts=Cerebral Palsy

## Appendix C – Clinical evidence study selection

Clinical evidence study selection for evidence review question B2: Which mental health assessment tools are clinically useful for adults with cerebral palsy?

**Figure 1: Flow diagram of clinical article selection for mental health assessment tools review**



## **Appendix D – Clinical evidence tables**

Clinical evidence study selection for evidence review question B2: Which mental health assessment tools are clinically useful for adults with cerebral palsy?

No clinical studies were identified for this review.

## **Appendix E – Forest plots**

Forest plots for evidence review question B2: Which mental health assessment tools are clinically useful for adults with cerebral palsy?

No forest plots were included in this review.

## **Appendix F – GRADE tables**

GRADE tables for evidence review question B2: Which mental health assessment tools are clinically useful for adults with cerebral palsy?

No clinical studies were identified for this review.

## **Appendix G – Economic evidence study selection**

Economic evidence study selection for evidence review question B2: Which mental health assessment tools are clinically useful for adults with cerebral palsy?

No economic evidence was identified for this review.



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

Economic evidence tables for evidence review question B2: Which mental health assessment tools are clinically useful for adults with cerebral palsy?

No economic evidence was identified for this review.

## **Appendix I – Health economic evidence profiles**

Health economic evidence profiles for evidence review B2: Which mental health assessment tools are clinically useful for adults with cerebral palsy?

No economic evidence was identified for this review.

## **Appendix J – Health economic analysis**

Health economic analysis for evidence review B2: Which mental health assessment tools are clinically useful for adults with cerebral palsy?

No economic analysis was included in this review.

## Appendix K – Excluded studies

List of clinical and economic excluded studies tables for evidence review B2: Which mental health assessment tools are clinically useful for adults with cerebral palsy?

### Clinical studies

**Table 6: Excluded clinical studies for monitoring and assessing mental health**

<b>Excluded studies - B.2 Which mental health assessment tools are clinically useful for adults with cerebral palsy?</b>	
<b>Study</b>	<b>Reason for Exclusion</b>
Aman, M. G., Richmond, G., Stewart, A. W., The Aberrant Behavior Checklist: Factor structure and the effect of subject variables in American and New Zealand facilities, <i>American Journal of Mental Deficiency</i> , 91, 570-578, 1987	Aberrant behaviour rather than mental health assessment.
Balandin, S., Berg, N., Waller, A., Assessing the loneliness of older people with cerebral palsy, <i>Disability and Rehabilitation</i> , 28, 469-479, 2006	Not mental health problems - measured loneliness.
Borkowska, Aneta Rita, Anxiety level and self-esteem in youth with cerebral palsy, <i>Current Issues in Personality Psychology</i> , 3, 159-165, 2015	Compares anxiety and self-esteem between a group with CP (mean age 20 years) and a control group without CP.
Cox, Barbara Joanne, Predictors of depression in adults with cerebral palsy: A biopsychosocial model, <i>Dissertation Abstracts International: Section B: The Sciences and Engineering</i> , 60, 1847, 1999	Abstract only - study looked at factors associated with depression.
Davis, Renee, A study examining the relationship between congenital disability and depression in adults with cerebral palsy, <i>Dissertation Abstracts International: Section B: The Sciences and Engineering</i> , 69, 1320, 2008	Abstract only - study looked at factors associated with depression.
Hove, O., Havik, O.E., Developmental level and other factors associated with symptoms of mental disorders and problem behaviour in adults with intellectual disabilities living in the community, <i>Social Psychiatry and Psychiatric Epidemiology</i> , 45, 105-113, 2010	Results for those with epilepsy (N=134) and CP (N=54) were combined.
Ignjatovic, P., Jovic, N., Cognitive and psychological problems in patients with cerebral palsy and epilepsy, <i>European Neuropsychopharmacology</i> , 21, S171-S171, 2011	Abstract only, not assessment of mental health problems, mean or median age not reported.
Margetis, K., Papageorgiou, G., Gatzonis, S., Politis, K., Siatouni, A., Sakas, D., Intrathecal baclofen improves psychiatric symptoms in spasticity patients, <i>Journal of Clinical Psychopharmacology</i> , 34, 374-379, 2014	Summarises the effect of baclofen on psychological distress symptoms - patients with learning disability or symptoms of psychosis were excluded, 8/15 had CP.
Mathiasen, Rene, Hansen, Bo Molholm, Forman, Julie Lyng, Kessing, Lars Vedel, Greisen, Gorm, The risk of psychiatric	Looks at cerebral palsy as a risk factor for psychiatric disorders.

### Excluded studies - B.2 Which mental health assessment tools are clinically useful for adults with cerebral palsy?

Study	Reason for Exclusion
disorders in individuals born prematurely in Denmark from 1974 to 1996, <i>Acta Paediatrica</i> , 100, 691-699, 2011	
Rasmussen, K. G., Zorumski, C. F., Jarvis, M. R., Electroconvulsive-Therapy in Patients with Cerebral-Palsy, <i>Convulsive Therapy</i> , 9, 205-208, 1993	4 case reports of treatment - not assessment of mental health problems in CP.
Ravesloot, C., Ward, B., Hargrove, T., Wong, J., Livingston, N., Torma, L., Ipsen, C., Why stay home? Temporal association of pain, fatigue and depression with being at home, <i>Disability and Health Journal</i> , 9, 218-225, 2016	Cerebral palsy not reported.
Van Lieshout, R. J., Boyle, M. H., Saigal, S., Morrison, K., Schmidt, L. A., Mental health of extremely low birth weight survivors in their 30s, <i>Pediatrics</i> , 135, 452-459, 2015	No analysis of those with cerebral palsy.

CP: cerebral palsy; N: number of participants.

### Economic studies

No economic evidence was identified for this review.

## **Appendix L – Research recommendations**

Research recommendation for evidence review question B2: Which mental health assessment tools are clinically useful for adults with cerebral palsy?

No research recommendation was made for this review.