Table 5: Review protocol for monitoring respiratory health in adults with cerebral palsy

Field (based on PRISMA-P)	Content
Review question	What is the most effective protocol for monitoring respiratory health in adults with cerebral palsy?
Type of review question	Intervention (test & treat) / diagnostic test accuracy
Objective of the review	The aim of this review is to assess the impact of formal monitoring protocols on respiratory health outcomes.
Eligibility criteria – population/disease/condition/issue/domain	Adults aged 25 and over with cerebral palsy
Eligibility criteria – intervention(s)/exposure(s)/prognostic factor(s)	Protocol for monitoring respiratory health defined by: • Setting (residential, primary care, secondary care) • Tests used (e.g. assessment of vital capacity, sleep disordered breathing, assessment of fatigue, cough peak flow, aspiration risk, infections, oxygen saturation) • Who carries out the monitoring (e.g. GP, specialist) • Frequency of monitoring
Eligibility criteria – comparator(s)/control or reference (gold) standard	Any other monitoring protocol No formal monitoring
Outcomes and prioritisation	Critical outcomes • Respiratory health • Overall survival • Hospital admission Important outcomes

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	• Secondary conditions (e.g. colds, asthma, sleep apnoea, Daytime sleepiness (Epworth Scale), etc.) • Respiratory function • Health related quality of life • Satisfaction Minimally important differences • Any statistically significant improvement in overall survival will be considered clinically important • Other dichotomous outcomes will use default MIDs [RR thresholds of 0.80 and 1.2] • Other continuous outcomes will use default MIDs [0.5 times the SD of the control group] • Published MIDs for respiratory function used in COPD: FEV1 100ml, dyspnoea TDI score 1 unit, heath status SGRQ score 4 units. The thresholds for clinical usefulness of tests: Sensitivity and specificity (sensitivity will be prioritised): • High >90% • Moderate 75-90% • Low <75% Positive likelihood ratio: • Very useful test >10 • Moderately useful test 5-10 • Not a useful test <5 Negative likelihood ratio: • Very useful test <0.1 • Moderately useful test 0.1 to 0.2 • Not a useful test>0.2

Field (based on PRISMA-P)	Content
	Reliability, validity, or internal consistency • Poor < 0.4 • Moderate reliability ≥0.4 to 0.6 • Good >0.6 to 0.8 • Excellent > 0.8
Eligibility criteria – study design	This review will look for so-called "test and treat" studies - because an effective monitoring protocol will lead to treatment or management changes that should improve clinical outcomes. Only published full text papers – • Systematic reviews of RCTs • RCTs • Comparative cohort studies (only if RCTs unavailable or limited data to inform decision making) Consider conference abstract only if related to RCTs In the absence of test and treat studies diagnostic accuracy studies (cohort studies) will be reviewed – and the committee will consider the likely consequences of the true positives, false positives etc. of respiratory health monitoring on clinical outcomes.
Other inclusion exclusion criteria	None
Proposed sensitivity/sub-group analysis, or meta-regression	In the presence of heterogeneity, the following subgroups will be considered for sensitivity analysis: • Population subgroups: ○ Level of functional disability

Field (based on PRISMA-P)	Content
	○ Physical issues which may impact respiratory condition (scoliosis, kyphosis, barrel chest etc.) ○ Feeding or swallowing problems ○ Learning disabilities • Intervention subgroups: ○ Setting (residential versus others) ○ Which tests or assessment were used ○ Who carried out the tests and assessments ○ Frequency of assessments Physical issues and level of functional disability will be also considered important confounders which ideally should be adjusted for in any included comparative observational studies.
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)	STAR was used to sift through the references identified by the search, and for data extraction Diagnostic analysis was done using Cochrane Review Manager (RevMan5).
Information sources – databases and dates	Database(s): Embase 1974 to Present, Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) 1946 to Present
Identify if an update	This is 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 Developing NICE guidelines: the manual 2014
Search strategy – for one database	For details please see appendix B.

Field (based on PRISMA-P)	Content
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).
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 Developing NICE guidelines: the manual 2014 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 http://www.gradeworkinggroup.org/ Please document any deviations/alternative approach when GRADE isn't used or if a modified GRADE approach has been used for non-intervention or non-comparative studies.
Criteria for quantitative synthesis	For details please see section 6.4 of Developing NICE guidelines: the manual 2014
Methods for quantitative analysis – combining studies and exploring (in)consistency	For details please see the methods in supplementary document C.
Meta-bias assessment – publication bias, selective reporting bias	For details please see section 6.2 of Developing NICE guidelines: the manual 2014.
Confidence in cumulative evidence	For details please see sections 6.4 and 9.1 of Developing NICE guidelines: the manual 2014
Rationale/context – what is known	For details please see the introduction to the evidence.
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 Developing NICE guidelines: the manual 2014. Staff from NGA undertook systematic literature searches, appraised the evidence, conducted meta-analysis and cost-effectiveness analysis where appropriate, and

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	drafted the guideline in collaboration with the committee. For details please see the methods in supplementary document C..
Sources of funding/support	NGA is funded by NICE and hosted by the Royal College of Obstetricians and Gynaecologists.
Name of sponsor	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

COPD: Chronic obstructive pulmonary disease; FEV: Forced expiratory volume; GRADE: Grading of Recommendations Assessment, Development and Evaluation; MID: minimally important difference; NICE: National Institute for Health and Care Excellence; NIV: Non-invasive ventilation; RCT: randomised controlled trial; RoB: risk of bias; RR: risk ratio; SD: standard deviation; SGRQ: St. George's respiratory questionnaire; TDI: Transition dyspnoea index;