Meaningful Change in Childhood Participation

A systematic review protocol for child- and caregiver-anchored estimates in neurodevelopmental disability

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Review status: Exploratory scoping and reference verification have begun. Formal eligible-study searches, screening, extraction, appraisal and synthesis have not begun.

Abstract

Background: A change in participation score does not establish whether children or caregivers consider it important. Published estimates may represent different constructs, reporters and statistical quantities, limiting their use as individual decision thresholds.

Objective: To identify and appraise child- or caregiver-anchored estimates of important change in childhood participation, distinguish their interpretations, and map evidence gaps.

Methods: Eligible longitudinal studies will derive, evaluate or explicitly attempt an important-change estimate for participation attendance or involvement among children with a prespecified neurodevelopmental condition who are younger than 18 years at baseline. Later assessments crossing age 18 will be retained and flagged. Searches are planned in PubMed, Embase, CINAHL, PsycINFO, ERIC and ProQuest Dissertations and Theses Global, supplemented by citation, registry and preprint searching. Two human reviewers will independently select reports, extract data and appraise estimates. The analysis unit is an estimate or documented failed attempt within a study family. Participation content, anchor, reporter and estimand will be coded separately. Individual responder thresholds, anchor-defined mean change and longitudinal group contrasts will retain distinct interpretations. An adapted domain-level appraisal will assess respondent alignment, anchor relevance, association with target change, precision and the importance represented by the anchor contrast. The co-primary outputs are an estimate catalogue and an evidence-gap and credibility map. Narrative synthesis will preserve instrument scales and study dependence; meta-analysis is not planned.

Discussion: The review will distinguish supported interpretations from uncertainty and missing evidence, including if few estimates are eligible. It may guide future anchor studies; it will not establish proprietary-instrument validity or treatment effectiveness.

Registration: PROSPERO submission is planned before formal screening, subject to eligibility and completion of the required declarations. No identifier has been assigned.

Keywords: participation; meaningful change; minimal important change; neurodevelopmental disability; child report; caregiver report; systematic review protocol

Strengths and limitations

- Estimate-level analysis retains study-family links and documented failed attempts.
- Item, occupation or subscale mapping distinguishes participation from related constructs.
- Reporter, anchor, direction and estimand remain explicit throughout appraisal and synthesis.
- Sparse evidence will be mapped without relaxing eligibility to increase yield.
- Search access, translation resources and overlap with recent reviews remain unresolved.

1 Introduction

1.1 Meaningful change and participation

Participation is central to childhood disability research. The World Health Organization's International Classification of Functioning, Disability and Health situates participation within functioning and environmental context [1]. The United Nations Convention on the Rights of Persons with Disabilities addresses children's views, inclusive education and rehabilitation [2]. The WHO-UNICEF global report highlights participation across home, school and community and challenges in measuring it reliably [3]. Interpreting participation-score changes requires complementary measurement evidence.

Minimal important change concerns whether change matters; standard error of measurement and minimal detectable change concern measurement error. Statistical significance or a fraction of a standard deviation alone does not establish important within-child change [4].

Participation comprises attendance and involvement in life situations. Activity competence, preferences and sense of self are related constructs rather than interchangeable outcomes [5,6]. Because instruments may combine participation, task performance, satisfaction and environmental support, eligibility requires verification of the content actually scored.

Minimal and more-than-minimal important change will be distinguished by the actual anchor contrast; a broad important-change category will not be relabelled minimal. The labels minimal important change (MIC), minimal important difference (MID) and minimal clinically important difference (MCID) are used inconsistently. Estimates may represent individual responder thresholds, average change in anchor-defined groups or between-group differences. The review will preserve the reported label while classifying the quantity estimated; group differences will not be interpreted as individual decision thresholds.

1.2 Relationship to existing reviews

McColl and colleagues examined the evidential basis for clinically significant change on the Canadian Occupational Performance Measure (COPM) [7]. Yuine and colleagues reviewed important and detectable change in the Canadian Occupational Performance Measure across populations [8]; Spiess and colleagues reviewed participation measurement in children and adolescents [9]. Adair and colleagues mapped participation instruments to related constructs [6], and Resch and colleagues assessed participation measurement properties, including detectable and clinically important change in preschool participation [10].

These reviews provide complementary foundations. Terwee and colleagues already distinguish change quantities and document unsuccessful anchor estimation [4]. The present review applies established principles across instruments to a focused population, participation construct and child/caregiver perspective. Its planned contribution is a linked catalogue of estimates and documented unsuccessful attempts, classified by scored content, anchor respondent, estimand and credibility. It does not claim to invent these distinctions or to be the first review of participation interpretability.

Full-text comparison with the recent Yuine and Spiess reviews remains incomplete. Their accessible records establish relevance but do not settle every overlap. Supplementary Methods provides a six-review predecessor comparison with explicit read status. That comparison will be updated as sources become available; any material change to scope will be recorded before formal screening. This access limitation qualifies the added-value assessment.

1.3 Objective

Among children with eligible neurodevelopmental conditions who are younger than 18 years at baseline, what evidence supports child- or caregiver-anchored estimates of important change in participation attendance or involvement? How do interpretation, credibility and applicability vary by estimand, measure, reporter, diagnosis, age, setting, language and interval?

Registry summary: Population: baseline-under-18 children with eligible neurodevelopmental conditions; index: participation attendance or involvement scores; anchor: child or caregiver judgement of meaningful change; outcomes: important-change estimates or documented unsuccessful attempts.

The co-primary outputs are an estimate and failed-attempt catalogue, and an evidence-gap and credibility map. Secondary outputs address applicability,

supporting measurement-error evidence and priorities for anchor studies.

2 Methods

2.1 Reporting and registration

The protocol was prepared using PRISMA-P; the completed review will use PRISMA 2020 and PRISMA-S. Applicable PRISMA-COSMIN items will inform reporting of supporting measurement-property appraisal [11,12,13,14]. The companion checklist maps each reporting item to the protocol and records execution requirements.

PROSPERO registration is planned, subject to eligibility. This version fixes the published prospective methods. Before formal screening, the team will resolve search access and peer review, complete individual declarations and registry fields, appoint an unconflicted adjudicator, and update the predecessor assessment. Actual stages and dates will be reported; changes to this published plan require amendments. Amendments will retain superseded text, date, rationale, stage and whether relevant results were known. If registration is unavailable, the reason and a timestamped repository protocol will be reported.

Figure 1 outlines the review structure.

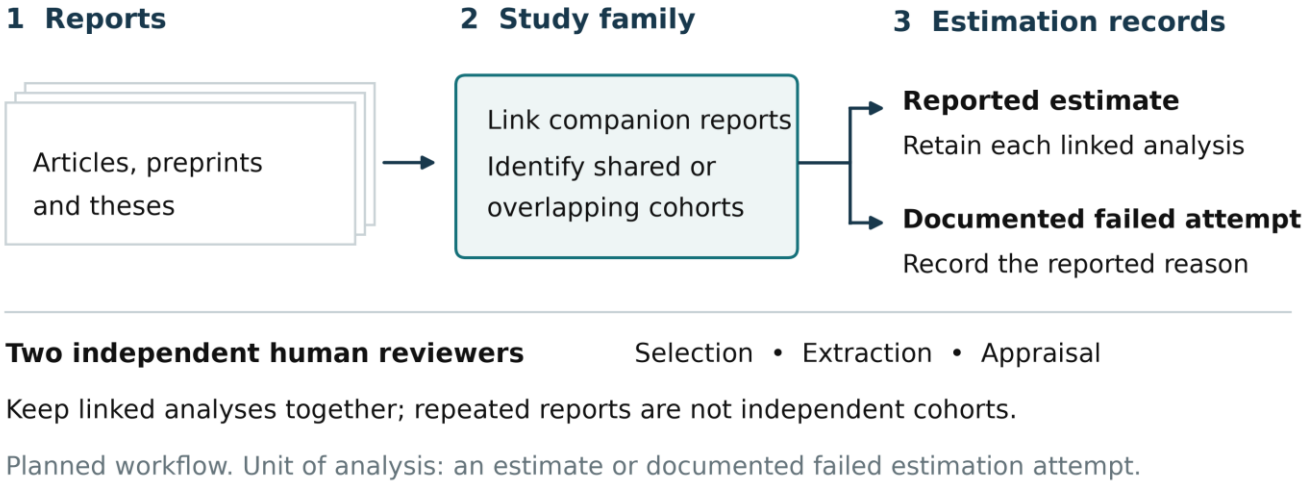

Figure 1. Planned evidence structure and independent review. Reports form study families; each estimate or documented failed attempt remains linked to its cohort. Repeated reports and analyses are not independent cohorts. This original conceptual diagram contains no observed counts.

2.2 Eligibility

Population: Participants must be younger than 18 at the baseline used for change analysis. Later reassessments crossing 18 remain eligible and will be flagged. Mixed-age cohorts require a separately extractable baseline-eligible estimate; mean age below 18 is insufficient. Cohorts mixing eligible and ineligible diagnoses require separable estimates.

Eligible conditions are autism, intellectual disability or global developmental delay, cerebral palsy, developmental coordination disorder, attention-deficit/hyperactivity disorder, developmental language disorder and specific learning disorder. Diagnosis and ascertainment will be recorded; both reviewers must agree on equivalence of older terminology. These conditions define the operational clinical scope, rather than a uniform diagnostic classification. Acquired brain injury and isolated later-acquired conditions are excluded. Developmental syndromes qualify when an eligible condition is documented.

Construct: Scores must measure attendance or involvement in home, school or community life. Child, caregiver or observer outcomes may qualify, but the anchor must express child or caregiver judgement of change meaningful for the child. Outcome reporter and anchor respondent will be distinguished. Generic quality of life, symptoms, motor capacity, activity competence, environmental accessibility and nonseparable daily-living totals are excluded from the primary construct.

Analysis: Original longitudinal analyses must derive, evaluate or explicitly attempt an estimate intended to interpret important change using an eligible anchor. Analyses nested within trials or observational cohorts may qualify. Anchor-based evaluation of an existing threshold is eligible; applying a published cutoff without evaluating it against an eligible anchor is not. Cross-sectional contrasts are excluded. Eligible longitudinal contrasts and unclear estimands remain separately labelled under Section 2.4.

Clinician-only anchors and related nonparticipation estimates encountered in otherwise relevant reports will be catalogued as context, not systematically reviewed.

Journal articles, public preprints and theses with adequate methods are eligible; related versions form one study family. Abstract-only or inaccessible reports remain unresolved leads unless sufficient information is obtained. No date or language exclusions are planned. Access and translation gaps will remain visible; resource-driven restrictions require documentation before implementation.

2.3 Candidate measures and construct mapping

Table 1 is an open retrieval and screening aid, not evidence that eligible estimates exist. Reviewers will check versions and scored content against primary descriptions and accessible manuals, resolving ambiguous mapping before inclusion. Public files will respect instrument-item rights.

Table 1 Candidate measures and screening rules

Candidate measure	Prespecified construct check
Participation and Environment Measure for Children and Youth (PEM-CY); Young Children's Participation and Environment Measure (YC-PEM)	Separate attendance or frequency from involvement. Environmental support and desire for change are contextual unless independently used as eligible change anchors.
Child and Adolescent Scale of Participation (CASP)	Verify the life situation; distinguish participation from independence or task competence.
Children's Assessment of Participation and Enjoyment (CAPE)	Diversity and frequency may represent attendance; enjoyment may represent involvement. Verify the analysed score.
Preferences for Activities of Children (PAC)	Preference alone is contextual; an anchor requires explicit assessment of meaningful change.
Assessment of Life Habits for children (LIFE-H)	Separate participation from difficulty, assistance and accomplishment. Mixed composites require a separable participation estimate.
Children Participation Questionnaire (CPQ)	Verify version and dimension; separate independence, satisfaction and environmental features from attendance or involvement.
Child Engagement in Daily Life (CEDL)	Separate family and recreation participation from self-care performance.
Assessment of Preschool Children's Participation (APCP)	Verify diversity or intensity and the anchor for important change; detectable change alone is insufficient.
School Function Assessment (SFA)	Conditional: map items and scores, including Part I, whose exclusive participation alignment has been questioned [10]. Task support and activity performance do not automatically qualify.
Canadian Occupational Performance Measure (COPM)	Require rated occupations and the analysed score to concern attendance or involvement. Generic performance or satisfaction scores remain contextual unless this link is demonstrated.

Mapping uses the family of participation-related constructs [5,6]. Official PEM-CY and YC-PEM descriptions distinguish participation and environment [15,16]; Resch informs COPM and SFA interpretation [10]. Newly identified measures will receive a dated mapping record under the same criteria.

2.4 Anchor taxonomy and estimands

An anchor supplies the external judgement used to interpret important change. Reviewers will record wording, options, respondent, timeframe and analysed contrast. Current satisfaction or importance alone is insufficient; anchor category does not determine estimand.

Table 2 Anchor categories

Anchor category	Rule for interpretation
Global or domain-specific change rating	Record recalled interval and distinguish minimal or substantial improvement, no change and deterioration.
Satisfaction or importance	Require an explicit link to important participation change; baseline importance or current satisfaction alone is insufficient.
Goal attainment	Require a participation goal and child or caregiver meaning; exclude circular reuse of the target outcome as its own anchor.
Expectation fulfilment	Record whether expectations preceded follow-up and whether fulfilment concerns participation change. Expectations alone are insufficient.
Other child or caregiver judgement	Preserve the definition and justify eligibility.

Methods determine four estimand classes: **A**, a rule classifying meaningful within-child change; **B**, mean within-child change in an anchor-defined group; **C**, a longitudinal between-group contrast; **D**, unclear. All require an eligible important-change analysis; classes B-D will not be treated as individual responder thresholds. Improvement and deterioration will be analysed separately, without assuming symmetry.

Estimate identifiers combine study family, measure version, participation dimension, outcome reporter, anchor respondent and category, estimand, direction and interval. Alternative analyses create linked estimates, not independent cohorts. A failed attempt requires documented intent to estimate and a reason estimation failed or was withheld; absence of evidence is not a failed attempt. Reported failed attempts cannot estimate the field-wide failure frequency because unpublished and unreported attempts are incompletely observed.

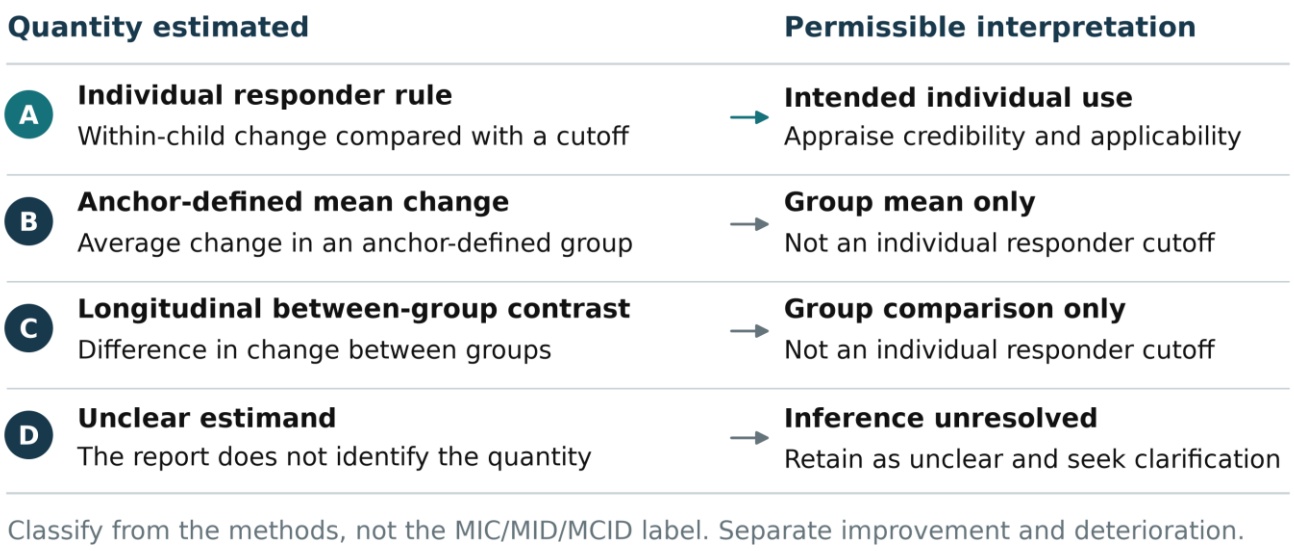

Figure 2. Estimand classification and permitted interpretation. Class A identifies intended individual use, not a validated cutoff. Classes B and C cannot establish individual thresholds; class D requires clarification. This original conceptual diagram applies the protocol's rules, informed by measurement principles [4].

2.5 Sources and search

Planned sources are PubMed, Ovid Embase, EBSCOhost CINAHL, Ovid APA PsycINFO, EBSCOhost ERIC and ProQuest Dissertations and Theses Global, subject to access. PubMed will be reported distinctly from MEDLINE. Platform changes and translated strategies will be recorded. Coverage extends from inception to the actual search date.

Strategies combine paediatric or eligible-condition terms, participation, and broad measurement or change terms. Reporter and anchor terms are not mandatory filters. Instrument-name searches, backward and forward citation searches, registries and public preprints will be logged separately. Acquired brain injury will be excluded during screening rather than by a negative search filter.

The working supplement contains six unexecuted draft strategies; their inclusion is not evidence of database access, syntax testing or completed search peer review. An information specialist will check vocabulary and syntax, test prespecified leads and document peer review using PRESS [17]. Strings, sources, interfaces, dates, coverage, restrictions, counts and raw exports will be retained for PRISMA-S reporting [13]. Searches will be updated before review submission. For each included version, a targeted search will combine instrument/version synonyms with reliability, measurement-error and responsiveness terms, without mandatory anchor, age or diagnosis filters. It will use the approved primary-source platforms, retain primary-search leads and citation routes, and apply eligibility during dual screening. Supplementary Methods M6 specifies population, version, reporter and property eligibility, compatibility recording, the PubMed template and platform-translation requirements. This bounded component will not expand if no eligible primary attempts are found.

2.6 Selection and report linking

Two human reviewers will independently screen titles and abstracts, then full texts. Either reviewer's inclusion or uncertainty advances a record. Calibration uses 25 records and five full texts spanning clear and borderline cases, repeated if important ambiguities persist. These are workflow quantities, not validation of reviewer reliability.

A screening tool with machine-learning prioritisation may order records. Every record, including low-priority records, will receive two human decisions; no automated exclusions or priority-based stopping rule will be used. The tool, version and actual use will be reported.

Auditable deduplication will retain source identifiers. Companion reports and publication versions will be linked to identify shared or overlapping cohorts. The fullest report supplies methodological details, supplemented by nonconflicting information; conflicts will be recorded and clarified.

Disagreements proceed from discussion to human adjudication. Reviewers who contributed to a study or have direct development or commercial interests in its instrument cannot make its final eligibility, extraction or credibility decisions; unconflicted reviewers are required. The adjudicator and any necessary alternate will be recorded before screening.

Full-text exclusions use one reason, in order: population or age; construct; design or change analysis; anchor; nonseparable estimate. Unavailable reports remain not retrieved or awaiting information rather than receiving an unsupported scientific exclusion.

2.7 Extraction

Both reviewers will extract independently after piloting three eligible reports, or all if fewer exist. Reconciliation will preserve original entries and decisions. Study-family identifiers will prevent duplicate counts.

Fields include sample, setting, diagnosis and ascertainment; baseline and follow-up age; language, version, score range and scored content; participation dimension and reporters; anchor wording and categories; interval and baseline dependence; reported terminology and estimand; estimation and validation methods; threshold, direction and uncertainty; total and anchor-group denominators; missingness and follow-up losses; failed-attempt reasons; funding and developer involvement.

Calculations require retained inputs, formulae and independent checking. Original scales and values will be preserved, with any reverse-coding transformation recorded. Missing data will not be imputed. Patient-level records will not be requested or reconstructed.

2.8 Credibility appraisal

Two reviewers will independently assess domains informed by Devji: respondent alignment, anchor relevance, association with target change, precision and whether the contrast supports the claimed importance [18]. Transition anchors additionally require scrutiny of recall and relationships with baseline, follow-up and change. Proxy adaptations and observer-outcome mismatches will be recorded.

Supplementary Methods M2–M5 operationalises each domain as limited, some or major concern, insufficient information, or not applicable, with observed evidence, source locations and reasons. Missing reporting is distinguished from an observed defect. Five labelled synthetic examples and independent pilot appraisal of three study families support calibration; no calibration has yet occurred. The independently worded rules are a review-specific adaptation, not a validated replacement instrument. Use of the original instrument will follow its permissions. No summed score or paper ranking will be calculated.

Correlation type, sign, score orientation, target quantity and confidence interval will be extracted. After checking expected direction, descriptive magnitude bands are below 0.30, 0.30 to below 0.50, and at least 0.50. Terwee discusses 0.30 as a minimum association for MIC estimation [4]; Devji uses at least 0.50 as one credibility consideration [18]. These bands supplement

domain judgement rather than exclude weak estimates or failed attempts. Unreported correlations remain unreported.

Precision will be interpreted from confidence intervals against an explicit scale-based interpretation, with estimation and anchor-group denominators. Separate fields record derivation, internal or external validation; cutoff selection and optimism; anchor prevalence; baseline selection and regression to the mean; missing follow-up; and selective or dependent analyses. Baseline-score stratification can create misleading baseline dependence [19]. Derivation-sample performance will not establish validation in new children.

Two reviewers will independently select, extract and appraise supporting measurement-property studies. Reliability and error will use the relevant COSMIN 2020 tool [20]. Responsiveness of child/proxy-reported scores will use the 2024 COSMIN guideline/manual version 2.0 and risk-of-bias checklist version 3, Box 10; use for observer/performance scores will be labelled an adaptation [21]. Comparison hypotheses will be recorded before numerical extraction. Matching version, construct, language, reporter, population, setting and interval will determine whether evidence is directly matched, related paediatric evidence or context only. The supplement gives the operational rules. This is selective use of COSMIN methods, not a complete instrument-selection review or a COSMIN grade for MIC. MIC will not be increased merely to exceed minimal detectable change.

2.9 Synthesis and evidence gaps

The catalogue, failed-attempt table and evidence-gap and credibility map will distinguish study families from estimates. Map cells will be organised by measure and participation dimension, stratified by reporter and estimand, and identify contributing families and appraisal concerns. Empty cells indicate no eligible evidence found by the documented search, not instrument failure.

Comparisons will preserve version, population, setting, language, direction and interval. Ranges will not imply interchangeable thresholds. Estimates from one cohort will remain linked; significance will not be vote-counted or a cutoff selected because it is favourable.

Meta-analysis is not planned. Pooling would require an amendment before calculation specifying compatible estimands and scales, uncertainty, cohort overlap and within-study dependence. Otherwise, tables and plots remain descriptive.

Sensitivity displays will distinguish child and caregiver anchors, reporter alignment, preprints and journal articles, cohorts crossing age 18, and association bands; these are not powered subgroup tests. Sparse or absent evidence will be reported through searches, exclusions, unresolved leads and gaps without relaxing scope or predicting yield.

Evidence sets will be defined before interpreting concordance by version/subscale, participation dimension, outcome reporter, anchor perspective, importance contrast, estimand, direction and interval. Language, diagnosis and setting form separate initial strata. Broader discussion requires a recorded justification without merging the underlying estimates.

Both reviewers will prepare a structured narrative for each set covering available cohorts and estimates, credibility, consistency, precision, directness/replication and missing evidence. Supplementary Methods M7 specifies the permitted conclusions: failed attempts alone yield no threshold; B/C evidence alone supports no individual rule; one derivation cohort establishes no independent replication; essential missing facts remain uncertainty. No numerical certainty score, formal GRADE category or transferred COSMIN property grade will be assigned.

2.10 Missing evidence and amendments

Unclear anchors, scored content, denominators and uncertainty will be logged. The team may seek author clarification using a standard request and one reminder approximately 14 days later, recording contacts and responses. Nonresponse will remain uncertainty.

Available protocols, theses, preprints and final reports will be compared for selective reporting and attempted analyses lacking estimates. Funnel plots and small-study-effect tests are not planned. Access failures, translation gaps and unresolved reports will remain explicit limitations. Amendments will preserve superseded text and actual dates.

3 Discussion

This review will distinguish evidence that a change matters from evidence supporting its use as an individual decision threshold. A credible estimate from one cohort may justify further validation without supporting transfer across versions, respondents, settings or intervals. Conversely, failure to estimate a threshold can identify a specific problem with the anchor, sample or analysis rather than establish that participation change is unimportant. Reporting these distinctions alongside gaps should make a sparse evidence base informative for study design. Interpretation will remain conditional on the retrieved

evidence: methodological credibility, independent replication and applicability are separate considerations, and neither this review nor an important-change estimate establishes treatment effectiveness.

4 Ethics and dissemination

4.1 Patient and public involvement

No patient or public involvement has occurred. A parent or caregiver adviser will be invited to assess anchor relevance and interpretive clarity. Actual involvement, accessibility arrangements and resulting changes—or lack of involvement—will be reported.

4.2 Ethics and dissemination

The review uses public aggregate reports without recruiting participants or collecting identifiable patient data. Institutional requirements will be checked if the design changes; no ethics approval or waiver is claimed.

This protocol is released as a versioned Zenodo preprint with its operational supplement and empty execution forms. Prospective registration is planned before formal screening, subject to eligibility and completion of required information; the identifier will be linked when assigned. A protocol journal submission will follow author-specific declarations and journal requirements. A completed review will be submitted only after the planned work is performed. Protocol, preprint and peer-reviewed article status will remain explicit. A plain-language summary will accompany the completed findings. Journal selection will follow scope and cost checks.

5 Declarations

5.1 Team and authorship

Koti Reddy Saripalli is lead and corresponding author and authorises this protocol release. Raghupathi Ramtenki and Srikanth Yadav Boini are the named independent reviewers; Saripalli confirms their acceptance. These are planned roles, not claims of completed screening or appraisal. The two displayed ORCID identifiers were checked against public records; no verified identifier is available for Boini. Review-specific coauthor affiliations, individual declarations and contribution/approval records remain to be completed for registration and journal submission. Unverified affiliations are omitted. Authorship requires substantive contribution, critical review, final approval and accountability; each author must approve the registry and journal records.

5.2 Funding

No cash grant supports this review. Bharath Healthcare Laboratories Private Limited provides staff time and administration. Database-access arrangements and publication-fee funding remain unconfirmed as of 18 September 2026.

5.3 Competing interests and intended use

Saripalli is founder and chairman of Bharath Healthcare Laboratories Private Limited, holds an equity interest, and is Chief Architect of PinnacleAI GPT-OS™. He is an inventor on filed patent applications, including Indian application 202541014547 concerning AbilityScore; according to his declaration, none is granted. The company is associated with Pinnacle Blooms Network. Collaborator declarations remain incomplete.

The review will inform anchor design for future company instrument-validation research, including AbilityScore; it does not validate that instrument. Company-linked and external evidence will receive identical eligibility and appraisal criteria. Relevant relationships will be disclosed and linked evidence assigned to unconflicted reviewers.

The review team controls interpretation. The two reviewers will maintain data and an audit trail subject to source rights. Bharath Healthcare Laboratories Private Limited has no veto over interpretation or publication.

5.4 AI assistance and data availability

AI tools, including ChatGPT/Codex, assisted drafting, exploratory retrieval, reference verification and document production. Human authors remain responsible for source checks, methods and claims. The completed review will report tools, available versions, tasks and verification; AI will not substitute for independent human review or authorship.

No completed review dataset exists. The package contains the operational methods manual, labelled synthetic training examples, predecessor comparison, draft searches, coding definitions, reporting and registration worksheets, and empty forms. The synthetic examples are not research findings. The scientific figures are original conceptual diagrams, not result visualisations. Permissible extraction data, logs, decisions, code and amendments will be deposited with version identifiers. Restricted articles, instrument items and personal correspondence require relevant rights before public release.

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