

**Instructions of
pediatric outcomes
assessment tool for
TRACK-TBI**

Pediatric Assessments

Tests are performed at 2 weeks, 3 months, 6 months and 12 months after TBI in the CA and CA + MRI cohort. (B) In the BA Cohort, only GOSE-Peds and GOSE are performed.

Age	Tests
0-2	<p>All visits: Vineland Adaptive Behavior Scale-II^(Parent)</p>
3-4	<p>All Visits: COAT^(Child) (only general orientation and memory, do not administer temporal orientation questions) GOSE-Peds^(Parent) (B) Vineland Adaptive Behavior Scale-II^(Parent) Health and Behavior Inventory (HBI)^(Parent)</p> <p>From 3 month visit onwards: Pediatric Quality of Life Inventory (PedsQL)^(Parent) (2-4 year old parent version)</p> <p>From 6 month visit onwards: Strengths and Difficulties Questionnaire (SDQ)^(Parent) (2-4 year old parent version) <i>NIH toolbox* is supplemental; see below</i></p>
5	<p>All Visits: COAT^(Child) (only general orientation and memory, do not administer temporal orientation questions) GOSE-Peds^(Parent) (B) Vineland Adaptive Behavior Scale-II^(Parent) Health and Behavior Inventory (HBI)^(Parent)</p> <p>From 3 month visit onwards: Pediatric Quality of Life Inventory (PedsQL)^(Parent) (5-7 year old parent version) Pediatric Quality of Life Inventory (PedsQL)^(Child) (5-7- year old young child version)</p> <p>From 6 month visit onwards: Strengths and Difficulties Questionnaire (SDQ)^(Parent) (4-10 year old parent version) <i>NIH toolbox* is supplemental; see below</i></p>
6-7	<p>All visits: COAT^(Child) (only general orientation and memory, do not administer temporal orientation questions) GOSE-Peds^(Parent) (B) PTBI* (only if face to face)^(Child) Vineland Adaptive Behavior Scale-II^(Parent) Health and Behavior Inventory (HBI)^(Parent)</p> <p>From 3 month visit onwards: Pediatric Quality of Life Inventory (PedsQL)^(Parent) (5-7 year old parent version) Pediatric Quality of Life Inventory (PedsQL)^(Child) (5-7- year old young child version)</p> <p>From 6 month visit onwards: Strengths and Difficulties Questionnaire (SDQ)^(Parent) (4-10 year old parent version) <i>NIH toolbox* is supplemental; see below</i></p>
8-10	<p>All visits: COAT^(Child) (administer full test) GOSE-Peds^(Parent) (B) PTBI* (only if face to face)^(Child) Vineland Adaptive Behavior Scale-II^(Parent) Health and Behavior Inventory (HBI)^(Parent) Health and Behavior Inventory (HBI)^(Child)</p>

	<p>From 3 month visit onwards: Pediatric Quality of Life Inventory (PedsQL)^(Parent) (8-12 year old parent version) Pediatric Quality of Life Inventory (PedsQL)^(Child) (8-12 year old child version)</p> <p>From 6 month visit onwards: Strengths and Difficulties Questionnaire (SDQ)^(Parent) (4-10 year old parent version) <i>NIH toolbox* is supplemental; see below</i></p>
11-15	<p>All visits: COAT^(Child) (administer full test) GOSE-Peds^(Parent) (B) PTBI* (only if face to face)^(Child) Vineland Adaptive Behavior Scale-II^(Parent) Health and Behavior Inventory (HBI)^(Parent) Health and Behavior Inventory (HBI)^(Child)</p> <p>From 3 month visit onwards: Pediatric Quality of Life Inventory (PedsQL)^(Parent) (8-12 year + 13-18 year old parent version) Pediatric Quality of Life Inventory (PedsQL)^(Child) (8-12 year + 13-18 year old child and teens version)</p> <p>From 6 month visit onwards: Strengths and Difficulties Questionnaire (SDQ)^(Parent) (11-17 year old parent version) Strengths and Difficulties Questionnaire (SDQ)^(Child) (11-17 year old child/self version) <i>NIH toolbox* is supplemental; see below</i></p>
15-16	<p>All visits: GOSE-Peds^(Parent) (B) PTBI* (only if face to face)^(Child) Vineland Adaptive Behavior Scale-II^(Parent) Health and Behavior Inventory (HBI)^(Parent) Health and Behavior Inventory (HBI)^(Child)</p> <p>From 3 month visit onwards: Pediatric Quality of Life Inventory (PedsQL)^(Parent) (12-18 year old parent version) Pediatric Quality of Life Inventory (PedsQL)^(Child) (13-18 year old teen version)</p> <p>From 6 month visit onwards: Strengths and Difficulties Questionnaire (SDQ)^(Parent) (11-17 year old parent version) Strengths and Difficulties Questionnaire (SDQ)^(Child) (11-17 year old child/self version) <i>NIH toolbox* is supplemental; see below</i></p>
17	Adult battery – see adult outcomes

*All tests can be administered either in person or via phone except PTBI and the NIH toolbox. These tests will be left out during the 3 month telephone follow-up assessment.

^(Parent) Tests are performed via parent

^(Child) Tests are performed via child

^(B) In the Brief Assessment Cohort, only GOSE-Peds and GOSE are performed

Supplemental NIH toolbox for children 3-16 could include:

EXECUTIVE FUNCTION

NIH Toolbox Flanker Inhibitory Control and Attention Test

NIH Toolbox Dimensional Change Card Sort Test

ATTENTION

NIH Toolbox Flanker Inhibitory Control and Attention Test

EPISODIC MEMORY

NIH Toolbox Picture Sequence Memory Test

NIH Toolbox Auditory Verbal Learning Test

LANGUAGE

NIH Toolbox Picture Vocabulary Test

NIH Toolbox Oral Reading Recognition Test

PROCESSING SPEED

NIH Toolbox Pattern Comparison Processing Speed Test

NIH Toolbox Oral Symbol Digit Test

WORKING MEMORY

NIH Toolbox List Sorting Working Memory Test

SCORES

NIH Toolbox Fluid Cognition Composite Score

NIH Toolbox Crystallized Cognition Composite Score

NIH Toolbox Cognitive Function Composite Score

NIH Toolbox Early Childhood Composite Score

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Instructions of pediatric outcomes assessment tool for TRACK-TBI:

Peds-QL:

Parents, children aged 8-12 and teens aged 13-18 are allowed to self administer the test after receiving instructions from the administrator. This is an option; you can also interview the subject if that is preferred.

Available tests:

- 2-4 year old parent version
- 5-7 year old parent version
- 5-7- year old young child version
- 8-12 year old parent version
- 8-12 year old child version
- 13-18 year old parent version
- 13-18 year old child and teens version

If interview is performed:

- Read the questions out loud.
- For the Young Child (aged 5-7) version questions need to be read word for word.
- At the beginning of each subscale repeat the recall interval instructions (whether you are discussing the last 7 days or the last month).
- When reading the items aloud, intonation should be kept neutral to avoid suggesting an answer.
- If a child has difficulty understanding the questions you may administer a test version for younger children (e.g. administer the Young Child (5-7) version to an 8 year old).

- The parent and child should complete the questions independent of each other. Discourage them from consulting each other during the completion of the questionnaires.
- When administering the test to the child the child should be facing away from the parent.
- If the subject had a question about what an item means or how they should answer, do not interpret the question for them. Instead repeat the question to them verbatim. Ask them to answer the way they think it should be answered. If they have trouble answering ask them to choose and answer option that comes closest to how they feel.

The option of not answering is available if they really do not know the answer.

If questions are self administered:

- Provide the subject with a pen(cil) and a solid writing surface.
- Remain nearby should questions or concerns arise.
- When the test is returned ensure all answers have been completed, verify no answer had more than one response. If errors are found ask the subject to correct them.
- Ask the subject whether they had any difficulty completing the questionnaire.

Example for test introduction of children:

The PedsQL™ asks you questions about how you feel and what you think about your health. It is not a test, and there are no right or wrong answers. It takes about 5 minutes to complete. If you have any questions, please let me know.

Example of test introduction of the parents:

*The PedsQL™ is a questionnaire that assesses health-related quality of life in children and adolescents. It contains questions about your child's physical, emotional, social, and school functioning **in the past one month** (or for the Acute version, **in the past 7 days**).*

*The PedsQL™ is brief and typically takes less than 5 minutes to complete. It is not a test, and there are no right or wrong answers. Please be sure to read the instructions carefully and choose the response that is the closest to how you truly feel. Please do not compare your answers with your child's responses. We are interested in your and your child's **individual** perspectives. However, feel free to discuss the questionnaire with your child **after** you have both completed it and returned it to me. If you have any questions, please let me know.*

(Source: Varni, 1998)

Strength and difficulty questionnaire (SDQ):

Self report is suitable for young people aged 11-16 yrs old depending on their level of literacy, this up to the judgment of the administrator.

Available tests:

- 2-4 year old parent version
- 4-10 year old parent version
- 11-17 year old parent version
- 11-17 year old child/self version

No further instructions available

(Source: youthinmind, 2012)

GOSE-E Peds:

Instructions are given per question

Question 1:

Eye movements are not reliable evidence of meaningful responsiveness

Question 2a:

For an older child:

Complete independence (and a “no” answer) should mean he/she can get washed, put on clean clothes without prompting, prepare food for themselves, deal with callers and minor domestic emergencies.

He/she should be able to carry out activities without needing prompting or reminding and should be able to be alone for an age appropriate time.

For young children:

He/she should be able to accomplish age appropriate developmental milestones without assistance.

Question 2b:

For a “no” answer they should be able to look after themselves at home for up to 8 hours during the day, though they need not actually look after themselves.

Question 3a:

This question consider shopping and travelling always in the context of age appropriate behavior.

Question 5a:

He/she might not have resumed all previous leisure activities, but should not be prevented from doing so by physical or mental impairment

Question 6a:

Typical post-traumatic personality changes: quick temper, irritability, aggressive acts, insensitivity to others, mood swings, depression and unreasonable or childish behavior that is not age appropriate.

Question 7a:

Typical problems: headaches, dizziness, tiredness, sensitivity to noise or light, slowness, memory failures, concentration problems etc.

(Source: QuesGen, 2014)

Vineland:

General instructions:

- The Vineland is an assessment of a person's daily functioning.
- The Vineland will take about 25 to 90 min to administer.
- The Vineland is done via interview, not with the subject itself but with someone who is familiar with the subject's behavior (third party method).
- The Vineland is administered via a "semi-structured interview". (page 19 in Vineland manual give a good example)
- For TRACK-TBI use the Chronological age of the subject (for instructions on how to calculate these see: Vineland manual (including pre-mature infants)). Please fill in calculation on cover of test booklet.
- The subject concerned should not be present during the interview with the third party.

During the intro emphasize the following:

- There are no "right" or "wrong" answers.
- You should describe what the subject *actually does*, not what he/she might be capable of.
- Each person is different; not everyone performs activities at the same age. It is okay to say he/she does not do something (yet).
- Some behaviors are needed more than others. Scores should reflect the frequency with which the individual performs the behavior when it is needed.

Determining the starting point:

- This should be chronological age (see page 13 of the Vineland manual for calculation explanation)

Scoring:

- “Don’t know” (DK) is a valid answer (after thorough questioning) if the responded does not know the frequency the subject performs and activity. A maximum of 3 x DK is allowed per sub domain.
- When starting the interview you start at the starting point determined by the subject’s chronological age.

You then need to determine whether this is the subject “Basal” point. The subject’s basal is the first 2 clusters of questions within a sub-domain that are scored 3 and 4 only.

If you start with the chronological age point and the subject scores below 3 then you should go a step back until the subject scores two consecutive clusters of questions with 3’s and 4’s. This is then considered the “basal” point. Everything before the “basal” point can be scored with a 4.

- All items from the “basal” point to the end of the sub-domain should be scored. For some ages it will be obvious some activities are not age appropriate. It is reasonable for the examiner to exercise clinical judgment and score those items 0.

However caution should be noted, scores should be done precisely and accurately.

Completing the interview:

- Verify “basal” has been established for each sub-domain.
- Ensure that all items from “basal” till end of each sub-domain are scored.
- Complete the “About the interview” page (Page 42 of the Vineland test and see page 42 of the Vineland manual for instructions).

(Source: Sparrow, Chicchetti and Balla, 2008)

COAT

Awaiting instructions

HBI

No instructions can be found

PTBI

Referring to PTBI manual and Gillian Hotz

References:

QuesGen (2014) *GOS-E P* [Online] Available at: <https://www.studydata.net/qgen/nav/YNav.php>

Accessed 22 September 2014

Sparrow, S., Chicchetti, D. and Balla, A. (2008) *Expanded interview form manual; Vineland II*, 2nd edition, Bloomington: Pearson

Varni, J. (1998) *PedsQL Administration Guideline* [Online] Available at:

<http://www.pedsql.org/pedsqadmin.html> Accessed 22 September 2014)

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