The OCEANIC study – Summary of measures used

Child related measures

PedsQL™ 4.0 (Pediatric Quality of Life Inventory) Generic Core Scales *(2-17 years)* and Infant Scales *(1-23 months)* – Acute Version measures HRQOL in children and adolescents aged 1 month to 17 years old. Both sets of instruments have good validity and reliability, have been widely used, [1-8] and can be completed in 5-7 minutes.[8-11] The instruments can discriminate between healthy children and those with a wide range of acute and chronic health conditions.

PedsQL™ Multi-dimensional Fatigue Scale *(2-17 years)* – Acute Version [12] is an 18-item scale that encompasses three domains: (1) General Fatigue, (2) Sleep/Rest Fatigue and (3) Cognitive Fatigue. The Multidimensional Fatigue Scale comprises parallel child self-report and parent proxy-report formats. Items for each of the forms are essentially identical, differing in developmentally appropriate language, or first or third person tense.

PedsQL™ Pediatric Pain Questionnaire *(5-17 years)* is a generic symptom-specific instrument to measure pain in patients with acute and chronic health conditions. We will use question #1 and #2, which asks participants capable of self-reporting to identify a point on a 100 mm line that best shows the worst pain the child experienced ‘now’ and ‘in the past week’. Anchors include “no hurting, no discomfort, or no pain” and “hurting a whole lot, very uncomfortable, severe pain”. A parent report version will be used for child participants that are unable to self-report.

Functional Status Scale (FSS) ***(1 month-17 years)*** is a valid and reliable assessment method to quantify functional status.[13 14] The FSS includes 6 domains: mental status, sensory functioning, communication, motor function, feeding, and respiratory. The FSS is amenable to studies of this nature due to ease of administration, granularity, and objectivity of assessment compared to other available methods and has been used in other outcome studies.[13 15]

Pediatric Cerebral Performance Category (PCPC) and the **Pediatric Overall Performance Category (POPC)** ***(1 month – 17 years)*** quantify short-term cognitive impairments and functional morbidity.[16 17] The POPC scale is dependent on the PCPC scale, as the PCPC status is included in POPC. Scores range from 1 to 6 for both scales with 1: good, 2: mild disability, and 6: brain death. Studies of patients with scores of 1–4 at PICU discharge, hospital discharge, and one- and six-month follow-up show association with the Stanford Binet Intelligence Quotient, Bayley scales, and Vineland Adaptive Behaviour Scale. [16-19]

Strengths and Difficulties Questionnaire (**SDQ**) ***(2-17 years)*** [20 21] is a behavioural screening questionnaire used to evaluate emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems, and prosocial behaviour. The SDQ quantifies low, medium, and high risk of emotional, behavioural, hyperactivity concentration disorders, or any disorder.

Child Revised Impact of Events Scale (CRIES-8) ***(7-17 years)*** is an eight-item screen for post-traumatic stress symptoms in children aged between 7 and 18 years, with established reliability and validity.[22] It has been used previously in the PICU population.[23] A cut-off score of 17 or greater has been found to classify correctly over 80% of children with a diagnosis of post-traumatic stress disorder.[24]

Children's Hope Scale (CHS) ***(8-17 years)*** [25] is a brief, six-item self-report measure of children's perceptions that their goals can be met. It has been validated for use in children and young people aged 8-17 years consisting of both healthy populations and children with a range of physical illnesses. Internal consistency estimates (alpha) for the samples ranged from 0.72 to 0.86. Test-retest reliability estimates (over a one-month interval) ranged from 0.71 to 0.73 [25].

Parent related measures

PedsQL™ Family Impact Module (FIM) Version 2.0 measures the impact of pediatric health conditions on family functioning [26]. It is completed by the parents and includes eight dimensions (physical functioning; emotional functioning; social functioning; cognitive functioning; communication; worry; daily activities; family relationships).

State-Trait Anxiety Inventory 6 (STAI-6) [27] is a self-reported questionnaire that assesses symptoms of anxiety. It is a short version of the Spielberger State Anxiety Scale (SSA), with a cut-off point at 1 SD above the mean to indicate clinically relevant symptoms[27].

Patient Health Questionnaire-4 (PHQ-4) [28] is a 4 item inventory rated on a 4 point Likert-type scale. Its purpose is to allow for very brief and accurate measurement of depression and anxiety. PHQ–4 scores are strongly associated with decrements in multiple domains of functional impairment; the anxiety and depression subscales make unique overall contributions to the PHQ–4, both in terms of factorial and criterion validity; and perhaps most importantly: the results indicate that anxiety has a substantial independent effect on functioning, and even more so when comorbid with depression.

The Post Traumatic Stress Disorder (PTSD) Checklist for DSM-5 (PCL-5) is a 20-item self-report measure that assesses the presence and severity of PTSD symptoms [29]. Items on the PCL-5 correspond with DSM-5 criteria for PTSD. The PCL-5 can be used to quantify and monitor symptoms over time, to screen individuals for PTSD, and to assist in making a provisional or temporary diagnosis of PTSD. The PCL-5 is a psychometrically sound measure of DSM-5 PTSD. It is valid and reliable, useful in quantifying PTSD symptom severity, and sensitive to change over time [30 31].

Sibling related measures

The **PedsQL™ 4.0, SDQ** and **Children's Hope Scale** (as outlined in the Child related measures section above) will also be administered to sibling participants.

Multidimensional Assessment of Caring Activities (MACA-YC18) ***(8-17 years)*** [32] is an 18-item self-report measure that can be used to provide an index of the total amount of caring activity undertaken by the young person, as well as six subscale scores for domestic tasks, household management, personal care, emotional care, sibling care, and financial/practical care. The MACA-YC18 was designed as a short, easy to use, psychometric measure able to provide an index of the extent of caring activities that the young person is currently engaged in. Higher scores indicate greater levels of caring activity.[32 33]

Positive and Negative Outcomes of Caring (PANOC-YC20) ***(8-17 years)*** [32] a self-report measure that can be used to provide an index of positive and negative outcomes of caring. The PANOC-YC20 consists of two 10-item subscales: (1) positive responses, and (2) negative responses, which collectively assess the subjective cognitive and emotional impact of caring in young people with higher scores indicating greater positive and negative responses, respectively.

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