

Quality of Life after Brain Injury in Children and Adolescents (QOLIBRI-KID/ADO) – The First Disease-Specific Self-Report Measure after Traumatic Brain Injury

Online Supplement S1— QOLIBRI-KID/ADO item pool generation and item reduction

In the first step, an item pool was compiled based on results obtained from focus group interviews with children and adolescents after TBI. For details, see Krenz et al. (2021) [1]. The item number was reduced based on relevance of content, understandability, and appropriateness of item wording. Wording and content were made comparable for the two separate age groups (8–12 years and 13–17 years).

In a next step, five national and international experts (items were translated into English following a linguistic validation procedure [2]) rated the items with respect to the above criteria, resulting in adding and exclusion of items.

Additional items were added to the item pool following a literature search for instruments related to QoL, HRQoL, and/or TBI. Five national panels of experts (Delphi panels) then determined whether the new items included an additional aspect of HRQoL after TBI and what items ultimately to keep and which to add. In Delphi panels [3], items were rated by the experts according to importance, understandability, relevance of content, appropriateness of item wording, and applicability per age group. Items with an average agreement of at least 66%—weighted with respect to the number of participants per Delphi panel—were retained.

Finally, eight children and adolescents without TBI and six after TBI participated in a cognitive debriefing procedure [2,4]. All instructions, items, and response options were investigated across the age groups. The results showed that the current wording of the items and the response categories were understandable and appropriate for each age group. Smiley symbols clarified the response categories in the younger group.

Based on this procedure, items were again revised, and questionnaire versions with reduced item numbers were established for administration in the study reported here. These procedures resulted in an 83-item and an 87-item version, which were answered by the children and adolescents, respectively. Before psychometric reduction of items, they were analyzed in terms of their theoretical congruence with the assumed structure of the scale as derived from the QOLIBRI adult version. Items had to be present in both age groups and had to be associated with following dimensions according to expert rating and the underlying measurement model of the adult QOLIBRI version [4,5]: “Cognition”, “Self”, “Daily Life and Autonomy”, and “Social Relationships”. These should be rated using satisfaction judgments, whereas items for “Emotions” and “Physical Problems” should be evaluated in terms of feeling bothered. Forty-three items matched these criteria and were thus included in the psychometric analyses. For more details, see Figure S1.

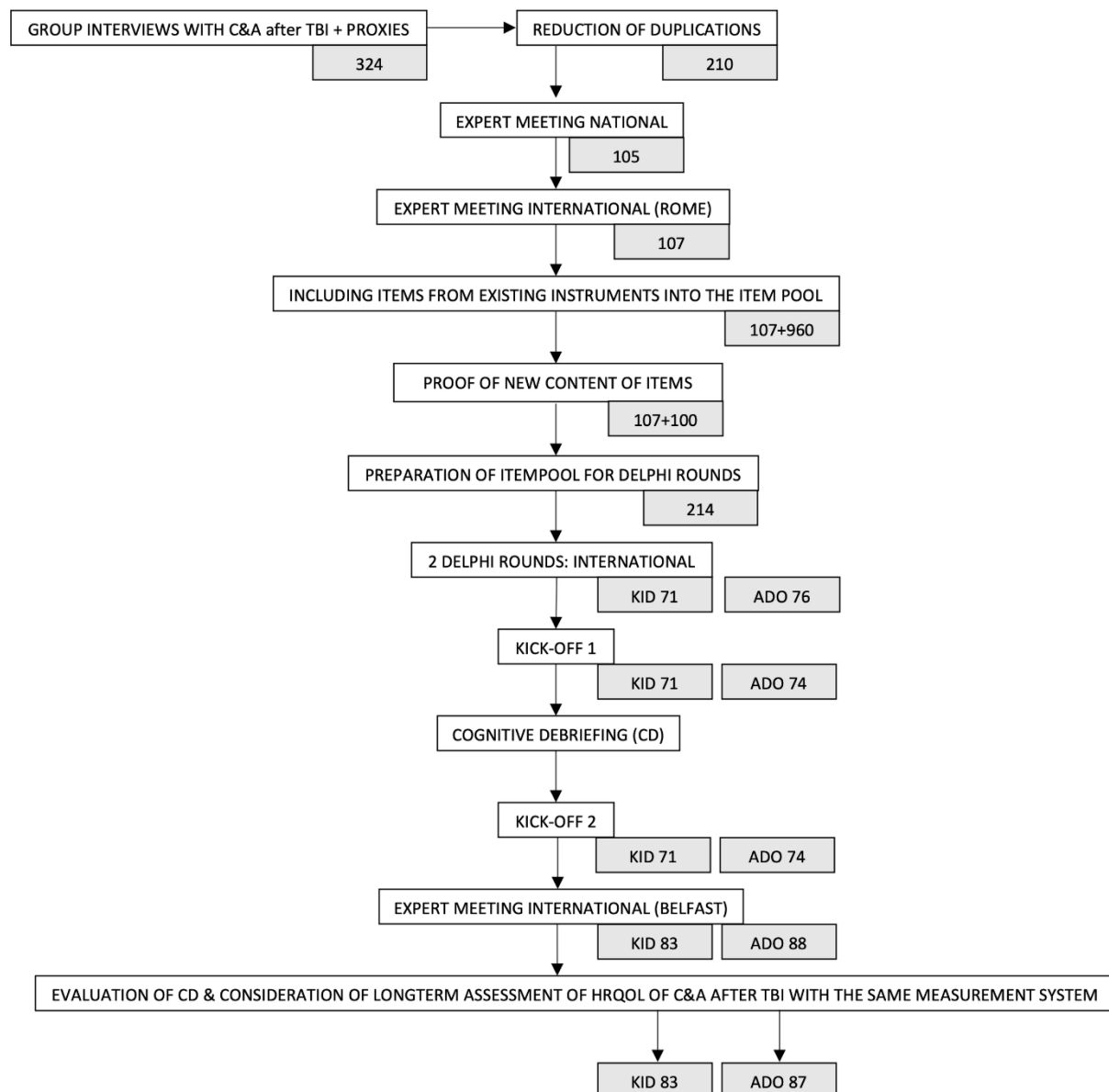


Figure S1. Process of item generation

Note: C&A = children and adolescents; TBI = traumatic brain injury.

* See acknowledgments for the names of the contributing experts.

¹ Adaptation of items from generic HRQoL instruments and other health-related instruments:

Caregivers Quality of Life Index—Cancer (CQOLC) [6]; Cerebral Palsy Quality of Life (CP QOL) [7]; Child Health Questionnaire (CHQ) [8]; Children's Health Rating Scale Items (CHRS) [9]; Health Utility Index (HUI) Mark 3 [10]; DISABKIDS [11]; Generic Children's Quality of Life Measure (GCQ) [12]; KIDSCREEN-27 [13]; KINDL [14]; PedsQL [15]; PROMIS Neuro-QOL Item Bank [16]; TNO/AZL Adult Quality Of Life (TAAQOL) [17]; Quality of Life in Epilepsy Inventory for Adolescents (QOLIE-AD-48) [18]; Quality of Life Questionnaire (17D) [19]; QOLIBRI [4,5]; Vecu et Sante Percue de l'Adolescent (VSP-A) [20].

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