

Outcome Measure	Paediatrics Care and Needs Scale (PCANS)
Sensitivity to Change	Yes
Population	Paediatrics
Domain	Social Role Participation & Competence
Type of Measure	Parent report
ICF-Code/s	d4, d5, d6, d9
Description	<p>The Paediatrics Care and Needs Scale – 2 (PCANS – 2) measures the type, extent and intensity of support needs for young people who have acquired brain injury. It is designed for young people (aged 5 to 15 years) at any stage in the recovery process, including inpatient rehabilitation in the early stages post-onset, as well as community living many years post-onset.</p> <p>The <u>CANS</u> has been designed for people aged 16 years and older. In special circumstances where a young person aged 16 years or older experiences profound disability the PCANS-2 may be more appropriate than the CANS, because it may be advantageous to have the detailed information on all 105 PCANS items, rather than the more abbreviated CANS.</p> <p>The PCANS-2 contains 105 items covering the following 13 domains:</p> <ul style="list-style-type: none"> (i) high level needs; (ii) personal hygiene; (iii) bathing/dressing; (iv) food preparation; (v) shopping; (vi) home activities; (vii) health, safety and medication use; (viii) money management; (ix) everyday devices; (x) transport and outdoor surfaces; (xi) interpersonal relationships; (xii) leisure, recreation and play; (xiii) school. <p>There are four forms of the PCANS-2 corresponding to different age groups (A: 5-7 years; B: 8-11 years; C: 12-14 years; D: 15 years). Each form contains the same set of items, but the number of items administered differs among forms, depending on the young person's age. More specifically, normative data (see Soo et al. 2010b) were used to classify each of the PCANS-2 items into one of three levels, according to the young person's age band:</p> <ul style="list-style-type: none"> (1) independence is expected (IND), (2) independence is emerging (EM), (3) independence is not expected (NE). <p>For each of the four forms, only those items for which independence is</p>

	<p>expected (IND) or emerging (EM) are administered.</p> <p>Accordingly:</p> <p>Form A (5-7 years): 85/105 items are administered Form B (8-11 years): 92/105 items are administered Form C (12-14 years): 102/105 items are administered Form D (15 years): all 105 items are administered</p> <p>For most items, two responses are recorded: (i) the extent of Physical Assistance (PA) supports required and (ii) the extent of Supervision (S) supports required. Both Physical Assistance and Supervision supports are rated on a 3-point scale:</p> <p>0 = independent 1 = some supports 2 = a lot of supports</p>
<p>Properties</p>	<p>OVERVIEW</p> <p>The Paediatric Care and Needs Scale-2 (PCANS-2) is a scale that assesses support needs following childhood acquired brain injury (ABI). It yields three measures of support: overall, extent and intensity. The developmental process of the PCANS is described and concurrent and construct validity examined.</p> <p>ADMINISTRATION, RECORDING, SCORING AND PROCEDURES</p> <p><u>PART 1: Important information about administering the PCANS-2.</u></p> <p>The PCANS-2 is administered in an interview format with a respondent (usually the parent) who has current and detailed knowledge of the child's functioning in all 13 Domains sampled by the PCANS-2. Administration generally takes approximately 30 minutes. On occasion, some items may prompt a respondent to talk about other issues related to the particular item and when this occurs administration time may be increased. Sometimes respondents need to be redirected back to the items. With a single exception¹, only those items for which independence is expected (IND) or emerging (EM) are administered. As noted this corresponds to 85 items for Form A (5-7 years), 92 items for Form B (8-11 years), 102 items for Form C (12-14 years) and all 105 items for Form D (15 years). The interviewer should ensure that the correct version of the PCANS-2 is being used each time it is administered, that is, version A for ages 5-7, version B for ages 8-11, version C for ages 12-14, and version D for 15 year olds.</p> <p>Health professionals administering the PCANS-2 should use a guided interview approach, asking the respondent each of the relevant items from the PCANS-2. In most circumstances, the respondent's response is recorded without amendment. It is recognised, however, that there may</p>

be special circumstances when the interviewing health professional has detailed knowledge of the child's functioning over the preceding month that suggests a different response from that given by the respondent. In such a situation, the interviewer may use their clinical knowledge of the child to allocate the score which best reflects the child's current situation, even if it disagrees with the respondent's answer. In amending a respondent's response, it is important that (i) there are solid grounds on which such a change in response is made, and (ii) the interviewer provides substantiation for recording a response that differs from that which the respondent provided. Explanatory comments should be noted in the "Comments" section of the Record Form when the interviewer has allocated a different score to that of the respondent.

Administration Procedures

Coding of Independence, Emerging Skill, or Not Expected for each activity item: Each activity item is coded "IND" = independent, "EM"= emerging skill, or "NE"= not expected. These codes have been derived from the normative data, and provide an indication as to whether the child is expected to have mastered that activity based on his/her age. The interviewer should only ask the respondent about those activity items labelled "IND" and "EM". For example, for a child aged 6 years (PCANS-2 form A), items 9 to 14 in Domain II (Personal Hygiene) will be administered but item 15 will be omitted because it is NE (not expected). For each item responses are recorded numerically in the two central columns of the recording form for Physical Assistance (PA) and Supervision (S). Items are rated with a 3-point scale:

0 = independent
1 = some supports
2 = a lot of supports

Exceptions: There are three exceptions to this recording format:

1) Three items from Domain I (High Level Needs): item 1 (tracheostomy management), item 2 (nasogastric / PEG feeding), and item 3 (bed mobility), use a 2-point (rather than the 3-point) response format for Physical Assistance (PA) and Supervision (S). Thus items 1, 2 and 3 are scored as follows:

0 = no support required; OR
2 = supports required

The reason for this dichotomous response format is the nature of these items (tracheostomy management, nasogastric / PEG feedings and bed mobility) which, by definition, require a lot of supports.

2) The 13 items (72-84) in Domain XI (Interpersonal Relationships) are not scored for Physical Assistance due to the inherent nature of these items. Thus scores are recorded only for Supervision supports. On rare occasions a child may require physical intervention with respect to challenging interpersonal behaviours. In this case, for example where a child may need restraint when they punch or kick another person, scoring for that behaviour occurs in item 5 (Harmful Behaviours) in Domain 1 (High Level Needs).

3) Item 42, “Independently seeking adult support and guidance when needed” is not scored for Physical Assistance. Due to the inherent nature of this item it is not appropriate to score the item for Physical Assistance. Accordingly each item (except items 42 and items 72-84 as explained above) is scored for both Physical Assistance (PA) AND Supervision (S).

Physical Assistance (PA): Support considered Physical Assistance includes another person physically assisting with or performing an activity for the child. This includes a person performing the activity entirely or in part for the child, assisting physically with set-up for the activity, and/or physically assisting while the child does the activity. A response indicating that a child requires physical assistance for an item may be due to any number of reasons. If a child needs another person to assist with the item then the appropriate score should be recorded regardless of the reason that the physical assistance is required. For example, another person may have to physically assist with item 24 “Preparing simple snacks” because one child may have physical disability and so requires physical assistance to make a snack, whereas another child may require physical assistance to make a snack because he/she has cognitive or behavioural difficulties resulting in him/her forgetting appropriate sequencing.

Supervision (S): Support considered Supervision includes another person supervising or observing while the child does the activity, or providing reminders, encouragement or verbal prompts while the child performs the activity. The same approach should be taken with scoring Supervision as for scoring PA for each item. That is, if supervision is required it may be due to varying reasons. The cause may be due to physical difficulties and/or cognitive or behavioural reasons.

A note on equipment: If the child uses any equipment to perform an activity that does not necessarily indicate that they need support for that activity. The PCANS-2 score should reflect support, either physical and/or

supervision, which is provided by another person. If a child uses a piece of adaptive equipment and is able to perform the task independently, he/she would not be considered to need support. However, if the child uses adaptive equipment but also needs supervision and/or physical assistance to complete the task then that needs to be reflected in the scoring.

Other influences on scores: The PCANS-2 is rated according to current functioning of the child as a whole, this includes the way in which the child functions in the context of a pre-existing or co-morbid condition. It is recognised that in some situations there are influences on a child's score other than the difficulties arising from their ABI. Factors vary but could include pre-existing conditions (e.g. developmental delay, mental health problems, learning difficulties, previous injuries), cultural beliefs or habits (e.g. eating with the hands), non-ABI factors occurring concurrently or since the ABI (e.g. spinal cord injury, multiple fractures). To indicate when such factors do influence the score there is a column on the right of the scoring area which is to be used in these instances. The following key is to be used:

C = cultural beliefs or habits

N = non-ABI factors such as fractures, spinal cord injury occurring concurrently to the ABI

Pre = factors existing prior to the ABI including health, medical, learning or developmental problems

O = other influences for example but not restricted to medical conditions occurring since the ABI, change in family circumstances.

For any item where another factor influences the score the interviewer must write the appropriate letter in the "Other influences" column and additionally write an explanation of the factor on the front page of the score record form.

A note on administering the PCANS--2 with children 2 with high care needs high care needs high care needs:

It is recognised that for some children who have global and profound disability it may be insensitive to ask all of the applicable items in the PCANS-2.

A guide for the situation where this procedure may be applicable is children who score 2 for Physical Assistance in the following:

- i) items 1, 2 or 3
- ii) and/or item 6 (Communicating basic needs due to language impairments)

- iii) and/or item 7 (Eating)
- iv) and/or item 8 (Transfers/indoor mobility).

In this special situation the interviewer may choose not to administer all the items of the PCANS-2, BUT it is vital that all IND and EM items are still scored. A comment should be made in the “Comments” section that the score was deemed by the scorer. Care should be taken to ensure that all items are given due consideration for the particular person being assessed.

A note on administering the PCANS--2 with anyone 16 years and older: as indicated on page 7 of this manual the PCANS-2 may be used for a person aged 16 years and older who has profound disability where it may be advantageous to have the detailed information on all 105 PCANS-2 items rather than the more abbreviated CANS. By the same token the CANS may none-the-less be appropriate for profoundly disabled young people. In the case where the PCANS-2 is administered with young people aged 16 years or older:

- 1) Form D should be used for all those aged 15 years and over regardless of their level of functioning
- 2) Note that there is no normative data for those aged 16 years and over
- 3) There is no normative data for those aged 16 years and older hence no “Summary Score Form” is available.
- 4) It is expected that adults in the general population would score as independent on the PCANS-2 therefore this level of function should be used as a guide in interpretation in this special circumstance.

Scoring Instructions

After administering the PCANS-2 the scores then need to be processed in order to calculate domain and summary scores. This processing is done on the PCANS-2 Score record Form, on the appropriate Scoring Work Sheet attached to each Score Record Form and on the Summary Score Form appropriate to the child’s chronological age. Note that while the Score Record Forms are in age bands (A-D), there are 11 Summary Score Forms, one for each chronological age (5 - 15 years inclusive). A worked example appears on pages 19-20 of this manual. The Summary Score Forms are in this manual following each appropriate Score Record Form. Hence Summary Score Forms for ages 5, 6 and 7 follow Score Record Form A; for ages 8, 9, 10 and 11 follow Score Record Form B; for ages 12, 13 and 14 follow Score Record Form C; and for age 15 follows Score Record Form D. All relevant items to the child’s age band (i.e. those classified as IND or EM) are scored. All items are scored 0 (independent), 1 (some physical

assistance/supervision), 2 (a lot of physical assistance/supervision) for Physical Assistance and Supervision, with three exceptions (High level needs items 1, 2 and 3, Interpersonal Relationships items 72 - 84, and item 42). A score should be recorded in every allocated space on the Record Form.

Steps in the scoring process:

For the purposes of scoring you will need to have the (i) Score Record Form, (ii) the Scoring Work Sheet, and the (iii) Summary Score Form for the child's age.

Step 1: On the Score Record Form calculate the "TOTAL RAW SCORE" for PA and S in each domain by adding the raw score for each item in the Domain.

Step 2: Transfer the TOTAL RAW SCORE for PA and S in each domain from the Score Record Form to column 1 of the Scoring Work Sheet (attached to the appropriate Record Score Form A-D).

Step 3: Check the Score Record Form to ensure the number of items administered in each domain concurs with the number in column 2 (Number of applicable items) on the Scoring Work Sheet. This should only vary for Domain II Personal Hygiene because of item 15 "Period management/shaving". If the number of items administered in any domain varied from the number in column 2 (i.e., the number of applicable items) you should record the actual number of items administered in column 3 on the Scoring Work Sheet. In the event that a score for an item is missing, care must be taken to record in column 3 of the Scoring Work Sheet the correct number of items actually administered (hence scored). For example, if the score for item 41 (Washing up dishes) is missing, the following steps are taken: Item 41 comes from Domain 6 Home activities which contains 6 items. For a 5 year old child all 6 of these items are administered, being the IND and EM items. But in the case where only 5 of the 6 items have a score recorded, the interviewer must record in column 3 that 5 items were administered. In this case in Step 4 (below) the sum of the 5 scored items in that Domain is divided by the number of items actually scored, rather than the number of items contained in the domain (in this case 5, rather than 6).

Step 4: On the Scoring Work Sheet transfer the raw score from column 1 and the number of items actually administered (from column 2 and/or 3) to column 4. This is recorded as a fraction (for example $\frac{5}{8}$ which means a raw score for that Domain of 5 for the 8 items administered).

Step 5: Calculate this fraction correct to two decimal places and record that in column 5 (Mean score) for each domain. For example $5 \div 8 = 0.63$.

Step 6: When all the mean scores have been calculated for each domain

for PA and S add the means for domains I to XIII. This score then becomes the INTENSITY of support needs score (marked on the Scoring Work Sheet as score “A” for Physical Assistance and score “C” for Supervision). The range of Intensity of support needs for Physical Assistance Score (score “A”) must be 0-24, and the range of Intensity of support needs for Supervision Score (score “C”) must be 0-26.

Step 7: Calculate the EXTENT of support needs score by dividing the INTENSITY score (A or C) by the number of domains scored. The number of Domains scored will always be 12 for Physical Assistance and 13 for Supervision. Thus the Extent of Support Needs for Physical Assistance score will be score A divided by 12, and is indicated on the Scoring Work Sheet as score “B”. The Extent of Support Needs score for Supervision score will be score C divided by 13 and is indicated on the Scoring Work Sheet as score “D”. The range of each of the Extent of Support Needs for Physical Assistance Score (score “B”) and of the Extent of Support Needs for Supervision Score (score “D”) will be 0 - 2.

Step 8: Calculate the OVERALL INTENSITY of support needs for Physical Assistance and Supervision (score “E”) by adding Intensity of support needs for Physical Assistance (score A) and the Intensity of support needs for Supervision (score “C”). The range of score “E” is 0-50.

Step 9: Calculate the OVERALL EXTENT of support needs for Physical Assistance and Supervision (score “F”) by adding the Extent of Support Needs for Physical Assistance score (“B”) and the Extent of Support Needs for Supervision score (“D”) and divide the sum by 2. The range of score “F” is 0 – 2.

Step 10: From the Scoring Work Sheet transcribe the score references A, B, C, D, E and F that have been calculated to the “Summary Score Interpretation” table on the appropriate Summary Score Form for the child’s age (note that there are 11 separate Summary Score Forms, one for each age from 5 through to 15 years).

Step 11: Transcribe the Domain Mean Score for PA and S of each Domain from the Scoring Work Sheet to the “Domain Score Interpretation” table on the Summary Score Form.

EXTENT of support needs scores (scores B, D and F) indicate how much support the child needs based on the metric used where 0 = independent, 1 = some supports needed, and 2 = a lot of supports needed.

INTENSITY of support needs scores (scores A, C and E) indicate scope and breadth of support needed across all the child’s day-to-day activities. This takes into account the extent and the number and types or varieties of support required.

PSYCHOMETRIC PROPERTIES OF THE PCANS

Validating the PCANS

Soo, Tate, Williams, Waddingham and Waugh (2008) conducted a validation study of the PCANS in a sample of 32 children aged between 5 and 18 years recruited from the Brain Injury Rehabilitation Programmes of Sydney Children's Hospital (SCH, n=8) and the Children's Hospital at Westmead (CHW, n=24), Sydney, Australia.

Participants were caregivers of children who satisfied the following criteria: (1) a history of an ABI (e.g. encephalitis, stroke or hypoxia) or TBI where there was head trauma and loss of or altered consciousness as defined by Glasgow Coma Score (GCS), post-traumatic amnesia (PTA) or intra-cranial abnormalities on brain scan; (2) aged between 5–18 years at time of the interview; and (3) time post-discharge from hospital greater than 6 months.

Exclusion criteria were: (1) caregiver non-fluency in English and (2) child history of psychiatric illness, developmental disability or pre-injury neurological disorder.

- (1) The PCANS was validated against the following standardised questionnaires: (1) Vineland Adaptive Behaviour Scales (VABS; Sparrow et al. 1984);
- (2) Functional Independence Measure for Children (Wee-FIM; Braun et al. 1991);
- (3) King's Outcome Scale for Childhood Head Injury (KOSCHI; Crouchman et al. 2001);
- (4) Child Behaviour Checklist (CBCL; Achenbach et al. 2001). NOTE that these data were collected on the original PCANS, although we believe that they will be applicable in general terms to the slightly amended PCANS-2.

Median age at onset was 5.3 years and time post-onset was 60.4 months. The majority of the participants had sustained a TBI (n=84%). According to GSC score, where this information was available, the majority of injuries in the sample were severe.

Evidence was found for concurrent validity. All correlation coefficients for KOSCHI and VABS measures with PCANS support extent and intensity scores were statistically significant and moderate to strong ($r_s = -0.57$ to -

0.77, $p < 0.01$). Similarly, significant correlation coefficients of moderate to strong magnitude were found between Wee-FIM measures and the PCANS support intensity score ($r_s = -0.46$ to -0.69 , $p < 0.01$), with the one exception (Wee-FIM self-care measure at $r_s = -0.38$). Correlation coefficients for Wee-FIM measures with PCANS overall support and support extent were more variable ranging from $r_s = -0.23$ to -0.63 , with the lowest coefficients found for Wee-FIM against PCANS overall support items ($r_s = -0.23$ to $r_s = -0.32$).

Convergent validity: Correlation coefficients for the four domains of the PCANS against the VABS and Wee-FIM measures are displayed in Table 3. In terms of convergent validity, statistically significant correlation coefficients which were of moderate to strong magnitude were found between the following: VABS daily living skills and PCANS ADL items ($r_s = -0.71$, $p < 0.01$), VABS daily living skills and PCANS IADL items ($r_s = -0.43$, $p < 0.05$), VABS socialisation and PCANS psychosocial items ($r_s = -0.64$, $p < 0.01$), and VABS communication and PCANS psychosocial items ($r_s = -0.48$, $p < 0.05$). Moderate to strong and significant correlations were also found between Wee-FIM self-care and PCANS ADL items ($r_s = -0.64$, $p < 0.01$) and between Wee-FIM mobility and PCANS ADL items ($r_s = -0.63$, $p < 0.01$).

Divergent validity: Low and non-significant correlation coefficients between PCANS domains and unrelated constructs were found providing support for divergent validity (Table 3). These include coefficients for Wee-FIM self-care with the PCANS IADL items ($r_s = -0.11$) and Wee-FIM self-care with PCANS psychosocial items ($r_s = -0.29$). Interestingly, a number of significant correlation coefficients of moderate to strong magnitude were found between VABS daily living and socialisation scores and PCANS domains. This is somewhat unexpected given these VABS domains are not directly related to a number of these PCANS domains; for example, VABS socialisation and PCANS ADL items ($r_s = 0.59$, $p < 0.01$).

Discriminant validity: PCANS support extent and intensity scores were able to distinguish between sub-groups dichotomised by adaptive functioning and overall outcome. Table 4 presents data comparing PCANS scores between the dichotomised VABS and KOSCHI data. Lower scores on the PCANS represents lower support needs. Results of Mann-Whitney U tests indicated that compared to children with low functioning scores on the VABS ABC, those with high functioning scores had significantly lower PCANS extent and intensity scores ($p < 0.01$). Similarly, children in the higher functioning KOSCHI group had significantly lower PCANS intensity scores ($p < 0.01$) compared to the lower functioning group.

In summary, findings from this validation study showed support for the concurrent and construct validity of the PCANS.

Norming the PCANS

A normative study of the PCANS was conducted by Soo and colleagues (2010b) using a sample of typically developing children recruited from public schools in the metropolitan region of Melbourne, Australia.

Participants were parent/caregivers of typically developing children who satisfied the following selection criteria:

- (1) aged between 5 and 14 years at time of interview.
- (2) no diagnosis of ABI, other neurological, developmental or behavioural disorder, or a significant medical condition.

A sample of 300 parents was selectively recruited to represent 10 equal subgroups according to child's age at time of interview (n=30, aged between 5 years, 3 months and 14 years, 11 months). Efforts were also made to sample equal numbers of males and females within each age year.

Descriptive and background data for the total normative sample (n=300) and for each age year (n=30) are displayed in Table 5. An approximately equal ratio of males and females for each age year was generally achieved, with the percentage of males for the majority of age groups falling between 43.3 to 56.7%.

In terms of the "Like schools"² categories, 40.9% of children in the sample attended schools in Groups 1-3 ("less disadvantaged"), 29.7% children attended schools in Groups 4-6, and 29.4% of children attended schools in Groups 7-9 ("more disadvantaged"). A Kruskal-Wallis test revealed there were no significant differences in occupational skill level³ of the parents across the ten age-groups ($\chi^2=6.28$, $p>0.5$).

The largest proportion of families interviewed had two children (44.3%), and the eldest child was the subject of the interview (42.0%) in the highest proportion of cases. Almost all parents interviewed were biological parents of the child (97% for the total group). The percentage of families who spoke a language other than English at home ranged from 16.7% to 33.3% across age groups. Subsequent to the Soo et al (2010b) publication referred to above additional normative data were collected on 15 year old young people (n=30).

Comparison of support needs scores for physical assistance versus supervision: Wilcoxon tests showed that support needs were significantly higher for supervision compared to physical assistance for activities in the majority of PCANS domains ($z = -3.79$ to 13.44 , $p<0.01$). The exceptions to this pattern were for Home Activities, Shopping, Devices and Employment.

From PCANS to PCANS—2

Following collection of the normative data redundant items and poorly performing items were deleted along with the Employment Domain

	<p>because of low endorsement, resulting in the streamlined 105 item PCANS-2.</p> <p>Classification of items as Independent (IND), Emerging (EM) and Not Expected (NE):</p> <p>The PCANS-2 items were also re-classified as independent (IND), emerging (EM), and not expected (NE) based on the normative data. The following criteria were used:</p> <ul style="list-style-type: none"> i) If the percentage of “no support” ratings for the item was greater than or equal to 85% when the Physical Assistance scores for the appropriate age years of the PCANS age form (e.g. 5, 6, 7 year olds for PCANS A) were averaged, then the item was coded as “IND”. The same method was used for Supervision items. ii) If the percentage of either “a lot” or “NA” ratings for the item was greater than or equal to 80% when the Physical assistance scores for the appropriate age years of the PCANS age form (e.g. 5, 6, 7 year olds for PCANS A) were averaged, then the item was coded “NE”. Again, the same method was used for Supervision items iii) iThe item was coded “EM”, if neither of the above criteria (i or ii) were met. The normative dataset was then recalibrated for the 105-item PCANS-2.
Advantages	<ul style="list-style-type: none"> 1) Australia norm; 2) Evidence supporting psychometric properties by the authors.
Disadvantages	<ul style="list-style-type: none"> 1) Lack of studies on psychometric properties of PCANS besides that conducted by the authors.
Additional Information	<ul style="list-style-type: none"> 1) The PCANS-2 is administered in an interview format with a respondent, usually the parent, who has current and detailed knowledge of the child’s functioning in all 13 Domains sampled by the PCANS-2. 2) In most circumstances, the respondent’s response is recorded without amendment. It is recognised, however, that there may be special circumstances when the interviewing health professional has detailed knowledge of the child’s functioning over the preceding month that suggests a different response from that given by the respondent. In such a situation, the interviewer may use their clinical knowledge of the child to allocate the score which best reflects the child’s current situation, even if it disagrees with the respondent’s answer.
Reviewers	<p>Vicki Anderson Cathy Catroppa</p>

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