



## **PCANS-2 Frequently Asked Questions**

The PCANS-2 is designed to measure the type, extent and intensity of support needs of young people aged 5 to 15 years who have an acquired brain injury (ABI). It is administered by health care professionals who have experience working with young people with ABI. The clinician should be familiar with the young person's medical history and have an understanding of the young person's current status.

The PCANS-2 is administered by the clinician conducting a guided interview with a respondent. The respondent should be a person, usually the young person's parent, who has current and detailed knowledge about the young person's functioning in all 13 Domains. The clinician should use their knowledge about the young person and their clinical interviewing skills to guide the interview and facilitate responses to each item. The clinician should also have attended training on administration, scoring and interpretation of the PCANS-2. They should be familiar with the PCANS-2 manual and refer to it as needed, noting that the definitions of items may be very useful to refer to during the interview.

Since use of the PCANS-2 in clinical practice commenced in 2013 several questions have been raised. The following are some of the more frequent questions. It is hoped that this document will aid in administration of the PCANS-2.

• If a clinician is administering the PCANS-2 near the date of the young person's birthday which Score Record Form (A, B, C, and D) and which Summary Score Form (ages 5-15 years) would you use?

The form used (A, B, C or D) should be the appropriate form for the actual date on which the interview took place. So for example if the interview with the respondent took place on the day of the young person's birthday, or just after their birthday, and he or she turned 8 years old then Score Record Form B (B is applicable to 8-11 year olds) should be used along with the Summary Score Form for 8 year olds, which contains the normative data for 8 year olds. If the interview occurs the day before the young person's 8<sup>th</sup> birthday, then Form A (5-7 year olds) and the Summary Score Form for 7 year olds should be used.

- Can the PCANS-2 be completed with a young person with Spinal injury? The PCANS-2 has been validated for use with young people with ABI. It could be used with young people with other diagnoses but it must be understood that it has not yet been validated for use with young people with diagnoses other than ABI.
- Can the PCANS-2 be completed while the young person is an inpatient? The PCANS-2 was developed for use in the community setting. The focus of the PCANS-2 is on the "Participation" aspect of the ICF in terms of how the participant functions when in the community setting. It is not recommended for use in the inpatient setting.
- How long does it take to complete a PCANS-2?
  Feedback from the initial trial conducted with clinicians showed that the average time taken to administer the PCANS-2 was 47.5 minutes, with a range of 30 minutes to 1 hour; the average time to score was 16.5 minutes, with a range of 10-25 minutes. We have not received feedback

about time for interpretation or report writing related to the PCANS-2. It is worth noting that this during this initial trial it was the first experience that clinicians had in using the PCANS-2 so with more familiarity the administration and scoring time may be shorter. An electronic version of the PCANS-2 is now available which, if used, will reduce the time to score the PCANS-2 because it automatically calculates all the Domain and Summary Scores.

• The clinician needs to guide the interview by suggesting examples of supports which may be applicable to a particular young person. The following are <u>SOME</u> examples of supports that might be provided for some items. The clinician should use their knowledge and interviewing skills to elicit the appropriate responses from the respondent:

a) Item 5 "Management of harmful behaviours": Keep in mind that this item applies to challenging behaviours of sufficient severity to cause harm to self or others. A young person who has behaviours applicable to this item may receive SUPERVISION support in the classroom by the teacher asking him/her to go to the "visual story" which is a reminder of how to behave. If the teacher has to walk to the young person and physically guide the young person to sit and get out the "visual story" then this would be an example of PHYSICAL ASSISTANCE.

b) Item 29 "Cooking simple foods": PHYSICAL ASSISTANCE could be that someone else has to get the ingredients and utensils out of the cupboards for a young person because the young person does not have the skills to plan what ingredients and utensils are needed, or perhaps because of physical difficulty in reaching the necessary goods. SUPERVISION could be another person providing supervision while the young person heats up left over food because the young person is not safe to do it alone.

c) **Item 39 "Making own bed":** PHYSICAL ASSISTANCE could be someone having to assist while the young person makes the bed because the young person has upper limb weakness and cannot make the bed alone. SUPERVISION could be that someone has to remind the young person to make their bed.

d) **Item 95 "Understanding written notes":** PHYSICAL ASSISTANCE could be that someone has to read notes because the young person cannot read, or someone might have to sit with the young person and point to each word while the young person reads. SUPERVISION could be someone discussing with the young person what the young person reads in the notes to monitor their understanding of the notes.

e) **Item 99 "Telling the time":** PHYSICAL ASSISTANCE could be that someone has to locate and get a clock so that the young person can read the time. SUPERVISION could be that someone has to discuss with the young person what the young person is reading on the clock and hence interpret what the time is.

f) **Item 102 "Completing homework":** PHYSICAL ASSISTANCE could be that someone has to get out the young person's school diary and check what homework is to be done then get out the necessary books/laptop. SUPERVISION could be someone giving verbal prompts to do homework, or a discussion about what homework is due and which tasks are priorities to complete.

 In some instances a parent might be doing an item with the young person, for example helping the young person to do buttons and zippers up whilst dressing (item 16), but while they are doing it the parent is encouraging the young person to do some steps and observing/teaching them to become more independent in the task. Can this be scored as support for PHYSICAL ASSISTANCE and SUPERVISION?

Yes, this is a good example of when support would be both PA <u>and</u> Supervision. So for this example the score for PA and for S should reflect the amount of support needed by the young person across the preceding 4 weeks for this item.

- If an item is classified as Emerging, how would you score it as there are normally developing young people of that age who will receive some support with the item?
  Yes, certainly it is acknowledged that for items classified as "Emerging" there will be some normally developing young people who will require support to complete the item. A useful approach can be to suggest that the respondent compare the young person's level of support need with the expected support need of other young people of the same age. So the clinician may ask "compared to other young people you know who are the same age how much support does [young person's name] require for the item?" Additionally the framework about frequency of support need and/or quality of the young person's performance in an item can be explored. This is explained further in the PCANS-2 manual on page 15.
- How would you interpret a score of 2 for physical assistance and supervision recorded for emerging skills, because some young people in that age group will need help with the skill? Classification of an item as "Emerging" indicates that at least some young people in the normative sample required some support for the item. A score of 2 for PA and a score of 2 for Supervision suggests that the young person requires <u>a lot</u> of physical assistance and <u>a lot</u> of supervision for that particular item. Interpreting a young person's score can be done by comparison with the normative data for the appropriate age and the Domain.
- A young person's performance in an item (for example item 30 "Preparing and cooking a hot meal) might vary from one context to another. For example at school they might be independent in cooking tasks because the kitchen has been modified but at home the young person requires assistance because of the physical environment. How would you score this? The score for an item where performance might vary in different contexts depends on the item. For items such as item 30 the intention of the PCANS-2 is to reflect the support needed when the young person might have to prepare and cook a meal at home so the score should be based on meal preparation which is usually done at home. But other items might be more applicable across different contexts and the young person's performance might vary in different contexts. For example item 4 "Management of wandering behaviour" might require more support in the school environment than the home environment so this item should be scored across all contexts.
- How do you score an item which involves the young person using adapted equipment to perform the item?

The use of any equipment, whether it is adaptive equipment or normal household or school equipment does not necessarily mean the young person has a support need.

The score should reflect whether the young person needs <u>another person</u> to provide support when performing the tasks involved in the item. If the young person uses equipment while performing a task but does not need any physical assistance or supervision then the score would be PA = 0 and S = 0. But if, for example, the young person needs someone else to set-up the equipment or needs reminding to use the equipment then the score should reflect the type and amount of support needed.

• How do you score an item when a young person can do the activity but won't perform the item, such as a 14 year old who will not shower regularly?

The situation where a young person can do an activity but won't do it is a clinically significant one. The score for the item should indicate the type and amount of support needed for the item across the preceding four week period. The clinician should explore with the respondent how much Supervision is needed, so in this example it may include supports such as monitoring of how often the young person is actually showering or reminding the young person to shower. The score for Physical Assistance should indicate how much physical assistance is required for the item. So in the example when the young person won't shower regularly does the young person require assistance when they actually do have a shower and if so how much PA is needed. However if the item being scored is for example item 41 "Washing up dishes" and the young person will not perform this task when they are required to do so, and someone else has to wash up, then the amount of PA required for the item should be reflected in the score.

 If the respondent indicates that the young person requires support for an item of a type and level that is different to what the interviewer believes a young person is capable of, how would you score the item?

If the interviewer has detailed knowledge about the young person's performance in an item over the preceding month they can allocate a different score to the respondent – the score should best reflect the young person's current situation. But the interviewer must have solid grounds to do this and be able to substantiate the score. They must also write a comment indicating that the score was deemed by the interviewer.

 In some circumstances items are difficult to score because the item could be considered "not applicable", such as if a young person lives in an area where there are no bus services or if the young person has no need to use a train/tram. How would you score an item in such a situation?

The respondent should be encouraged to respond to the item anticipating how much support the young person would need if hypothetically they were to perform the task. So in the first case above the respondent should be asked "If (young person's name) was to have to catch a bus do you think they would need any support? And if so would they require Physical assistance and/or Supervision? And if so, how much - a lot or some?" The interviewer would then record the score and make a comment to indicate that the score is based on the hypothetical situation. If the respondent cannot project a score and if the interviewer is very familiar with the young person's status the interviewer should determine the appropriate score for the item. However if the interviewer does not consider that he/she has sufficient familiarity with the young person's status to deem a score the item should not be scored. In this case the score for the item should be treated as missing data and care taken in the score calculations using procedures outlined during training and in the PCANS-2 manual.

• If a 15 year old is taught to manage a tracheostomy, should she/ he be scored a 2 for physical assistance?

The score for item number 1, Tracheostomy management, should reflect the type and level of support required by the young person. The PCANS-2 scoring guidelines state that if the young person requires any support for item 1 then it is to be scored as PA = 2 and S = 2. As detailed in the Item Definition in the PCANS-2 manual, item 1 includes all tasks required for tracheostomy management including cleaning equipment, managing dressings. In the rare event when a young person may be independent in all aspects of managing his/her tracheostomy then the score for PA and S could be = 0.

Rehabilitation Studies Unit Northern Clinical School Sydney Medical School

Located at: Kolling Institute Royal North Shore Hospital Pacific Highway, St Leonards NSW 2065 Australia T +61 2 9926-4785

E <u>rtate@med.usyd.edu.au</u> dwakim@med.usyd.edu.au

www.rehab.med.usyd.edu.au