

# CPQOL

## Cerebral Palsy Quality of Life

### -Manual

Version 3 July 2013

Quality of Life Questionnaire  
for Adolescents (CP QOL-Teen)





# Cerebral Palsy Quality of Life Manual (CP QOL-Teen)

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## Preface

This manual describes the development of the Cerebral Palsy Quality of Life Questionnaire for Adolescents (CP QOL–Teen), a condition-specific quality of life (QOL) questionnaire for adolescents with cerebral palsy aged 13 to 18 years. CP QOL –Teen extends on the Cerebral Palsy Quality of Life Questionnaire for Children (CP QOL- Child), developed for children with cerebral palsy aged 4-12 years. The CP QOL-Teen was developed by a multidisciplinary team of clinical and adolescent health researchers, in collaboration with parents, and adolescents with cerebral palsy.

Following the development of the Cerebral Palsy Quality of Life Questionnaire for Children (CP QOL-Child) we received many requests for an instrument that captures the quality of life of adolescents with cerebral palsy.

The CP QOL–Adolescent is a measure of quality of life for adolescents with cerebral palsy that can be used by researchers, clinicians, health professionals and educators to measure and assess changes in adolescent’s QOL. This manual provides only basic information about administering and scoring the CP QOL-Teen. Readers interested in background literature, development of the CP QOL-Teen and psychometric properties should refer to academic publications.

# Authors

## Dr Elise Davis

Jack Brockhoff Child Health and Wellbeing Program, McCaughey Centre, Melbourne School of Population Health, University of Melbourne, Australia

## Dr Melanie Davern

McCaughey Centre, Melbourne School of Population Health, University of Melbourne, Australia

## Professor Elizabeth Waters

Jack Brockhoff Child Health and Wellbeing Program, McCaughey Centre, Melbourne School of Population Health, University of Melbourne, Australia

## Associate Professor Roslyn Boyd

Cerebral Palsy and Rehabilitation Research Centre, University of Queensland, Royal Children's Hospital, Herston, Queensland, Australia

## Professor Dinah Reddihough

Department of Developmental Medicine, Royal Children's Hospital, Melbourne, Australia

## Professor H Kerr Graham

Department of Orthopaedics, Royal Children's Hospital, Melbourne, Australia

## Professor Andrew Mackinnon

Orygen Youth Research Centre, University of Melbourne, Australia

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# Section 1: The Cerebral Palsy QOL Questionnaire for Adolescents (CP QOL-Teen)

## *What is the CP QOL Adolescent?*

The Cerebral Palsy Quality of Life Questionnaire for Adolescents (CP QOL-Teen) is a measure of quality of life for adolescents with cerebral palsy. It has been developed specifically for adolescents with cerebral palsy. The CP QOL-Teen was developed in consultation with parents, adolescents and health professionals. Further information about the background literature, development and results are provided in academic publications (refer to Appendix 1).

## *Who is the CP QOL Adolescent designed for?*

The CP QOL-Teen was developed and tested for use with adolescents with cerebral palsy. It is designed for adolescents aged 13-18 years. There are two versions of the CP QOL-Teen:

1. Adolescent self-report version (for adolescents aged 13-18 years), comprising 72 items.
2. Parent-proxy version (for parents of adolescents aged 13-18 years), comprising 88 items;

Parents and adolescents may report different levels of QOL. Consequently, it is recommended that both versions are used, if possible. Statistical analyses should be conducted on both parent proxy and adolescent self-report scores and both should be reported and interpreted.

### ***What does the CP QOL- Teen measure?***

The CP QOL-Teen measures the following seven areas of an adolescent's life:

- General wellbeing and participation
- Communication and physical health
- School wellbeing
- Social wellbeing
- Access to services
- Family Health
- Feelings about functioning

\*Access to services, and Family health are only included in the parent proxy version of the questionnaire.

### ***When can the CP QOL-Teen be used?***

The CP QOL Adolescent can be used by researchers, clinicians, health professionals and educators for a variety of purposes, including: conducting research to determine whether an intervention has increased an adolescent's QOL and as an assessment to gain insight into several aspects of adolescents' lives.

## Section 2: Administering the CP QOL-Teen

### *Consenting to Complete the CP QOL-Teen*

The parent proxy version of the CP QOL-Teen is suitable for parents of adolescents with cerebral palsy aged 13-18 years. The adolescent self-report version of the CP QOL-Teen is suitable for adolescents with cerebral palsy aged 13-18 years. The user should consider and obtain the necessary consent.

It is important to assess whether an adolescent has the intellectual ability to complete the adolescent self-report questionnaire. To determine whether an adolescent can complete the questionnaire, it is useful to ask the adolescent's parents or guardians. It is important to explain to the parent or guardian what type of questions would be asked of the adolescent and how the adolescent would need to record their responses. The adolescent does not need to physically fill out the questionnaire. However they do need the ability to understand the questions and choose an answer.

The CP QOL-Teen has been tested using two methods of administration:

1. Face to face interview;
2. Mailout questionnaire.

Either method can be used. Instructions for each method follow.

## *Face to face Interview*

For either parent proxy or adolescent self-report, it is important that you read out the instructions on the first page of the questionnaire.

### **Parent Proxy Report**

‘We want to ask you some questions about how you think your adolescent FEELS about aspects of their life such as family, friends, health and school. Each question begins with “How do you think your teenager FEELS about.....?” It is important for you to report how you believe your adolescent feels. Sometimes it is difficult to know how your adolescent is feeling. Please just try and answer as best as you can. For each question we want you to circle the best number that shows how you think your adolescent FEELS. You can circle any number from 1 (Very unhappy) to 9 (Very happy). This questionnaire is measuring how your adolescent feels, not what they can do.’

### **Adolescent Self-Report**

‘We want to ask you some questions about your life such as your family, your friends, your health and your school. Each question begins with “How do you FEEL about.....?” For each question we want you to circle the best number that shows how you FEEL. You can circle any number from 1 (Very unhappy) to 9 (Very happy). This questionnaire is measuring how you feel, not what you can do.’

If either an adolescent or a parent asks the meaning of a question, the interviewer should ask the parent or adolescent to complete the questionnaire based on what they think the question means. If a parent or adolescent refuses to complete the CP QOL-Teen or starts to complete it and doesn’t want to finish it, they do not need to complete it; completion is voluntary.

## *Mailout questionnaire*

If the CP QOL-Teen is to be used in a mail survey, the researchers should ensure they have discussed the questionnaire with the parent, either in person or on the telephone. This is particularly important in order to determine whether the adolescent can complete the adolescent self-report questionnaire.

## *Data Entry, Cleaning and Scoring*

Information on data entry, data cleaning and scoring is provided in Appendix 2.

## Section 3: Contact Information

If you would like further information on the CP QOL-Teen, please visit the CP QOL website at

[www.cpqol.org.au](http://www.cpqol.org.au)

Alternatively, contact:

**Dr Elise Davis**

Associate Director, The Jack Brockhoff Child Health & Wellbeing Program  
McCaughey VicHealth Centre for Community Wellbeing  
Melbourne School of Population Health  
University of Melbourne  
207 Bouverie Street, Carlton  
Victoria, Australia 3010  
eda@unimelb.edu.au

**Professor Elizabeth Waters**

Director, The Jack Brockhoff Child Health & Wellbeing Program  
McCaughey VicHealth Centre for Community Wellbeing  
Melbourne School of Population Health  
University of Melbourne  
207 Bouverie Street, Carlton  
Victoria, Australia 3010  
ewaters@unimelb.edu.au

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## Appendix 1: Publications on CP QOL-Child & QOL

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## Appendix 2: Data Entry, Cleaning & Scoring

### *Data Cleaning*

Prior to scoring, it is important to check the range of values for each of the items against the expected or possible response values, and then clean the dataset. Cleaning will involve:

- Randomly checking for the accuracy of data entry (that is, every 10th questionnaire should be checked)
- Correcting any values of individual items which are found to be outside the appropriate range of expected values
- Implementing standardised systems for coding (for example, where a respondent has marked two response choices, the higher or lower value is chosen each time as the 'correct' response).

### *Scoring the CP QOL- Teen*

Scoring involves two steps:

- 1. Items are transformed to a scale with a possible range of 0-100;**
- 2. The algebraic mean of item values is computer for each domain.**

- 1. Items are transformed to a scale with a possible range of 0-100.**

Most can be recoded using the following formula:

If person scored 1, recode to 0  
If person scored 2, recode to 12.5  
If person scored 3, recode to 25  
If person scored 4, recode to 37.5  
If person scored 5, recode to 50  
If person scored 6, recode to 62.5  
If person scored 7, recode to 75  
If person scored 8, recode to 87.5  
If person scored 9, recode to 100

## Appendix 2: Data Entry, Cleaning & Scoring

There are a few exceptions for 9 items that need to be reverse coded. These include:

- concerned about having cerebral palsy?
- pain you/they have?
- level of pain you/they experience?
- level of discomfort you/they feel?
- ability to cope with pain?
- ability to control your/their pain?
- way pain gets in the way of your/their life?
- way pain stops you from being yourself/themselves?
- how pain takes you away from your/their everyday fun?

For these items:

If person scored 1, recode to 100

If person scored 2, recode to 87.5

If person scored 3, recode to 75

If person scored 4, recode to 62.5

If person scored 5, recode to 50

If person scored 6, recode to 37.5

If person scored 7, recode to 25

If person scored 8, recode to 12.5

If person scored 9, recode to 0

### 2. Calculating mean scale scores

Table 1 contains the items that are included in each domain for the Parent proxy questionnaire.

Table 2 contains the items that are included in each domain for the adolescent self-report questionnaire.

Please note that in our testing of the psychometric properties, 16 items had more than 30% missing values and thus were not included in the analyses and are not in Tables 1 or 2. These items may still be useful on an individual level basis or for a new factor analysis with a different sample of adolescents and thus have been retained in the questionnaire.

**Table 1: Domains and Items for the Parent Proxy version of the CP QOL-Teen**

Domains	Items
General wellbeing & participation	life in general? life as a whole? quality of life? the way they get along with other teenagers outside of school (not school friends)? hanging out on their own? hanging out with friends? the way they are accepted by other teenagers outside of school? doing things they want to do? having a go and trying new things? themselves? their positive attitude? their future? their opportunities in life? their ability to participate in leisure and recreational activities? their ability to participate in sporting activities? their ability to participate in social events outside of school? their ability to participate in the community? the way they get around? succeeding in things they want to be good at? their ability to get around in their neighbourhood? their ability to get from place to place?

Table 1 cont.

Domains	Items
Communication & physical health	<p>the way they get along with adults?  the way they are accepted by adults?  the way they are accepted by people in general?  their ability to keep up academically?  their ability to communicate with people they know well?  their ability to communicate with people they do not know well?  the way other people communicate with them?  the way their communicate with people using technology (SMS, internet)?  their overall health?  their physical health?  how they sleep?  changes happening to their body to do with puberty?  being able to do things by themselves with out relying on others?  what may happen to them later in life?  what they have achieved in their life?  their plans for the future?</p>
School wellbeing	<p>the way they get along with other teenagers at school?  the way they are included by other students at school?  the way they get along with their teachers at school?  the way they are accepted by other students at school?  the way they are accepted by staff and teachers at school?  the way they are treated the same as everyone as at school?  their ability to keep up physically?  their ability to participate at school?</p>
Social wellbeing	<p>how happy they are?  the way they get along with people generally?  the way they get along with you (parents)?  the support they get from their family?  the way they get along with their brothers and sisters?  going out on trips with the family?  the way they are accepted by their family?</p>

Table 1 cont.

Domains	Items
Access to Services	<p>How much pain does your teenager have?</p> <p>your teenagers access to treatment?</p> <p>your teenagers access to physiotherapy?</p> <p>your teenagers access to speech therapy?</p> <p>your teenagers access to occupational therapy?</p> <p>your teenagers access to specialised medical or surgical care?</p> <p>ability to get advice from a paediatrician?</p> <p>your teenagers access to community services and facilities?</p> <p>your teenagers access to extra help with learning at school?</p>
Family health	<p>How happy are you?</p> <p>Your physical health?</p> <p>Your work situation?</p> <p>Your family's financial situation?</p>
Feelings about functioning	<p>the way they use their arms and hands?</p> <p>the way they use their legs?</p> <p>their ability to dress him/herself?</p> <p>their ability to eat or drink independently?</p> <p>their ability to use the toilet by themselves?</p>

**Table 2: Domains and Items for the Adolescent Self-Report version of the CP QOL-Teen**

Domains	Items
General wellbeing & participation	your life in general? your life as a whole? your quality of life? the way you get along with other teenagers outside of school (not school friends)? hanging out on your own? hanging out with friends? the way you are accepted by other teenagers outside of school? doing things you want to do? having a go and trying new things? yourself? your positive attitude? your future? your opportunities in life? your ability to participate in leisure and recreational activities? your ability to participate in sporting activities? your ability to participate in social events outside of school? your ability to participate in the community? the way you get around? succeeding in things you want to be good at? your ability to get around in your neighbourhood? your ability to get from place to place?

Table 2 cont.

Domains	Items
Communication & physical health	<p>the way you get along with adults?  the way you are accepted by adults?  the way you are accepted by people in general?  your ability to keep up academically?  your ability to communicate with people you know well?  your ability to communicate with people you do not know well?  the way other people communicate with you?  the way you communicate with people using technology (SMS, internet)?  your overall health?  your physical health?  how you sleep?  changes happening to your body to do with puberty?  being able to do things by yourself with out relying on others?  what may happen to you later in life?  what you have achieved in your life?  your plans for the future?</p>
School wellbeing	<p>the way you get along with other teenagers at school?  the way you are included by other students at school?  the way you get along with your teachers at school?  the way you are accepted by other students at school?  the way you are accepted by staff and teachers at school?  the way you are treated the same as everyone as at school?  your ability to keep up physically?  your ability to participate at school?</p>
Social wellbeing	<p>how happy you are?  the way you get along with people generally?  the way you get along with your parents?  the support they get from your family?  the way they get along with your brothers and sisters?  going out on trips with the family?  the way you are accepted by their family?</p>

Domains	Items
Feelings about functioning	the way you use your arms and hands? the way you use your legs? your ability to dress yourself? your ability to eat or drink independently? your ability to use the toilet by yourself?



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