

# **The ConQol Questionnaire**

**A disease-specific measure of  
health-related quality of life for  
children with congenital heart  
conditions**

**A brief user's guide**

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### ***What is it?***

The ConQol Index (CQI) is an instrument for measuring health-related quality of life in children with congenital heart conditions. It was developed from interviews with children and, unlike some other questionnaires, represents what *they* regard as the important elements of health-related quality of life.

### ***Uses of the questionnaire***

It can be used:

1. for clinical use, to screen the children who come through your care to check that they are not experiencing problems in a particular area of their life. Used in this way it can form the basis for discussion with the child and a way of 'opening up' areas of difficulty
2. for audit or research. For example to compare different treatment methods in a randomised trial or to check that the result from your interventions are meeting the needs of your patients.

### ***It produces three measures***

1. a *descriptive profile of the frequency symptoms* experienced by the child in the past week
2. a weighted *symptom index score* summarising how difficult these symptoms had made respondents' lives
3. a *quality of life index score* based on questions about activities, relationships, coping and control.

Symptoms are scored separately from the other items because children may experience a lot of symptoms but still perceive their quality of life as good.

The measure of symptoms has been included because these may be of interest to clinicians, for example in comparing the effects of different medications or interventions. It should, however, never be reported on its own as a measure of the child's perception of their quality of life.

***How do you know that it is accurate?***

It has been validated in a multicentre study involving 730 children from five paediatric cardiology centres in the UK. It was shown to have good validity and reliability, to be well regarded by children and to be easy to use.

This study produced *norms* for age and sex by complexity of the underlying problem so you can see if the child has an unusual level of problems (these tables can be found in the main manual).

***Different age groups***

During the interviewing it became clear that at around 12 years of age the factors that impact on a child's HRQOL change, so there are two versions.

The 8–11-year version consists of 29 items that cover three dimensions:

1. symptoms (13 items)
2. activities (8 items)
3. relationships (10 items).

The 12–16-year version consists of 35 items covering four dimensions:

1. symptoms (13 items)
2. activities (9 items)
3. relationships (10 items)
4. control and coping (5 items).

In addition both versions contain one item that requires the child to indicate how they have felt in the past week compared to how they feel most of the time. This is a simple check to ensure that they've not reported an atypical week.

***Who is it appropriate for?***

Children and young people with a congenital heart condition, aged between 8 and 16 years, except those whose neuro-cognitive status limits their ability to understand and complete the questionnaire.

***How to help children complete the questionnaire***

The questionnaire can be used by post or in clinic.

In the clinic the child should be provided with a relatively quiet place to complete the questionnaire so that they will not be distracted or their responses overlooked or interfered with by other children.

There is an example of how to complete the questionnaire on the first page and this can be shown to and discussed with the child to make sure that he or she understands what is expected of them.

It should be explained that:

- the questionnaire is not a test and there are no right or wrong answers
- because the questionnaire is for lots of different people there may be questions about situations or symptoms that they have not experienced

themselves and the fact that they are there does not mean that you think they will experience them.

- every question must have an answer, even if it does not apply to them, because otherwise we won't know if they have just missed one out by mistake.

The child should then complete the questionnaire, which usually takes no more than 10–15 minutes. If possible they should do this unaided but help can be given by reading out the items if the child finds this difficult. The person who administers the scale, rather than a parent or carer, should do this. This ensures that the child is able to give his or her own response without the influence of a parent. Work previously done with quality of life measures have shown that parental and child perceptions often vary a great deal. If at all possible check that all of the questions have been completed before the child leaves, as missing responses may make the score unreliable.

### ***How to score the questionnaire***

The scores for each item are *weighted*, that is they have different values and cannot be simply added up. The weighting score for each item was arrived at by asking the children how important they felt each item was in determining their quality of life.

The manual gives full details of the weighting system but, to make this process as easy as possible, a Microsoft Excel© spreadsheet has been designed that will automatically carry out all of the calculations.

### ***Using the Excel scoring template***

Two scoring templates are provided, one for each age group.

Click on the appropriate sheet.

First enter the 'identifier' for each child, this can be a name or a case or NHS number. If you are going to use the spreadsheet to store data you will be required to meet data protection standards, each trust has someone who can advise you about this.

Then simply work through the questionnaire entering the number endorsed by the child under the column for each of the questions. The programme will automatically calculate the *symptom index* and the *quality of life index*.

### ***Where can I get the questionnaires?***

The questionnaires, the Excel scoring spreadsheet and the full manual can be downloaded from [www.cardiacrehabilitation.org.uk](http://www.cardiacrehabilitation.org.uk) or by writing to: Dr Yvonne Birks at the address on the front cover.

### ***What does it cost?***

There is no charge for using the questionnaires or the spreadsheet.