# The MacDQoL

**The MacDQoL is owned by Health Psychology Research Ltd. ("HPR"). Users must have a licence from HPR, which is contactable either via its website at www.healthpsychologyresearch.com or by email at info@healthpsychologyresearch.com**

## Comment

The MacDQoL was developed in 2000 and is based on the ADDQoL (Audit of Diabetes Dependent Quality of Life). The RetDQoL measure of the impact of diabetic retinopathy on QoL has been developed alongside the MacDQoL and improvements to one have influenced improvements to the other. Evidence for the psychometric properties of the MacDQoL has been published. Translations/adaptations of the MacDQoL are available in 15 languages.

## Content and Scoring Instructions

- *Two overview items:* scored individually (present quality of life and impact of macular disease (MD) on quality of life (QoL).
  - Generic (present) QoL. Scored from +3 (*excellent*) through 0 (*neither good nor bad*) to –3 (*extremely bad*).
  - MD-specific QoL. Scored from to –3 (*very much better* i.e. severe negative impact of MD on QoL) through 0 (*the same* i.e. no impact of MD on QoL) to +1 (*worse* i.e. positive impact of MD on QoL)
- *Specific domains:* a weighted score for each domain is calculated as follows:

  *Weighted impact (WI) score* = impact rating (-3 to +1) x importance rating (0 to 3). Possible range is from –9 (maximum negative impact of MD on QoL) to +3 (maximum positive impact of MD on QoL).

  NB "Unimportant" domains score 0, regardless of magnitude of impact of macular disease. Domains with no impact of macular disease score 0, regardless of their importance to QoL. Any non-applicable domains are not scored.
  - The item '*work*' is applicable to very few people. It is not included in the final, average weighted impact score, but may be used as a separate score where required.
- *Average Weighted Impact Score:* To be calculated from a maximum of 22 specific domains.

$$= \frac{\text{Sum of weighted ratings of applicable domains}}{\text{N of applicable domains}}$$

Possible range is from –9 (maximum negative impact of MD on QoL) to +3 (Maximum positive impact of MD on QoL).

- *Internal consistency reliability* (Cronbach's alpha) for the 22-item scale = 0.944.

*Missing data.* The AWI score can be computed despite some missing data. Missing data for up to 8 items can be tolerated before Cronbach's alpha falls below 0.9. Missing data for up to half the items can be tolerated without Cronbach's alpha falling below 0.8. The AWI score can be calculated from the items for which responses have been given providing at least 11 items have complete responses.

## Format of the MacDQoL

The MacDQoL is designed for self-completion by people with MD. The font is Arial 16 bold. All text is justified to the left (to make it easier to follow the vertical line down the page) and the use of upper case is avoided except where dictated by grammar, as capital letters are less easy to differentiate from each other than lower case letters. Dotted lines guide the respondent from questions to response options (see examples below). All instructions and information are enclosed in boxes. Where respondents are required to write text, boxes rather than lines are used to contain the text, since lines often appear distorted or incomplete to people with MD and are difficult to write on.

The MacDQoL is suitable for administration by telephone interview or face-to-face interview. However, the method of administration does affect the scores and it is recommended that different methods are not used in the same sample. Telephone interview (or face to face interview) is preferable except where all participants are able to read large print and can self-complete the MacDQoL without help. Instructions for interviewers are available in English.

## Availability

The MacDQoL is made available to users by formal arrangement with Health Psychology Research Ltd. Requests should be made to info@healthpsychologyresearch.com. A user agreement is necessary to avoid breach of copyright and to ensure that the latest and most appropriate version of the questionnaire is used.

Evidence of licensing may be required by regulators, editors and/or examiners.

## Contact Information

For permission to use the MacDQoL and to ensure that you have the most up-to-date version, please contact:

E-mail: info@healthpsychologyresearch.com

Website: www.healthpsychologyresearch.com

## Selected References

### Key references to MacDQoL design and development

Mitchell J, Bradley C. (2004) Design of an individualised measure of the impact of macular disease on quality of life (the MacDQoL). *Quality of Life Research*; **13** (6): 1163-1175.

Mitchell J, Wolffsohn JS, Woodcock A, Anderson SJ, McMillan CV, ffytche T, Rubinstein M, Amoaku W and Bradley C (2005). Psychometric evaluation of the MacDQoL individualised measures of the impact of macular degeneration on quality of life. *Health and Quality of Life Outcomes* **3**:25 http://www.hqlo.com/content/3/1/25

Mitchell J, Wolffsohn JS, Woodcock A, Anderson SJ, ffytche T, Rubinstein M, Amoaku W and Bradley C (2008). The MacDQoL individualised measure of the impact of macular degeneration on quality of life: reliability and responsiveness. *American Journal of Ophthalmology* 146 (3) 447-454. http://www.ncbi.nlm.nih.gov/pubmed/18547542?ordinalpos=3&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_RVDocSum

### Further references to MacDQoL development

Mitchell J and Bradley C (2005) Measuring quality of life in macular disease: what use are utilities? *Proceedings of Vision 2005; International Congress Series 1282,* Vol 1282, 654-658.

Berdeaux G et al (2006) Metric properties of the MacDQoL in French, German, Italian and American populations: an individualised QoL instrument specific to Macular Disease (MD). *Value in Health* **9** (6) A372-A373.

Mitchell J and Bradley C (2004) Comparison between telephone interview and self-completion of the MacDQoL. *Quality of Life Research* **13** (9) 1548, Abstract 1064.

### Background references

Bradley C et al (1999) The development of an individualised questionnaire measure of perceived impact of diabetes on quality of life: the ADDQoL. *Quality of Life Research* **8**, 79-91.

Bradley C and Speight J (2002) *Patient perceptions of diabetes and diabetes therapy: assessing quality of life.* Diabetes Metabolism Research and Reviews **18***: S64-S69.*

Bradley C (2001) Importance of differentiating health status from quality of life. *The Lancet* **357**, 7-8.

Woodcock AJ et al (2001) Problems with the performance of the SF-36 among people with Type 2 diabetes in general practice. *Quality of Life Research* 10, 661-670.

Woodcock A, Bradley C, Plowright R, ffytche T, Kennedy-Martin T and Hirsch A (2004) The influence of diabetic retinopathy on quality of life. Interviews to guide the design of a condition-specific, individualised questionnaire: the RetDQoL. *Patient Education and Counseling* **53**, 3, 365-383.

**Format of the 2 overview items (showing the scores assigned)**

## I) In general, my present quality of life is:

- **excellent ……....** 3
- **very good……...** 2
- **good……...** 1
- **neither good nor bad……** 0
- **bad ……** -1
- **very bad……** -2
- **extremely bad…….. ....** -3

## II) If I did not have MD, my quality of life would be:

- **very much better…….....** -3
- **much better……...** -2
- **a little better……..** -1
- **the same ……** 0
- **worse……..…...** 1

**Format of a condition-specific domain (showing the scores assigned)**

**7a) If I did not have MD, my friendships and social life would be:**

- **very much better……..** -3
- **much better……..** -2
- **a little better……..** -1
- **the same……** 0
- **worse……..** 1

**7b) My friendships and social life are:**

- **very important……..** 3
- **important…… ...** 2
- **somewhat important……** 1
- **not at all important ……** 0

## Summary of the 23 domain-specific items (and their response options) and final open question

| NB. All items begin with the phrase: If I did not have MD, | | |
|---|---|---|
| 1 | I could handle my household tasks | very much better – worse |
| 2 | I could handle my personal affairs | very much better – worse |
| 3 | My experience of shopping would be | very much better – worse |
| 4 | †*My working life and work-related opportunities would be | very much better – worse |
| 5 | *My closest personal relationship would be | very much better – worse |
| 6 | *My family life would be | very much better – worse |
| 7 | My friendships and social life would be | very much better – worse |
| 8 | My physical appearance (including clothes and grooming) would be | very much better – worse |
| 9 | Physically I could do | very much more - less |
| 10 | I could get out and about (e.g. on foot, or by car, bus or train) | very much better – worse |
| 11 | *My holidays would be | very much better – worse |
| 12 | I could enjoy my leisure activities and interests (e.g. reading, TV, radio, hobbies) | very much more – less |
| 13 | My self-confidence would be | very much better – worse |
| 14 | My motivation to achieve things would be | very much better – worse |
| 15 | The way people in general react to me would be | very much better – worse |
| 16 | My feelings about the future would be | very much better – worse |
| 17 | My financial situation would be | very much better – worse |
| 18 | I could do things independently | very much more - less |
| 19 | I could do things for others as I wish | very much better – worse |
| 20 | I would have mishaps or would lose things | very much less - more |
| 21 | I could enjoy meals | very much more - less |
| 22 | The time it takes me to do things would be | very much less - more |
| 23 | I could enjoy nature | very much more - less |
| 24 | Does MD affect your quality of life in any ways that have not been covered by the questionnaire? If yes please describe in the box provided (open text response). | yes, no |

† Item not included in average weighted impact score. * Item has ‘not applicable’ option