

PUBLICATIONS on the MacDQoL

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Paper on original design of the 26 item MacDQoL (now superseded)

Mitchell J and 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.
<http://www.springerlink.com/content/wt01005015q20167/>
http://www.ncbi.nlm.nih.gov/pubmed/15287282?ordinalpos=178&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_RVDocSum

Papers reporting development and psychometrics of the subsequent 23-item MacDQoL

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 measure 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>.
http://www.ncbi.nlm.nih.gov/pubmed/15831093?ordinalpos=1&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_RVDocSum

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

Book chapter describing development and use of MacDQoL

Mitchell J and Bradley C (2009) Measuring quality of life in macular degeneration. In VR Preedy and RR Watson (Eds) *Handbook of Disease Burdens and Quality of Life Measures*. New York: Springer, 2633-2648. DOI:10.1007/978-0-387-78665-0_153, Print ISBN 978-0-387-78664-3, Online ISBN 978-0-387-78665-0.
<http://www.springerlink.com/content/q357850112n97243/>

General commentary

Bradley C (2001) Importance of differentiating health status from quality of life. *The Lancet*, **357**, 7-8.
http://www.ncbi.nlm.nih.gov/pubmed/11197385?ordinalpos=97&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_RVDocSum

Commentary on FDA draft guidance on patient reported outcome measurement

Bradley C (2006) Feedback on the FDA's February 2006 draft guidance on Patient Reported Outcome (PRO) measures from a developer of PRO measures. *Health and Quality of Life Outcomes* **4** (1) 78, <http://www.hqlo.com/content/4/1/78>

Reports of use of the MacDQoL with people with Age-related Macular Degeneration

Mitchell J and Bradley C (2002) Design of the MacDQoL individualised measure of the impact of macular disease on quality of life. *Quality of Life Research*, **11** (7) 697, Abstract 302. <http://www.jstor.org/stable/4037926>

Mitchell J, Woodcock A and Bradley C (2004) Comparison between telephone interview and self-completion of the MacDQoL. *Quality of Life Research* **13** (9) 1548, Abstract 1064. <http://www.jstor.org/stable/4039161>

Mitchell J and Bradley C (2005) Measuring quality of life in macular disease: what use are utilities? *Proceedings of Vision 2005; International Congress Series*, Vol 1282, 654-658. <http://eprints.rhul.ac.uk/507/>.

Berdeaux G, Mesbah M and Bradley C (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, Reeves A and Bradley C (2009) Eccentric vision training for people with macular disease (MD) improves MacDQoL measures of quality of life. 2009 International Society for Quality of Life Research meeting abstracts. The *QLR Journal*, A-48, Abstract #1328.

Berdeaux G, Mesbah M and Bradley C (2011) Metric properties of the MacDQoL, individualized macular-disease-specific quality of life instrument, and newly identified subscales in French, German, Italian and American populations. *Value in Health* **14** (1) 110-120. doi: 10.1016/j.jval.2010.10.027. <http://www.ncbi.nlm.nih.gov/pubmed/21211493>

Reviews referring to the MacDQoL

Covert D, Berdeaux G, Mitchell J, Bradley C and Barnes R (2007) Quality of Life and Health Economic Assessments of Age-Related Macular Degeneration. *Survey of Ophthalmology* **52** (1) S20-S25. http://www.ncbi.nlm.nih.gov/pubmed/17240252?ordinalpos=357&itool=EntrezSystem2.PEntrez.Pubmed.Pubmed_ResultsPanel.Pubmed_RVDocSum

Finger RP, Fleckenstein M, Holz FG and Scholl HPN (2008). Quality of life in age-related macular degeneration: a review of available vision-specific psychometric tools. *Quality of Life Research* **17** (4); 559-574.

Mitchell J and Bradley C (2009) Measuring quality of life in macular degeneration. In VR Preedy and RR Watson (Eds) *Handbook of Disease Burdens and Quality of Life Measures*. New York: Springer, 2633-2648. DOI:10.1007/978-0-387-78665-0_153, Print ISBN 978-0-387-78664-3, Online ISBN 978-0-387-78665-0. <http://www.springerlink.com/content/q357850112n97243/>

Mitchell J and Bradley C (2006) Quality of life in age-related macular degeneration: A review of the literature. *Health and Quality of Life Outcomes* **4**:97. <http://www.hqlo.com/content/pdf/1477-7525-4-97.pdf>
'White paper' sponsored by the AMD Alliance International for initial publication on their website and subsequent publication in slightly edited form in HQOLO.

Editorials referring to the MacDQoL

Mitchell J. (2007) Investigating the burden of wet macular degeneration. *Archives of Ophthalmology* ;125 1266-1268

Chakravarthy, U. (2006). Age related macular degeneration. *BMJ* **333**, 869-870.
<http://www.bmj.com/cgi/content/full/333/7574/869>

Similar QoL measures developed for other conditions

Diabetes

Bradley C, Todd C, Gorton T, Symonds E, Martin A and Plowright R (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** (3), S64-S69.

DAFNE Study Group* (2002) Training in flexible, intensive insulin management to enable dietary freedom in people with type 1 diabetes: the dose adjustment for normal eating (DAFNE) randomised controlled trial. *British Medical Journal* **325**, 746-749 (full 6 page version of paper published on BMJ website <http://bmj.com/cgi/content/full/325/7367/746>). (Trial showing major improvement in ADDQoL scores).

*Amiel S, Beveridge S, Bradley C, Gianfrancesco C, Heller S, James P, McKeown N, Newton D, Newton L, Oliver L, Reid H, Roberts S, Robson S, Rollington J, Scott V, Speight J, Taylor C, Thompson G, Turner E and Wright F.

Wee, H.L., Tan, C.E., Goh, S.Y. & Li, S.C. (2006). Usefulness of the Audit of Diabetes-Dependent Quality-of-Life (ADDQoL) Questionnaire in Patients with Diabetes in a Multi-Ethnic Asian Country. *Pharmacoeconomics*, 24(7), 673-82. Psychometric evaluation of the ADDQoL19 for the first time with English speakers in Singapore.

Diabetic Retinopathy

Woodcock A, Bradley C, Plowright R and Hirsch A (2002) How does diabetic retinopathy affect quality of life? Interviews to guide the design of a condition-specific, individualised questionnaire: the RetDQoL. *Diabetic Medicine* 19 (Suppl 2), 98-99.

Woodcock A, Bradley C and Plowright R. 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 Counselling* **53**, 365-383.

Other Eye conditions

Brose, L.S., Plowright, R., Mitchell, J. & Bradley, C. (2008). Design of an individualised measure of Quality of Life (EyeDQoL) and a measure of Treatment Satisfaction (EyeTSQ) for people with eye conditions. Vision 2008, 9th International Conference on Low Vision, Montreal, QC, 85.2.

Growth Hormone Deficiency

McMillan CV, Bradley C, Gibney J, Russell-Jones DL and Sönksen PH (2006) Preliminary development of the new individualised HDQoL questionnaire measuring quality of life in adult hypopituitarism. *Journal of Evaluation in Clinical Practice* **12** (5) 501-514. <http://www.ncbi.nlm.nih.gov/pubmed/16987112>

Age-Related Hormone Decline

McMillan CV, Bradley C, Giannoulis M, Martin F and Sönksen PH (2003) Preliminary development of a new individualised questionnaire measuring quality of life in older men with age-related hormonal decline: the A-RHDQoL. *Health and Quality of Life Outcomes* **1**:51 <http://www.hqlo.com/content/1/1/51>

Hypothyroidism

McMillan C, Bradley C, Razvi S and Weaver J (2008) Evaluation of new measures of the impact of hypothyroidism on quality of life and symptoms: the ThyDQoL and ThySRQ. *Value in Health* **11** (2) 285-294. <http://www.blackwell-synergy.com/doi/abs/10.1111/j.1524-4733.2007.00232.x?journalCode=vhe&volume=11&issue=2>. <http://eprints.rhul.ac.uk/99/>

Renal Failure

Bradley C (1997) Design of a renal-dependent individualised quality of life questionnaire: RDQoL. *Advances in Peritoneal Dialysis* **13**, 116-20.

Phillips L, Davies S, White E, Barendse S, Bradley C and Sprosen T. (2000) Quality of Life with Peritoneal Dialysis (PD). An evaluation using the Renal Dependent Quality of Life Questionnaire (RDQoL). *Peritoneal Dialysis International* **20** (1) 116.

Diabetes in the frail elderly

Speight, J., Woodcock, A., Plowright, R. & Bradley, C. (2003). Design of an individualised measure of the impact of diabetes on the quality of life of elderly people: the ADDQoL Senior. *Quality of Life Research*, **12**(7), 863.

Diabetes in teenagers and younger children

McMillan, C.V., Honeyford, R.J., Datta, J., Madge, N.J. & Bradley, C. (2004). The development of a new measure of quality of life for young people with diabetes mellitus: the ADDQoL-Teen. *Health Qual Life Outcomes*, **2**(1), 61.

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