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**Title: Design of an individualised measure of the impact of macular disease on quality of life (the MacDQoL)**

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## **Abstract**

The aim of this study was to design an individualised questionnaire to measure the impact of macular disease (MD) on quality of life (QoL). Principles underlying the SEIQoL interview method and the ADDQoL diabetes-specific questionnaire influenced the MacDQoL design.

The MacDQoL specifies domains of QoL that were selected using focus group methodology and refined following a postal pilot study of members of the UK Macular Disease Society. Respondents rated the impact of MD on each domain and the importance of each domain to their QoL.

Mean domain scores from 69 respondents indicated that MD had a negative impact on all the domains of QoL investigated in the measure. There was preliminary evidence of good internal consistency reliability (Cronbach's  $\alpha=0.93$ ,  $n=37$ ). Respondents who were registered partially sighted or blind reported poorer QoL than those who were not registered (Kruskal Wallis:  $X^2 = 14.03$ ,  $N = 62$ ,  $p < 0.001$ ). This evidence suggests that the measure will be sensitive to subgroup differences. The instrument has been further refined following the pilot study. The MacDQoL is being used in clinical trials and psychometric evaluation of the measure will be carried out using trial data. The measure is available for clinical use and has been linguistically validated in fifteen other languages.

**Keywords: macular disease; quality of life; individual differences**

**Abbreviations:**

**ADDQoL:** Audit of diabetes-dependent quality of life

**C-SQoL:** Condition-specific quality of life

**FS:** functional status

**HS:** health status

**LVA:** low vision aid

**MacDQoL:** Macular disease-dependent quality of life measure

**MD-QoL:** MD-specific quality of life

**MD:** macular disease

**MDS:** Macular Disease Society

**MDSQ:** Macular Disease Society Questionnaire

**P/S:** Partially sighted

**QoL:** quality of life

**SEIQoL:** Schedule for the evaluation of individual quality of life

## **Introduction**

Macular disease (MD) is a chronic, degenerative eye condition. It affects the central part of the retina, the macula, and results in loss of central vision. Peripheral vision is retained, but loss of acuity can be severe and sufficient for registration as blind. The condition most often affects people over the age of 50 years, when it is commonly referred to as age-related macular degeneration. Incidence increases with age. It is the most common cause of blindness in those aged over 60 years, and is the cause of 95% of new registrations as blind and partially sighted in that age group in the UK [1]. There are two types of MD. Dry MD, for which there is currently no treatment, progresses more slowly and it accounts for approximately 85% of all cases of MD. The more rapidly progressing wet MD affects about 15% of cases. A proportion of these may be treatable with photodynamic therapy, which has recently been approved for use in many countries, or with other, less successful treatments, including laser photocoagulation. For the majority of people with MD, management is limited to rehabilitation and low vision aid provision. With new treatments now being developed and evaluated, however, there is a pressing need for appropriate psychological outcome measures in the assessment of both medical and non-medical interventions.

The importance of measuring quality of life (QoL) in health care is increasingly recognised [2]. Often, however, instruments that are used to measure the construct would be more appropriately referred to as measures of health status (HS) or functional status (FS) [3]. HS instruments measure the quality of health rather than the QoL [4] while a visual function measure indicates the impact of vision loss on functioning rather than the perceived impact of vision loss on QoL [5]. Whereas HS and FS are related to QoL, they are not themselves measures of QoL. People do not all regard aspects of HS or FS as equally important to QoL, and some may be

regarded as not at all important. Therefore, when scores of perceived functional ability in a number of different areas are simply added together, this does not realistically represent a measure of an individual's QoL. Measuring HS and FS can be valuable in estimating the impact of medical conditions and their treatment but, as Joyce [6] commented, 'it is not the observed functioning of the individual that is of primary concern, but that individual's perceptions of and reactions to functioning' (p46). In ophthalmology, as elsewhere, clinicians recognise the value of measuring the impact of medical and rehabilitative interventions on QoL. As visual impairment may have an effect on length of life only indirectly (perhaps through falls, accidents or suicide) its impact is primarily on QoL [7]. Here too, in the ophthalmological literature, the distinction between FS, HS and health related QoL (HRQoL) is often overlooked. Measures of FS and HS are misused as measures of HRQoL (e.g. reference 7) and the terms are sometimes used interchangeably (e.g. reference 8). Studies that focus more specifically on MD that have purported to measure QoL or HRQoL, have used measures that actually assess FS or HS [9, 10, 11]. But visually impaired people do not necessarily regard visual impairment as a form of health impairment. For example, Mangione, Gutierrez , Lowe et al [9] reported that the SF-36 did not correlate with severity of MD. The SF-36 was also found to be unresponsive to changes in visual acuity over a two-year period in people with MD [12]. Bradley [4] commented that, when unsuitable measures are used to assess QoL, the interpretation of the data may be misleading and she emphasised the importance of enabling the individual's view of QoL to be measured. Joyce (6) noted that there is confusion about the use and meaning of the terms HS, FS and HRQoL. Since the term HRQoL has been so misused and, since conditions such as MD are not usually viewed as an aspect of health by individuals who have the condition, we prefer to use the term 'condition-specific quality of life' (C-SQoL) when referring to QoL as it is affected by a medical condition, and 'MD-specific

quality of life' (MD-QoL) when referring to QoL as it is impacted specifically by MD. This ensures that they are not confused with the terms HS and FS.

The Schedule for the Evaluation of Individual Quality of Life (SEIQoL) [13], is an individualised measure of QoL that differs fundamentally from previous measures. Earlier measures tend to consist of domains that have been derived from the views of researchers, health professionals or even other patients, but not from the individual patients themselves. The SEIQoL allows individual respondents to name five domains of life that they perceive to be the most important to their own QoL. The individual rates the present quality of each of those domains and the relative importance of each one to their overall QoL. The importance ratings are used to weight the domain ratings and the weighted ratings are summed to provide a single QoL score. A similar approach has been used in the Patient Generated Index [14] which is condition-specific in that it asks patients to name the five areas of their life that are most affected by their medical condition. Importance ratings are indirectly incorporated. Again, the relevance of domains for the patient is paramount. Weighting an assessment criterion by an 'importance' value is a strategy used in multi-criteria decision making (15). In a decision-making situation, multiple criteria are used to lead a decision-maker to his/her most desired solution to a problem. In QoL measures that use multiple criteria to assess domains of the measure, the purpose is to enable participants to indicate more accurately the impact of any situation (e.g. a chronic medical condition) on their QoL.

The philosophy underpinning the SEIQoL was adopted by Bradley and her colleagues in the development of an individualised diabetes-specific measure of QoL, the Audit of Diabetes-dependent Quality of Life (ADDQoL) [16]. Interviews with people with diabetes, together with research literature and experience, were

used to determine domains of life impacted by diabetes and important for QoL. In the interviews, participants were asked to specify ways in which their QoL would be affected if they were to find they no longer had diabetes. Eighteen domains are now included in the ADDQoL [17]. Those items in the ADDQoL that might not be relevant to all include a 'not applicable' option. Participants rate the impact of each applicable domain on a scale of -3 to +3 where 0 indicates that the particular domain would be 'the same' if they did not have diabetes. Participants then rate the importance of domains for QoL from 0 (not at all important) to 3 (very important). The ADDQoL includes two overview items. The first asks about QoL *per se* and the second asks about the impact of diabetes on QoL. Psychometric development work [16,17] provided support for the inclusion of importance ratings and included the finding that the full range of importance ratings (0, 1, 2 and 3) were used for all domains. A growing body of evidence attests to the value of the ADDQoL (e.g. 16, 17, 18, 19, 20). A similar measure has been developed for use with adults with renal failure [21] and adults with growth hormone deficiency [22].

In the work reported here the researchers set out to design an individualised, MD-specific measure of QoL, suitable for people with all types of MD. They were guided by the philosophy underpinning the SEIQoL, ADDQoL and related measures which incorporate participants' views of the importance of domains of life to their QoL. The ADDQoL format and the more generic items contained within it (e.g. domains concerning work, family, friends and social life) provided a useful starting point in the development of the Macular Disease-dependent Quality of life (MacDQoL) measure.

## **Method**

With the collaboration of a person who has MD, and with reference to the research literature and to data from a survey of 1420 members of the UK MD Society (MDS) [23], the authors designed a first draft of the MacDQoL. Generic items from the ADDQoL were modified for MD e.g. 'If I did not have diabetes (macular disease), my family life would be'. ADDQoL domains that were not appropriate to people with MD were omitted e.g. 'If I did not have diabetes, my freedom to eat as I wish would be'. Composite domains from the ADDQoL, that were likely to encompass greater proportions of time in the mostly retired MD population, were subdivided into two separate domains e.g. 'holidays and leisure' became both 'holidays' and 'hobbies and leisure activities'. Finally, new domains were added that were appropriate to people with MD e.g. 'correspondence and personal affairs', 'domestic tasks'. Two overview items similar to those in the ADDQoL, one generic ('In general, my quality of life is': excellent – extremely bad) and one MD-specific ('If I did not have MD, my quality of life would be': very much better – very much worse), were included in the MacDQoL.

The layout of the MacDQoL was designed to enable self-completion by people with MD. Arial font size 16 (bold) was used. All text was justified to the left, and the use of capital letters was avoided except where dictated by grammar. Heavy dotted lines led from the end of each statement to the response boxes. Instructions were enclosed in solid line boxes. Each item was contained on a separate page of the questionnaire and included two parts: the impact rating and the importance rating. The format of a domain-specific item of the MacDQoL is shown in Figure 1 though, prior to first use in focus groups, there were seven response options on the impact scale (as was the case for the ADDQoL): very much better, much better, a little better, the same, a little worse, much worse, very much worse.

(Figure 1 about here)

The first draft of the MacDQoL was tested during meetings at two local groups of the MDS. There were 6 participants at the first meeting and 11 at the second.

There were four parts to each meeting:

1. Using a statement similar to that used for participants in the ADDQoL interviews, group members were told:

*“Imagine you wake up tomorrow morning and discover that, by some magic, you no longer have macular disease and your central vision has been restored. In what important ways would that affect your quality of life?”*

Participants wrote down ways in which their QoL would change. Help was given to participants who were unable to see well enough to write.

2. Participants completed the draft MacDQoL. In some cases visual impairment meant help was required to complete the questionnaire. Help consisted of reading out the items and response options and/or entering the participants' responses on the questionnaire as necessary. Some people who were helped needed entire items reading out, others had difficulty with occasional words.
3. Participants discussed the MacDQoL and their ideas in small groups while the researchers reviewed lists generated in (1) and the questionnaires completed in (2). Domains mentioned in (1) but not yet included in the MacDQoL were identified, as were items in the MacDQoL that were not important or not impacted by MD.

4. A general discussion of the MacDQoL and QoL in people with MD was chaired by a researcher (CB). During the discussion, missing items and irrelevant items were identified and considered and wording for new items devised.

Domains used in the first draft of the MacDQoL are shown in Table 1

(Table 1 about here)

Following the 2 local group meetings and analysis of findings, changes were made to the measure:

- Participants had questioned the need for any measure of positive impact, saying that there were no ways in which MD could make a positive impact on QoL. It is possible, however, that there may be a positive impact in some domains, such as social life, which might improve for a lonely individual who joins a self-help group and makes new acquaintances there. Registration as blind entitles people to financial assistance, which may improve finances for some. It was agreed, however, that only one level of positive impact was necessary both for the domain-specific items and the MD-specific overview item.
- Three new items were added to the measure. Several group members said shopping was troublesome. Apart from the difficulty of identifying products and prices and handling money, the pleasure had gone from shopping.. The time taken to do things was a source of frustration for some, as was the risk of losing things or of mishaps such as dropping or spilling things.

A postal pilot was used to test the second draft of the MacDQoL. The measure was sent to 65 members of the MDS randomly selected from those completing the MDSQ survey [23] in earlier work who had expressed a willingness to take part in

subsequent studies. The MDSQ had a response rate of 71%, of whom 81% had indicated that they were willing to participate in further studies. The high response rate suggested that respondents were a representative sample of members of the MDS. Written consent was obtained, in accordance with the Helsinki Declaration. In addition, further data were collected using the second draft at a third MDS local group (5 participants) during the testing of an electronic data collection system.

The data from the 69 participants were entered on SPSS 9.0. These were collected from all phases of the development work. A breakdown of the sources of data is shown in Figure 2. There were 51 women and 17 men (one did not specify sex). The mean age of the sample was 76.6 years (range 39 – 100, s.d. 12.2). Eleven people had MD in only one eye and 52 people reported bilateral involvement (no data for 6 people). Twenty-eight people were registered blind, 18 were partially-sighted and 16 were not registered (no data for 7) (In the UK this is generally assessed using the familiar optometrist's chart, known as the 'Snellen' chart. People who cannot read the top line of the chart have a visual acuity that makes them eligible for registration as blind. Those who can read only the top line of the chart are eligible for registration as partially sighted). The missing data are due to the fact that members of the first two local groups were not asked for full details of their MD, although some gave unsolicited information on their questionnaires.

(Figure 2 about here)

### Scoring

The impact of MD on each domain is scored from –3 (high negative impact) through 0 (no impact) to +1 (positive impact). Importance is scored from 0 (not at all important) to 3 (very important). A weighted impact score for each domain is obtained by multiplying impact ratings by importance ratings. Some domains have

a 'not applicable' option. Where a participant indicates that a domain is not applicable to him/her, the impact and importance ratings are not completed. An average weighted impact score is obtained by summing all weighted impact scores and dividing by the number of applicable domains rated. The generic QoL overview item is scored from -3 (extremely bad) through 0 (neither good nor bad) to +3 (excellent). The MD-specific overview item is scored from -3 (high negative impact of MD on QoL) through 0 (no impact of MD on QoL) to +1 (positive impact of MD on QoL).

## **Results**

The second version of the MacDQoL contained 5 items that were newly designed for the instrument, two that were modified from ADDQoL items and 15 items that were taken directly from the ADDQoL (Table 1). Fifteen of the items in the measure were mentioned spontaneously by participants in the two focus groups (Table 1).

MD had a negative impact on every domain in the MacDQoL. Table 2 shows the mean impact scores in descending order of impact. The mean importance ratings are also shown together with the position of each domain in order of weighted impact. The rankings of the domains were changed in some cases after the impact ratings were weighted. The full range of importance ratings was used in 14 of the 22 domains (Table 2). A positive impact of MD was indicated by single participants in each of 4 domains and by 2 participants in one domain ('society's reaction') (Table 2).

(Table 2 about here)

Scrutiny of the raw data revealed that impact scores and importance ratings were often the same, other than when either score was zero. Correlations between impact and importance scores ranged between  $-0.195$  (correspondence and personal affairs) and  $0.865$  (worries about the future) (Table 3). When cases with zero scores for either impact or importance were removed, the correlation between the weighted impact score and the importance score was very high in all domains except work (Table 3). It was considered that a simpler use of the data, which might achieve equivalent results, would be to change to zero any impact scores for which the corresponding importance score was zero, and then analyse the impact scores rather than the product of impact and importance scores. This procedure was carried out for all domains. Using this method, the rank order of domains remained the same as that of the unweighted impact scores with two exceptions: Domains 4 and 5 ('shopping' and 'hobbies and leisure activities') were reversed and domains 13 and 14 ('worries about the future' and 'friends and social life') were reversed.

The mean weighted impact scores are shown in Figure 3. The greatest mean weighted impact score is for 'work and work-related opportunities' ( $-7.42$ ), followed by 'correspondence and personal affairs' ( $-6.54$ ). The data show that MD had the least impact on 'finances' ( $-1.20$ ) and sex life ( $-0.73$ ) in this sample.

Figure 4 shows the mean weighted impact scores of domains common to the MacDQoL and the 18-item ADDQoL. These two measures are scored in the same way except that the ADDQoL has three levels of positive impact, whereas the MacDQoL has only one level of positive impact. For comparison purposes, any positive ADDQoL scores were recoded as 1. With the exceptions of the domains 'enjoyment of food' and 'sex life', MD had a greater negative impact on QoL than did diabetes in all domains that the two questionnaires had in common.

(Figures 3 and 4 about here)

Justification for the inclusion of domains in the scale and for combining them to achieve an average weighted score was sought by carrying out internal consistency reliability analysis (Cronbach's alpha). With all items included, the alpha coefficient was 0.92. Alpha-if-item-deleted statistics showed that the alpha coefficient would be improved by the omission of 'sex life', 'living conditions', 'work' and 'finances'. It was decided to remove only 'sex life' and 'living conditions' at this early stage. The influence of the domain 'work' on the reliability may have been due to the small number of people ( $n = 7$ ) for whom the domain was applicable. 'Finances' had a high negative impact for a few people, and it was decided to leave that domain in the questionnaire until it has been further evaluated. The new alpha coefficient, after removal of 'sex life' and 'living conditions', was 0.93.

The sensitivity of the MacDQoL to subgroup differences was investigated by comparing the average weighted impact scores of those participants registered blind, those registered partially sighted and those not registered as visually impaired. A Kruskal-Wallis test with post hoc Mann Whitney comparisons was carried out. There were significant differences between average weighted impact scores of those not registered and both the blind and the partially sighted groups (Table 4). There was no difference between the blind and the partially sighted groups. The analyses were repeated using only impact scores, with any impact score with a corresponding importance rating of zero recoded as zero (as used to investigate the rank order of domains, reported above). This method showed slightly less sensitivity to subgroup differences but, in this sample, the significance levels remained the same. The two overview items were also used to investigate differences between the three groups. They were found to be less sensitive than

the average weighted impact score (Table 4), although they did indicate the same differences that were shown using the average weighted impact score, with the exception that the generic item did not differentiate between the partially sighted group and those not registered.

(Table 4 about here)

Spearman's correlations were carried out to investigate the association between the two-overview items and the average weighted impact score (Table 5). The highest correlation was between the MD-specific overview item and the average weighted impact score, although all the correlations were significant.

(Table 5 about here)

## **Discussion**

Members of the focus groups mentioned 12 of the original 19 domains of the MacDQoL spontaneously. This justified their inclusion in the measure for further evaluation and offered evidence of content validity. Additional evidence to support the inclusion of these and three new, spontaneously mentioned domains was provided in the reliability analysis. The internal consistency reliability coefficient alpha is a measure of the degree to which the items within the scale measure the same concept. Of the four domains that detracted from the alpha, only one had been mentioned spontaneously by participants (work). It is likely that 'work' did not contribute to the reliability because of the small number of people for whom it was applicable. The weighted impact scores of the remaining three detractors showed that they are not affected strongly by MD. The domain 'finances' was left in the measure for further investigation with a larger dataset. The reliability coefficient, after the removal of the domains (sex life and living conditions), is very satisfactory

(0.93). Nunnally and Bernstein [24] recommended an alpha level of  $>0.9$  when a scale is used to assess individuals, and lower for use with groups.

The findings illustrate that MD has a substantial negative impact on QoL. In this study, all but one of the domains showed a mean weighted impact of between  $-1$  and  $-7.5$ . The altered rankings that resulted from weighting the impact ratings by the importance ratings show that weighting does, as expected from work on the ADDQoL (16), refine the measure. Such refinement is a characteristic of multi-criteria decision making (25) and it is particularly valuable when the full range of importance ratings is used, as was the case in 14 of the 22 MacDQoL domains. This refinement allows a more accurate representation of individuals' perceptions of the impact of MD on their QoL, since it reflects the individual variations in the perceived importance of each domain for QoL. Comparisons of scores obtained using the full range of weighting scores and those obtained by weighting using dichotomous rating of important versus not important showed that information is lost using the latter method. The differing rank order of domains produced by the two methods could have significant implications for clinical management. For example, identifying priorities in rehabilitation work with a patient might be done according to the rank order of the negative impact of MD on MacDQoL domains. Without the full range of weights being applied to impact scores, help may be given in an area that is of less importance to the patient and more important priorities overlooked. At a group level, the differences in ranks of domains produced by the two methods might result in less than optimal use of resources for rehabilitation. For example, in this sample, 'risk of mishaps and losing things' is the third most negatively impacted domain using the weighted impact scores, but falls to sixth when differentiating only between no importance and any importance. Thus using the latter data, improving organisation and safety in the home might inappropriately be given a lower priority than increasing ease of travel.

There are arguments in the literature in favour of [3,4] and against [23] weighting of C-SQoL domains. Trauer and Mackinnon [26] said that there are conceptual issues associated with applying weights to scores of domains in QoL measures. They suggested that, since domains for a C-SQoL measure are generally selected because they are considered to be important to C-SQoL, it is tautologous to include importance weightings in the measure. In the study reported here, however, the full range of importance scores was used for 14 of the 22 domains, showing that domains of considerable importance to some individuals were not at all important to others.

Comparing mean weighted impact scores for people with MD and people with diabetes on the domains common to the MacDQoL and the ADDQoL, there was a greater negative impact of MD than of diabetes in all but three domains ('sex life', 'enjoyment of food' and 'finances'). The findings of this study suggest that the seriousness of a condition, in terms of its potential to be life-threatening, does not necessarily correlate highly with its impact on C-SQoL and they illustrate the importance of measuring C-SQoL in all chronic medical conditions.

The MacDQoL average weighted impact scores were sensitive to subgroup differences when used to compare participants registered blind, partially-sighted and those not registered. The finding that the average weighted impact score was more sensitive than either of the overview measures emphasises the benefits of the systematic assessment of the impact of MD on QoL in a way that captures the relevance of that impact to each individual. The two overview measures and the average weighted impact score were all correlated, and the overview items are sufficiently sensitive to be useful when a measure that is quickly and easily administered is required and would provide valuable information for health economists and planners.

The design of the MacDQoL ensures that it is condition-specific in two ways. First, domains impacted by MD and of importance to QoL were selected or suggested by people who have MD and are therefore of particular relevance for people with MD. Secondly, respondents to the questionnaire are asked specifically to consider the effect of MD on these domains. The importance of including items that are of particular relevance in MD is emphasised by the fact that six of the seven items that were either designed specifically for the MacDQoL ('correspondence and personal affairs', 'mishaps and losing things', 'shopping', 'household tasks' and 'time taken to do things') or modified from the ADDQoL (hobbies and leisure activities') are among the 10 most highly negatively impacted domains (Figure 3) in this sample. The MacDQoL is likely to be more sensitive to change than a generic measure. It is also more likely to differentiate between the effects of MD and the effects of other comorbidity, as has been found in the ADDQoL measure in comparison with the SF-36 [18]. Woodcock et al reported that the ADDQoL differentiated between the effects of complications of diabetes and the effects of unrelated comorbidity whereas the SF-36 did not. The issue of comorbidity is particularly important in an elderly population such as people with MD.

In the present study only 17 participants (25%) were men, whereas in the MD population as a whole men account for about 33%. In future research, with larger samples, particular care will be taken to ensure that the properties of the MacDQoL make it equally suitable for assessing the impact of MD on QoL in men as well as women.

During the focus groups some participants needed help to complete the MacDQoL. In this study, the need for help is confounded by severity of MD and it is not possible to isolate the possible effect of help on responses. In a forthcoming validation study respondents who are able to read the MacDQoL will be allocated

at random to interview or self-completion groups to allow the effect of different completion methods to be compared.

### **Further developments**

The authors are also involved in developing a similar measure for use in diabetic retinopathy, the RetDQoL. The RetDQoL research team used in-depth interviews with 44 patients, 22 in UK and 22 in Germany, to determine questionnaire content and wording [27]. This collaboration has led to further changes to the MacDQoL, with the addition of new items. The wording of some items has been simplified, in particular the use of 'I could' instead of 'my ability to'. The modification was suggested in the German translation but it works well in English too. Table 6 shows the domains and response options of the latest version of the MacDQoL, which will be evaluated psychometrically in future work.

(Table 6 about here)

### **Conclusions and recommendations**

The newly designed MacDQoL has been linguistically validated in 15 languages for use in a multinational clinical trial of a new treatment for wet MD. The psychometric development of the measure [28] will be carried out using data from that trial. In addition, validation of the measure outside a clinical trial will begin shortly. The internal consistency reliability must be sufficient to warrant combining scores into average weighted impact scores. The present study offers preliminary evidence of such reliability. The possibility of subscales will be investigated in future in larger samples using factor analysis and reliability analysis. The sensitivity to subgroup

differences reported here suggests that it is likely to be sensitive to change, and this will be investigated using data from the trial now in progress and in the forthcoming validation study.

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If I did not have MD, my friendships and social life would be:

- very much better.....
- much better.....
- a little better.....
- the same.....
- worse.....

My friendships and social life are:

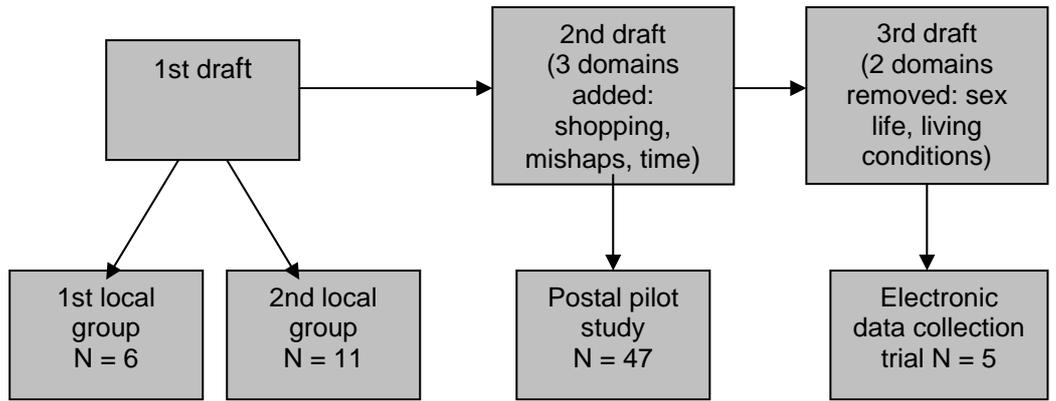
- very important.....
- important.....
- somewhat important.....
- not at all important.....

**Figure 1**

<u>Existing Domains</u>	1st focus group (n = 6)	2 <sup>nd</sup> focus group (n = 11)
household tasks #	2	4
personal affairs #	4	4
working life *		4
family life *	2	2
social life *	1	8
physical appearance *	3	5
physically do *	2	1
sex life *		
Holidays ~		
Travelling *	4	11
hobbies and leisure ~	6	10
Confidence *		1
Motivation *		
society's reaction *		1
worries about future *		
Finances *		
Dependency *	1	5
living conditions *		
enjoyment of food *		
<u>Additional domains</u>		
Shopping #	1	8
mishaps/losses #		2
time #		1

# newly designed for MacDQoL; ~ modified from ADDQoL; \* unchanged from ADDQoL

**Table 1**



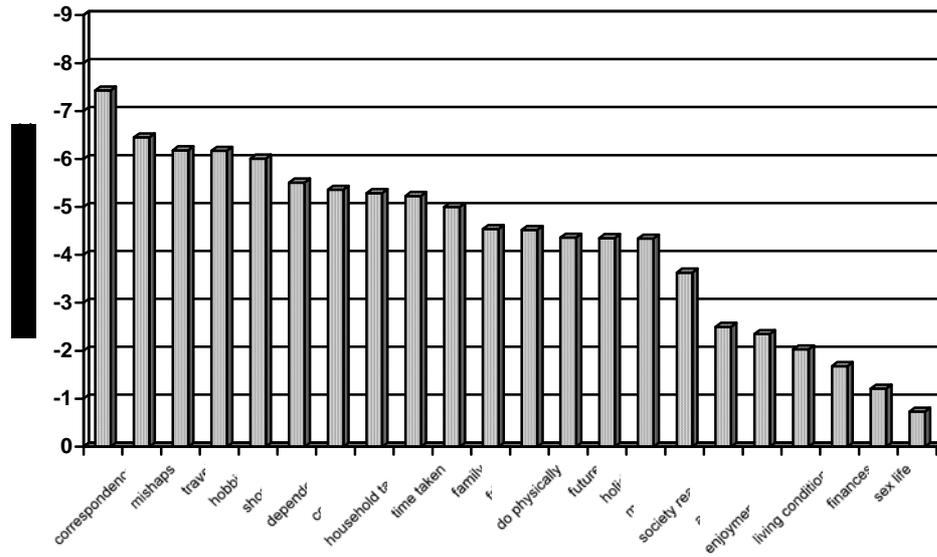
**Figure 2.**

		<u>Mean impact score (s.d.)</u>	<u>Min</u>	<u>Max</u>	<u>Mean importance rating (SD)</u>	<u>Min</u>	<u>Max</u>	<u>Position in order of weighted impact</u>
1	work	-2.57 (0.79)	-3	-1	2.86 (0.38)	2	3	1
2	correspondence	-2.46 (0.93)	-3	0	2.61 (0.63)	1	3	2
3	travel	-2.38 (0.97)	-3	0	2.49 (0.66)	0	3	4
4	shopping	-2.31 (1.05)	-3	0	2.18 (0.89)	0	3	6
5	hobbies	-2.3 (0.88)	-3	0	2.45 (0.74)	1	3	5
6	mishaps, losing things	-2.24 (1.06)	-3	0	2.54 (0.68)	1	3	3
7	domestic tasks	-2.19 (0.91)	-3	0	2.26 (0.75)	1	3	9
8	dependency	-2.06 (1.11)	-3	1	2.36 (0.81)	0	3	7
9	confidence	-2.03 (1.01)	-3	0	2.47 (0.74)	0	3	8
10	time taken	2.02 (1.09)	-3	1	2.27 (0.75)	1	3	10
11	holidays	-2.02 (1.11)	-3	0	2.03 (0.87)	0	3	15
12	do things physically	-1.81 (1.00)	-3	0	2.28 (0.70)	0	3	13
13	worries about future	-1.77 (1.23)	-3	1	2.03 (1.05)	0	3	14
14	friends and social life	-1.75 (1.18)	-3	1	2.43 (0.67)	1	3	12
15	family life	-1.67 (1.15)	-3	0	2.63 (0.60)	1	3	11
16	motivation to do things	-1.53 (1.15)	-3	0	2.21 (0.80)	0	3	16
17	society's reaction	-1.03 (1.09)	-3	1	1.94 (0.98)	0	3	17
18	appearance	-0.97 (1.04)	-3	0	1.88 (1.01)	0	3	18
19	enjoyment of food	-0.89 (1.11)	-3	0	1.80 (0.88)	0	3	19
20	living conditions	-0.73 (0.99)	-3	0	2.03 (0.92)	0	3	20
21	finances	-0.49 (1.08)	-3	1	1.78 (0.95)	0	3	21
22	sex life	-0.27 (0.80)	-3	0	1.6 (0.99)	0	3	22

**Table 2**

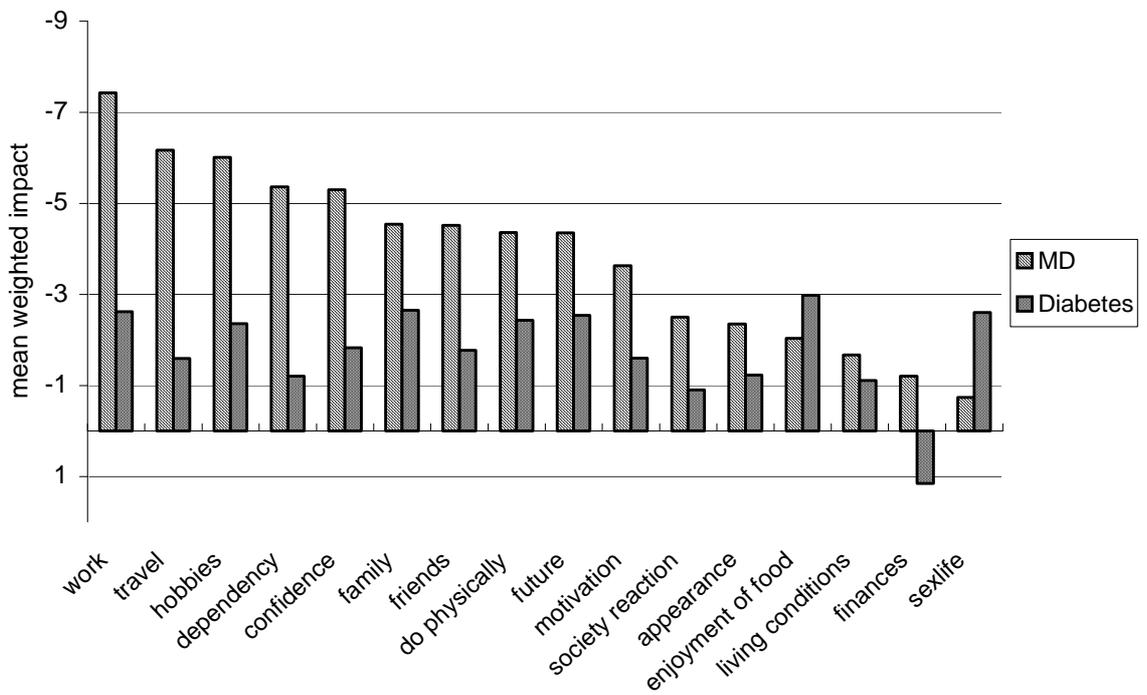
**Table 3**

<u>Domain</u>	<u>Correlation between impact and importance</u>	<u>Correlation between impact and importance after removal of scores of 0 for importance</u>
work	-0.320	-0.320
correspondence	-0.195	-0.838
travel	-0.460	-0.911
shopping	-0.553	-0.861
hobbies	-0.601	-0.937
mishaps, losing things	-0.752	-0.967
domestic tasks	-0.648	-0.915
dependency	-0.677	-0.953
confidence	-0.436	-0.933
time taken to do things	-0.596	-0.926
holidays	-0.419	-0.828
do things physically	-0.527	-0.939
worries about future	-0.865	-0.973
friends and social life	-0.382	-0.934
family life	-0.258	-0.953
motivation to do things	-0.741	-0.965
society's reaction	-0.587	-0.950
appearance	-0.551	-0.967
enjoyment of food	-0.279	-0.928
living conditions	-0.448	-0.954
finances	-0.473	-0.744
sex life	-0.422	-1.000



**Figure 3**

**Figure 4**



Kruskal-Wallis Test		Mann Whitney Post hoc comparisons			
QoL Measure	Chi-square, N, df & p-value	Vision Category	Comparison categories	Mean difference	Mann Whitney value
Average weighted impact (Mean = -4.09)	$\chi^2 = 14.03$ N = 62, df = 2 p < 0.001	Not registered	Blind	2.66	52.0**
			P/s	2.34	86.0**
		Blind	P/s	-0.32	226.5
MD-specific overview item (Mean = -2.32)	$\chi^2 = 9.36$ , N = 61, df = 2 p < 0.01	Not registered	Blind	0.81	70.0*
			P/s	0.66	123.5#
		Blind	P/s	-0.15	221.5
Generic overview item (Mean = 4.73)	$\chi^2 = 7.81$ , N = 61, df = 2, p < 0.05	Not registered	Blind	1.14	70.0*
			P/s	0.42	157
		Blind	P/s	-0.72	176.0

\*\* significant at p < 0.001; \* significant at p < 0.01; # significant at p < 0.05

**Table 4**

Measure	Average weighted impact	Generic QoL overview
Generic QoL overview	0.541*	-
MD-specific QoL overview	0.688*	0.452*

\* significant at p < 0.01

**Table 5**

## **Table 6**

### **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 close personal relationship (e.g. marriage, living companion, steady relationship), now or in the future, 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. \*I would find long journeys: (very much easier – more difficult)
12. \*My holidays would be: (very much better – worse)
13. I could pursue or enjoy my leisure activities (e.g. reading, TV, radio, cinema): (very much better – worse)
14. I could pursue or enjoy my hobbies or interests (e.g. sports, crafts, pets, gardening): (very much better – worse)
15. My self-confidence would be: (very much better – worse)
16. My motivation to achieve things would be: (very much better – worse)
17. The way people in general react to me would be: (very much better to worse)
18. The way society at large reacts to me would be: (very much better – worse)

19. My feelings about the future (e.g. worries, hopes) would be: (very much better – worse)
20. My financial situation would be: (very much better – worse)
21. I would have to depend on others when I do not want to: (very much less – more)
22. I could do things for others as I wish: (very much better – worse)
23. I would have mishaps or would lose things: (very much less – more)
24. My enjoyment of food would be: (very much increased – decreased)
25. The time it takes me to do things would be: (very much less – more)
26. I could enjoy nature: (very much more – less)

NB \* Indicates 'not applicable' option

**Table and figure captions**

**Figure 1. Format of the domain-specific items (with scoring indicated)**

**Table 1. Domains of 1<sup>st</sup> and 2<sup>nd</sup> drafts of MacDQoL and number of times listed spontaneously by members of two local MDS groups.**

**Figure 2. Participants taking part at each stage of development of the MacDQoL and summary of changes to domains in drafts 2 and 3**

**Table 2. Domains of MacDQoL in descending order of impact of MD on QoL, mean impact scores (sd), mean importance ratings (sd) and position of domains in order of impact.**

**Figure 3. Mean weighted impact scores of domains of MacDQoL**

**Figure 4. Mean weighted impact scores of domains common to ADDQoL and MacDQoL second draft**

**Table 3. Correlations between impact and importance scores and between weighted impact and importance scores after removal of cases with zero in either variable**

**Table 4. Comparison of QoL scores of people registered blind, partially sighted and not registered (Kruskal-Wallis tests and Mann Whitney post hoc comparisons): MacDQoL average weighted impact scores, MD-specific QoL overview item scores and generic QoL overview item scores.**

**Table 5 Correlations between MacDQoL average weighted impact, generic QoL overview and MD-specific overview.**

**Table 6. Domains contained in latest version of MacDQoL\*, and response options.**

\*MacDQoL © Prof Clare Bradley: 1.7.00.  
English for UK (standard). Latest revision 31.01.02.  
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