1) Introduction

Macular Disease (MD)

- is a chronic, progressive eye condition. The macula is a small area of the retina responsible for detailed central vision needed for tasks such as reading, driving and face recognition.
- damages the macula, resulting in loss of central vision. Peripheral vision is retained.
- mainly affects people over the age of 55 years.
- is the cause of over 90% of new registrations as blind people over 65 years in the UK and the US.
- can sometimes be treated to stabilize but not cure. Appropriate tools are needed to measure psychological outcomes including quality of life (QoL) in the evaluation of new treatments and rehabilitation. An MD-specific measure was developed that asked people to consider the impact of MD on their QoL.

2) Methods

- Structure of the ADDQoL\(^1\) used as a starting point.
- Items relevant to MD selected from ADDQoL\(^1\) and ROQoL\(^2\) to form the MacDQoL.
- In two focus groups participants asked to:

  - Say how QoL would be affected if sight regained
  - Complete draft MacDQoL
  - Discuss MacDQoL

- Following focus groups MacDQoL modified and 2nd draft pilot tested by post to 65 members of the UK MD Society

3) Results

Table 1. Domains used in 1st and 2nd draft

<table>
<thead>
<tr>
<th>Domain</th>
<th>Mean</th>
<th>Ordinal position</th>
</tr>
</thead>
<tbody>
<tr>
<td>I could do things for others as I wish: (very much better – worse)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>average weighted impact (AWI) scores for domains ranged from –7.43 (worse) to 0.733 (better) (Figure 2).</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Impact of MD on each domain of QoL scored from –3 (high negative impact) to 0 (no impact) to 1 (positive impact).
| Importance of each domain to individual’s QoL scored from 0 (not at all important) to 3 (very important).
| Impact and importance ratings multiplied to give weighted impact score of between –9 and +3.

Table 2. Domain average impact scores and ordinal positions after weighting with importance rating

<table>
<thead>
<tr>
<th>Domain</th>
<th>Mean</th>
<th>Ordinal position</th>
</tr>
</thead>
<tbody>
<tr>
<td>I could get out and about (e.g. on foot, or by car, bus or train): (very much better – worse)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Average weighted impact (AWI) scores for domains ranged from –7.43 (worse) to 0.733 (better) (Figure 2).</td>
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References


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