Title:

Age- and stage-appropriate measurement of vision-related quality of life (VQoL) of children and young people with visual impairment

Short title:

Vision-related quality of life of children/young people

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No conflicting relationship exists for any author.

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The following should appear online-only: Table 4 and Table 5.

ABSTRACT

Objective: Developmentally sensitive measures of vision-related quality of life (VQoL) are needed to capture age-specific concerns about the impact of living with visual impairment (VI) in children and young people. Our objective was to use our validated vision-related quality of life instrument for children and young people aged 10-15 years (the VQoL_CYP) as the foundation for development of age-specific extensions.

Design: Questionnaire development

Participants: A representative sample of children and young people aged 6-19 years with visual impairment, visual acuity of the logarithm of the minimum angle of resolution (LogMAR) worse than 0.50 in the better eye. They were identified and recruited from Paediatric Ophthalmology clinics at Great Ormond Street Hospital and Moorfields Eye Hospital and in the final phase of the study from 20 further UK hospitals.

Methods: Standard instrument development processes were followed across four phases. 29 semi-structured interviews with children and young people permitted draft age-appropriate instrument extensions. 28 cognitive interviews informed age-appropriate items and response options. Age-appropriate instrument extensions were pre-piloted on 49 subjects to ensure feasibility, and administered via a postal survey to a national sample of 160 for psychometric evaluation using Rasch analysis. Construct validity was evaluated through correlations with the Pediatric Quality of Life Inventory (PedsQL).

Main Outcome measures: Psychometric indices of validity and reliability of the instrument versions.

Results: Interviews confirmed the existing VQoL_CYP content and format were relevant across a wider age-range. Age-appropriate extensions were drafted for children (8-12 years) and young people (13-17 years). Psychometric item reduction produced 20-item child and 22-item young person versions, each with acceptable fit values, no notable differential item

functioning, good measurement precision, ordered response categories and acceptable targeting, and no notable differential item functioning on items common to both. Construct validity was demonstrated through correlations with health-related quality of life (r = .71).

Conclusions: Using an efficient child/young person-centred approach we have developed two robust, age-appropriate versions of an instrument capturing VQoL that can be used cross-sectionally or sequentially across the age-range of 8-17 years in research and clinical practice. This approach is likely to be applicable in other rare childhood ophthalmic disorders.

The use of patient-reported outcomes measures (PROMs) is now well established in both clinical practice and in research evaluating new treatments.[1] PROMs enabling self-report of health-related quality of life (HRQoL), which cannot be captured through objective clinical assessments, are particularly important. Generic HRQoL measures[2,3] designed with developmental differences in mind, have followed the standard approach of concurrent development of age-appropriate instrument versions across different age groups, by drawing on the whole population. This approach is challenging in populations with rare ophthalmic disorders such as those causing visual impairment or blindness (VI for brevity throughout).

Visually impairing disorders collectively affect about 2 per 1000 children and young people in industrialised countries.[4,5] Most children and young people with VI are affected from infancy. All will face significant lifelong challenges through the impact on development, education, social and emotional wellbeing alongside high economic costs for affected individuals, their families and society.[6] In the industrialised world and increasingly in developing countries, most affected individuals have disorders that are currently neither preventable nor curable. There is therefore a strong focus on maintaining residual vision and functional abilities in order to maximise vision-related quality of life (VQoL). However reliable and valid measures of VQoL in children and young people remain scarce, partly due to the challenges of research on populations with rare disorders.[7] Hitherto, most PROMs for children and young people with ophthalmic conditions, including those designed to assess VQoL, comprise either a single instrument used across a very wide age-range[8,9] or age-specific versions without age-appropriate items or response formats.[10] Thus, they do not take account of the development of children's understanding of illness, health and quality of life (QoL) and how this changes as they mature,[11] and cannot capture developmental differences or age-specific needs in terms of content, response options and ability to complete independently. Our decision to set the minimum age threshold at 8 years reflects the age from which self-report becomes reliable and our maximum age threshold the age of transition into adult services.[12]

We recently reported the first stage psychometric validation of a 35-item instrument measuring self-reported VQoL in children and young people with VI aged 10-15 years - the VQoL_CYP.[13,14] To ensure content validity, we undertook semi-structured and cognitive debriefing interviews. In the absence of both an existing conceptual framework and an established methodology for developing measures for this numerically small population, we deliberately targeted the 10-15 years age-group in this foundation research, as most capable of identifying the impact of living with VI through individual interviews and self-completing the instrument with ease. We now report our planned extension and adaption of that foundation instrument[13,14] to a broader age-range, including our novel approach of calibrating the new age-appropriate versions so that they can be used and compared in different age-groups at any given point but also be used to follow subjects over time as they grow older i.e. sequentially.

METHODS

The study was approved by the National Health Service (NHS) Research Ethics Committee for Essex and East of England, United Kingdom (UK) and followed tenets of the Declaration of Helsinki. Participants gave informed individual assent (if <16 years) or consent and parents gave informed consent to their child's participation (if <16 years).

Sample

Children and young people were eligible if they were *i)* visually impaired, severely visually impaired or blind (visual acuity in the better eye of LogMAR 0.50 or worse or Snellen worse than 6/18 or additional visual defects causing visual impairment) due to any visual disorder, but without any other significant impairment (i.e., learning, sensory or motor); and *ii)* aged 6-19 years (with age boundaries for the instrument determined later). They were drawn from 2 patient populations between September 2014 and May 2017 comprising those attending the Department of Ophthalmology at GOSH and the Pediatric Glaucoma Service and Genetic Eye Disease Service at Moorfields Eye Hospital, London UK supplemented

(final phase only) by patients attending 20 other hospitals across Britain (see Acknowledgments). By sampling across multiple sources nationally in the final phases, where largest samples are needed, we ensured our sample was as representative as possible of the UK population of children and young people with VI with respect to ethnic and socio-economic status.

Procedures

Instrument adaptation followed standard instrument development phases, with our 'foundation' research with 10-15 year olds[13,14] as the framework.

Phase 1: Item development and adaptation

To investigate whether the issues covered by the existing VQoL_CYP items (from the 10-15 year olds' instrument[13,14]) were relevant to children/young people outside the age-range of 10-15 years and identify any new age-specific issues not already included, we conducted individual in-depth semi-structured interviews with children younger than 10 and young people older than 15 years. Building on the foundation of the existing VQoL_CYP instrument, which was based on 32 interviews with 10-15 year olds, we reached data saturation after 29 interviews (12 with children aged 6-9 years, 17 with young people aged 16-19 years). Interviews were transcribed and coded using NVivo10.[15] We used the thematic framework developed through qualitative thematic analysis in the foundation study that produced the existing VQoL_CYP instrument for 10-15 year olds, to identify areas of overlap and discrepancy between the new interview data and the existing instrument. Where omissions were identified, new, age-appropriate items were developed.

Additionally, to ensure that the subsequent first draft version of the instrument version for younger children was developmentally appropriate, participants <10 years were asked to complete the existing VQoL_CYP (10-15 years)[13,14] with parental assistance and provide feedback to inform development of the subsequent age-appropriate version. This was not

considered necessary for participants older than 15 years, who were developmentally well placed to comprehend the existing VQoL_CYP (10-15 years) items.

Phase 2: Pre-testing

The upper and lower age boundaries of each new age-appropriate VQoL instrument version were developed empirically throughout Phase 2, whilst considering data also from the early interview phases of the VQoL_CYP (10-15 years) development.[13] Due to the extensive foundation work in development of the original instrument for 10-15 year olds and the resemblance of the new age-appropriate drafts to the published instrument, recruitment in this phase was focused primarily on participants younger than 10 and older than 15 years. Individual cognitive interviews with 12 children aged 7-10 years and 16 young people aged 13-18 years ensured comprehensibility of the new age-appropriate draft instrument versions. This was supplemented by parental feedback on the same items presented to children and young people and study group consensus. Items were refined accounting for importance, comprehensibility, difficulty and response format. Alongside re-reading of the original individual interviews with 10-15 year olds,[13] feedback from children and young people, their parents, and study group consensus was used to determine the age thresholds for the new instrument versions as 8-12 years (VQoL_Child) and 13-17 years (VQoL_Young Person).

Phase 3: Pre-piloting

Pre-piloting of the modified new instrument versions comprised a postal survey of 26 children aged 8-12 years and 23 young people 13-17 years, to ensure feasibility with respect to missing data and administration burden and to inform initial decisions about subsequent item reduction.

Participants received a pack comprising invitation letters, child and parent information sheets and consent/assent forms, the age-appropriate instrument versions in large print (including a link to an electronic version) and a postage-paid envelope for return of the completed

materials. Participants were invited to provide written qualitative feedback. Questionnaire data were verified by checking the study database, with no errors detected.

Phase 4: Piloting

Formal piloting comprised a large-scale postal survey of a national sample (UK) of 87 children aged 8-12 years and 73 young people aged 13-17 years to confirm psychometric properties of the two new instrument versions. The VQoL_Child and the VQoL_Young Person were administered alongside the Child (8-12 years) and Teenager (13-18 years) versions of the Pediatric Quality of Life Inventory (PedsQL[3]) to assess construct validity. The PedsQL, a validated generic HRQoL instrument, produces Total, Physical Health and Psychosocial Health Scores, with higher scores indicating better HRQoL.[3,16]

Participants received study packs as per previous phases. Questionnaire data were verified through double-checking the study database and any data-entry errors corrected.

Psychometric evaluation

In keeping with published criteria,[17] data from participants with >25% of item responses missing were excluded, as were items for which >50% of participant responses were missing.

Rasch analysis[18-22] was used for item reduction and psychometric assessment using Andrich's Rasch Rating Scale model.[23] Several criteria were used to assess the appropriateness of the two instruments,[17,24] as detailed in Table 2 and Figures 1 and 2. Prior to conducting Rasch analysis negatively worded items were reversed and 1-4 responses coded into 0-3 scores.

Calibration of VQoL_Child and VQoL_Young Person.

The model resulting from equating both instruments, as outlined by Lincacre[25] ensured that the age-appropriate instrument versions were capable of measuring the same construct in children and young people. This model, based on the overlapping items on both age-

dependent instruments provides continuity of measurement for ages 8 to 17 years, ensuring the instruments can be used in cross-sectional studies. It also allows comparisons of summary scores measured during follow-up of individuals as they grow older (i.e. *sequential* use). These scores are obtained as the sum of all individual item raw scores, and can be transformed into a Rasch person measures using Table 5 (available at www.aaojournal.org). This transformation assumes that all items have equal importance, and that response categories are scaled accordingly to yield an equal value with uniform increments between consecutive categories. To examine whether the equated Rasch person measures from the two age groups (8-12 and 13-17 years) were comparable in this way, a final differential item functioning (DIF) analysis was conducted using the 'core' set of items common to both.[26]

Unidimensionality was assessed using infit and outfit statistics, and the criteria described in Table 2.[17] DIF statistics, shown in Table 2 represent the effect size, in logits of the difference between the two classifications of persons.[27]

Construct validity

VQoL summary scores were calculated and converted into Rasch person measures ranging from 0 (severely reduced VQoL) to 100 (excellent VQoL) using the score-to-measure tables for each age-appropriate version (Table 5, available at www.aaojournal.org), ensuring the derived measures can be compared between age-appropriate versions despite differences in the number and wording of items.

Construct validity (i.e. instrument's ability to truly measure an intended outcome) was assessed through correlations between Rasch person measures on the VQoL_Child and VQoL_Young Person and scores on the Child and Teen PedsQL (Total and Psychosocial subscale summaries). Participants with any missing responses were excluded from the analyses. Additionally correlation between Rasch person measures on the VQoL_Child and VQoL_Young Person and visual acuity was examined, without anticipation of a correlation, in keeping with the 'disability paradox'.[28]

Correlations with PedsQL were examined using the Rasch person measures for each new VQoL version individually, before combining scores from both age-appropriate versions.

Spearman's Rank correlations were reported.

Rasch analysis was conducted using Winsteps, 4.0.1.[29] All other analyses were completed using SPSS.

RESULTS

Table 1 shows the participant characteristics across the study phases, illustrating an unbiased representation of the overall UK population of children and young people with VI with respect to clinical and socio-demographic characteristics and ophthalmic diagnoses (given the exclusion of participants with any other significant impairment).[5,13,14]

Phase 1: Item development and adaptation

Analysis of the new interview data revealed significant overlap between the issues raised by children younger than 10 and young people older than 15 years, and the issues covered by the existing VQoL_CYP instrument for 10-15 year olds.[13,14] Where age-related variation emerged it was in descriptions/and attributions of issues to QoL, rather than differences in the type of issues experienced, necessitating some adaptations. For the older age group, 11 items removed during the foundation research were reinstated based on views expressed in the interviews regarding relevance. A new item on tiredness and impact on sleep, as flagged by participants, was added.

The format involving the illustrative child/3rd person vignette was changed as a result of significant skew in VQoL_CYP items presented on the 'ideal status' scale in the foundation study.[14] All items were re-worded as first person statements (e.g. 'I feel left out because of my eyesight') and response categories amended accordingly whereby the responding child/young person reported how true each statement was about him/her. Four response categories were developed and refined, considering children and young people's natural

vocabulary used during interviews (1-Not at all true, 2-A little bit true, 3-Mostly true, 4-Completely true).

The resulting draft 31-item VQoL_Child and 37-item VQoL_Young Person versions for children aged <10 years and young people aged >15 years, were pre-tested.

Phase 2: Pre-testing

A small number of items considered ambiguous by participants were re-phrased or removed.

The minimum age threshold was agreed as 8 years and age boundaries re-adjusted as 8-12 years and 13-17 years, thus aligning to other child PROMs.[3] The resulting 29-item VQoL_Child and 39-item VQoL_Young Person extensions were pre-piloted.

Phase 3: Pre-piloting

The participation rates were 44.1 % and 31.1% for children and young people respectively.

Median completion time was 15 minutes (IQR=13) for children and 10 minutes (IQR=23.75) for young people, with 86% and 95% of children and young people respectively rating instrument completion as easy/very easy, and 95% and 100% respectively rating the instructions as easy/very easy.

Data from one child were excluded due to 76% missing data. There were no missing responses in the child dataset and a small (≤10.26%) number of missing values per item in the young people's dataset.

The number of items with over 50% of responses or 0% responses in an 'end' category were 8 and 4 respectively in the child and 5 and 13 in the young person dataset. Items with problematic distribution were flagged for potential removal during formal piloting of the 30-item VQoL_Child and 39-item VQoL_Young Person.

Phase 4: Piloting

The participation rates were 31.4% and 26.4% for children and young people respectively.

Missing data per item (completely at random) was <3% for both instrument versions. Two children (but no young people) were excluded from subsequent analysis based on having >25% missing data per person. All remaining missing data per person was found to be missing completely at random (MCAR),[30] and retained for Rasch analyses.[31]

Psychometric evaluation

Six items were removed from the VQoL_Child and 5 from the VQoL_Young Person due to significant skewness, and ceiling effects and a further 4 and 12 respectively during Rasch based on goodness-of-fit, response ordering and DIF statistics (Table 4, available at www.aaojournal.org). The resulting 20-item child and 22-item young person instrument versions showed these statistics to be within acceptable limits. One item fell just outside the acceptable criteria for only goodness-of-fit criterion but was retained in the VQoL_Young Person to preserve content validity and comparability with VQol_Child where it was retained (Table 2). For each version, the item probability plots showed good ordering, and acceptable differentiation between the 4 response categories (Figure 1) and targeting of items to respondents (the difference between person and item means = 0.81 logits (child version) and 0.76 (young person version)) although items were clustered around the mid-low end of the item difficulty scale (Figure 2). Each version showed good precision as indicated by indices for person separation (3.64 and 2.74 for child and young person versions respectively).[17,32]

The final 20 item VQoL_Child and 22 item VQoL_Young Person scales included 12 common 'core' items and 8 and 10 age specific items respectfully.

Calibration of the VQoL_Child and VQol_Young Person instrument versions

DIF analysis of overlapping core items showed no contrasts greater than 1 logit (Table 2), demonstrating they were not biased to either age group (after adjusting for the overall scores of respondents). Thus, all remaining overlapping items are productive for measurement of VQoL in both instrument versions despite the presence of additional, age-specific items.

Score-to-measure transformation

To enable easy and precise scoring, we developed conversion tables for transforming the summary scores to Rasch person measures as shown in Table 5 (available at www.aaojournal.org). These can be used to compare Rasch person measures when using either or both versions cross-sectionally or sequentially.

Construct validity

We excluded 6 children and 5 young people with missing data before analysing construct validity. Rasch person measures on the VQoL_Child and VQoL_Young Person correlated positively with Child and Teen PedsQL scores, substantiating the instrument's construct (convergent) validity (Table 3). As anticipated, acuity did not correlate significantly with VQoL.

DISCUSSION

We report an effective, efficient and child/young person-centred approach to developing an age-appropriate PROM for children and young people with VI. Using a novel approach for calibrating instruments and exploiting our prior research and original instrument for those aged 10-15 years,[13,14] we have generated two psychometrically robust versions of this measure that are suitable for a wider age-range, spanning 8-17 years, whilst retaining developmentally appropriate content through a modular structure of common core items alongside age-group specific items. Using this approach, we have improved feasibility for both patients and clinicians. Our final 20- and 22-item VQoL_Child and VQoL_Young Person instrument versions, respectively, are shorter than our original version for 10-15 year olds and reported to be easy to complete without sacrificing comprehensiveness. We have calibrated the two age-specific versions using overlapping core items, so that the correct instrument version can be used based on the age of children in the study at that time point and also so that VQoL can be measured without loss of continuity of measurement as the subjects get older by using the alternative instrument version. Thus, these versions can be

used both cross-sectionally (e.g. in trials with a wide age-range of subjects) and sequentially (e.g. in cohort studies or clinical follow up of individual patients) in future studies and research. Our log transformation tables, which convert summary scores into Rasch person measures, provide clinicians the means for using and interpreting scores with precision and ease. We also provide the model-based standard error of each measure, which should be used in future clinical research implementing the instruments.

Our two new instrument versions (like the original VQoL_CYP[13,14]), show good construct validity, correlating strongly with HRQoL on a generic measure (particularly its psychosocial component). As anticipated,[14] the VQoL scores for both children and young people were not associated with visual acuity. These findings align with the 'disability paradox'.[28,33,34] This phenomenon, whereby individuals with severe disabilities or illnesses report good QoL, exemplifies the importance of considering QoL to be a subjective construct.[35] Thus the child or young person with VI will construct his/her perception of their QoL from the subjective day-to-day experience of living with a visual disability and ultimately, their scores on a self-reported QoL measure will reflect this. This has important implications for how the VQoL_Child and VQoL_Young Person, and indeed any child QoL PROMs, should be used. For instance, in the context of trials of new interventions or therapies intended to improve vision, the implications of the 'disability paradox' must be recognised to avoid conclusions about impact of interventions being misconstrued.

Although the new VQoL instrument versions are age-group specific (for example, concerns about independent living in the future feature only in the VQoL_Young Person) the significant overlap in common content across the two versions, as well as with our original VQoL_CYP,[13,14] demonstrates the core life trajectory of children with VI whereby concerns (e.g. social inclusion and acceptance) and barriers (e.g. in education) emerge and establish across childhood and adolescence. This is likely to be true also for other child populations. Moreover, issues related to VI align with other disabilities as well as other chronic complex childhood conditions, as evidenced by the content of similar HRQoL measures[2,3,35] and by

the significant correlations with the PedsQL in our study, thereby affirming the strong content and construct validity of the VQoL_Child and VQoL_Young Person.

Although we achieved a good sized sample relative to the rarity of childhood VI, a more granular examination of the underlying domain structure in the instrument was not possible due to limited power. We followed the conventional approach of using infit and outfit statistics to remove items until all the stringent criteria have been met.[17] Unidimensionality, for each instrument version was sufficiently evidenced by the ranges of infit and outfit statistics which support the derivation of a summary score, and the scale items span the spectrum of aspects of QoL suggested by broader literature, [2,35] demonstrating good face validity.

Recognising the lack of instruments suitable for the youngest children with VI and cognisant that some children can self-report reliably from as young as 5 years,[12,36,37] we conducted some semi-structured and cognitive interviews with children younger than 8 years but found both recruitment and information capture challenging despite using different child-appropriate methods. This highlights an important direction for future research. In the meantime, the age-range served by our instrument coincides with that recommended and reported in the literature,[12,16] and enables complementary use of generic HRQoL instruments.

We found both the VQoL_Child and VQoL_Young Person to be somewhat better targeted to participants reporting lower VQoL. This is comparable to the targeting pattern we reported for our original instrument for 10-15 year olds[14] as well as that reported in the development of IVI_C,[8] which is a similar instrument developed in Australia to assess VQoL of children and young people with VI. Given that the items seem more suited to children with lower VQoL, these instruments may be particularly useful in assessing VQoL changes in visually impaired children and young people who are at risk of lower QoL, for instance, due to receiving less professional support (e.g. in education) and in the context of relevant interventions aimed at increasing such support.

DIF analyses can be unstable and produce spurious results when applied to small samples. In particular, they often reflect an increased chance of false positive findings (i.e. removal of too many items).[38] In the case of questionnaire development, this means that a shorter scale will be produced. This is not the case for the reduced VQoL_Child and VQoL_Young Person instrument versions which have a good coverage of all elements of VQoL.

Ethical and practical considerations involved in re-testing participants precluded examination of test-retest reliability and responsiveness of the measure over time. We will address this in our planned research on optimal approaches to routine implementation of vision PROMs in clinical practice, to assess how our VQoL instrument can best be deployed alongside our other vision PROM assessing functional vision[39] to enable a holistic assessment of impact and thus truly 'personalised' care.

It is challenging but possible to generate psychometrically robust and developmentally appropriate instruments usable by the whole age-range of children and young people with VI. Our novel approach for vision specific PROMs enables a measurement model in which instruments can be used cross-sectionally and sequentially in both clinical practice and research. We suggest the approach we have described is transferable to other childhood ophthalmic conditions and is a parsimonious approach useful in research on rare conditions. Small sample sizes, inherent in research on rare paediatric populations such as children and young people with VI can preclude *concurrent* de novo development of age-group specific measures. We have overcome the challenges posed by limited sample sizes by starting with a foundation instrument that is anchored to the middle of the overall age-range (10-15 years),[13,14] and using this as the basis for extending the age-range in both directions.

Figure 1: Category probability curves showing the probability of selecting response categories across the scale of item difficulty for age-appropriate extensions of the VQoL_CYP[40]

Figure 1a: Category probability curves for the 20-item VQoL_Child

Figure 1b: Category probability curves for the 22-item VQoL_Young Person

Figure 2: Item-person maps illustrating acceptable targeting of VQoL items (located on the right side of the dashed line) to responders (located on the left side of the dashed line and represented by X).[32] Participants with higher VQoL and items with higher difficulty to endorse as true are at the top half of the map.

Figure 2a: Item-Person map for the VQoL_Child

Figure 2b: Item-Person map for the VQoL_Young Person

M = mean; S = 1 standard deviation from the mean; T = 2 standard deviations from the mean.

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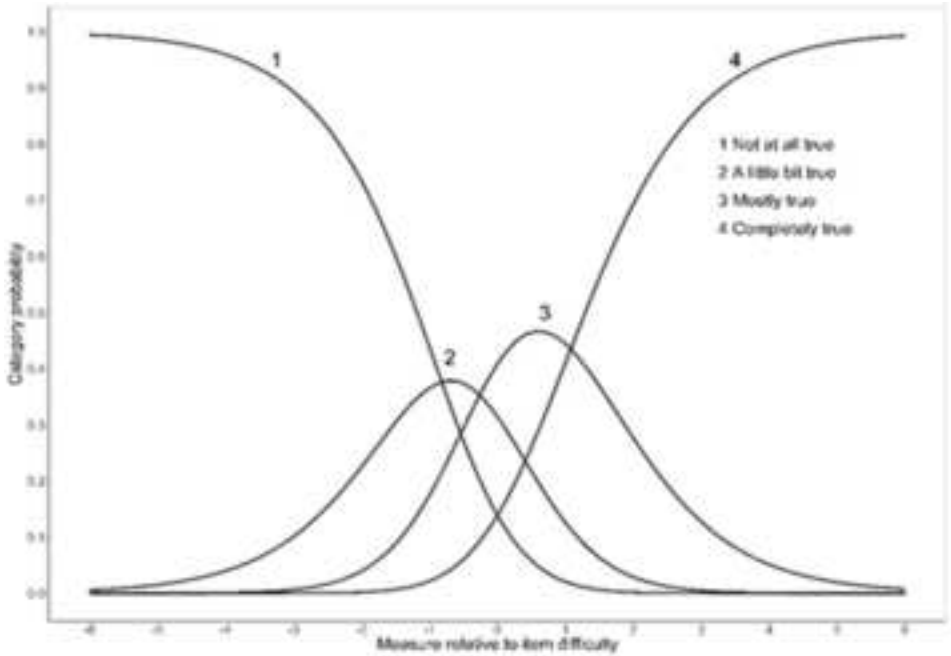
Figure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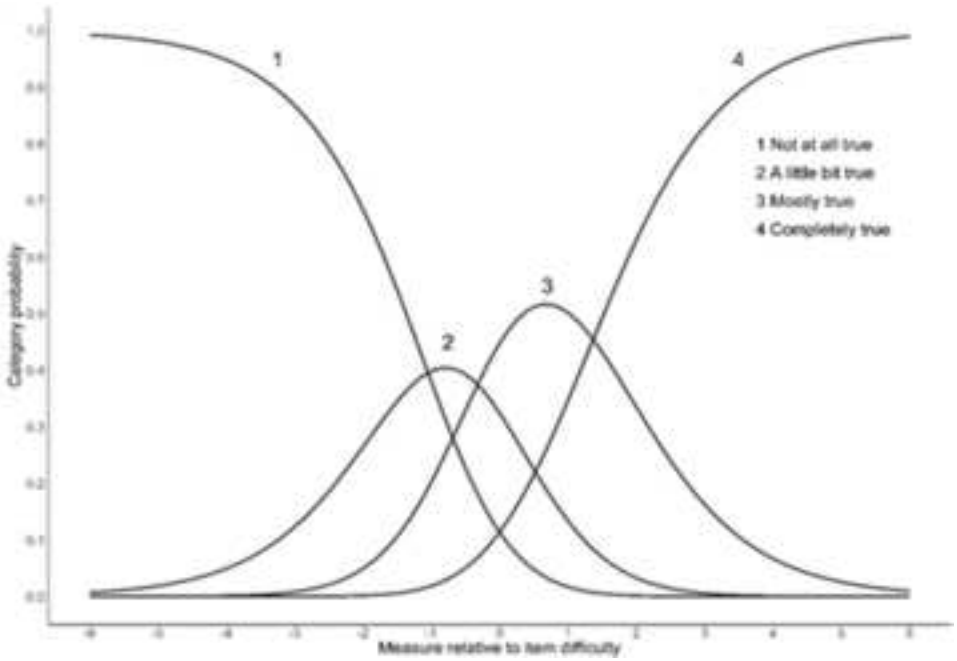
Category probability
Measure relative to item difficulty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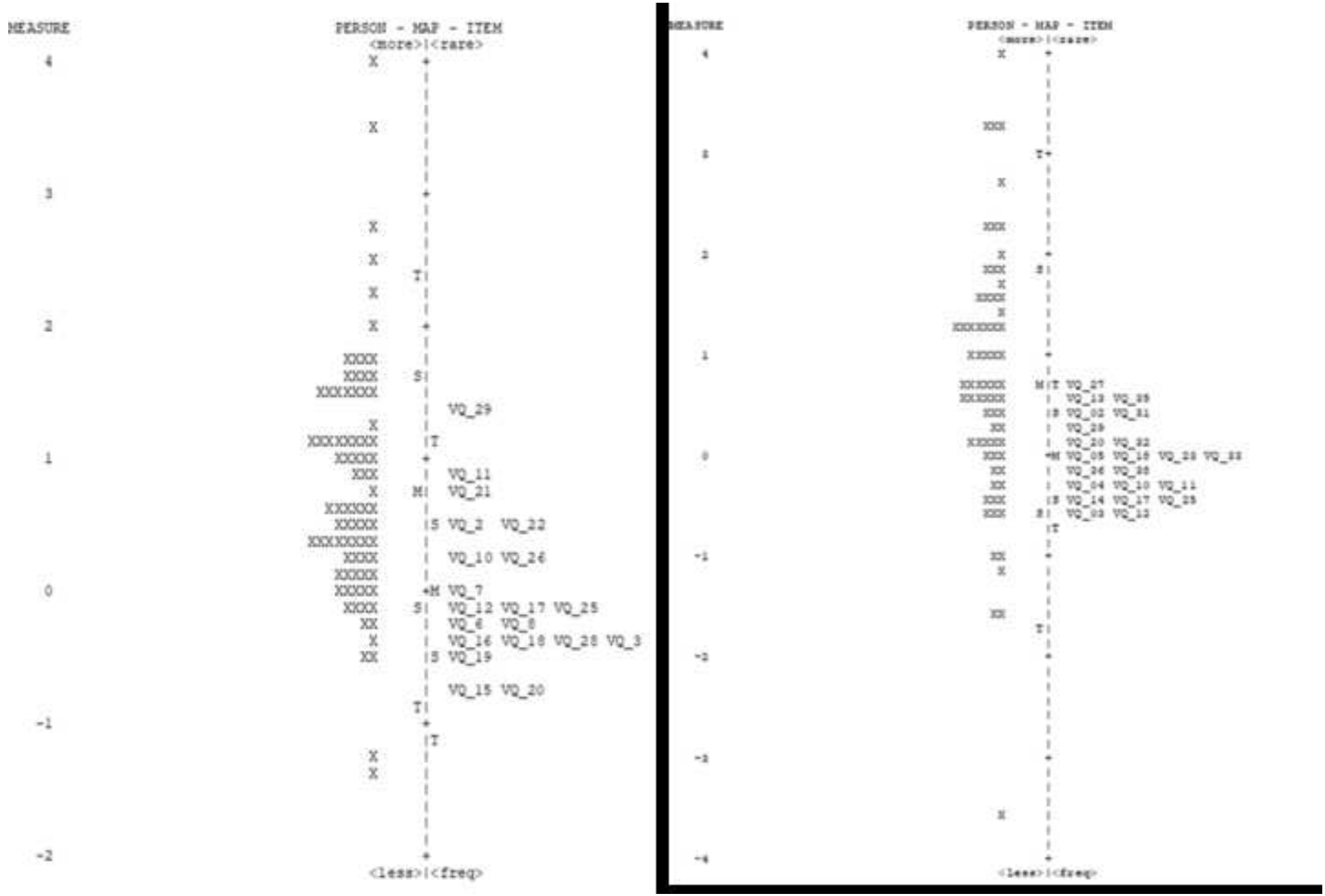
Category probability
Measure relative to item difficulty

Figure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VQ_05 VQ_19 VQ_38 VQ_33
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Table 1

Table 1. Demographic and clinical characteristics of participants in each phase of VQoL_CYP instrument adaptation.

	Phase 1		Phase 2		Phase 3		Phase 4	
Demographic characteristic	**Children (*n* = 12)**	**Young People (*n* = 17)**	**Children (*n* = 12)**	**Young People (*n* = 16)**	**Children (*n* = 26*)**	**Young People (*n* = 23)**	**Children (*n* = 87**)**	**Young People (*n* = 73***)**
Age								
6	1 (8.3)	-	-	-	-	-	-	-
7	-	-	2 (16.7)	-	-	-	3 (3.45)	-
8	4 (33.3)	-	6 (50)	-	3 (11.54)	-	19 (21.84)	-
9	7 (58.3)	-	3 (25)	-	4 (15.38)	-	22 (25.29)	-
10	-	-	1 (8.3)	-	6 (23.08)	-	9 (10.34)	-
11	-	-	-	-	8 (30.77)	-	16 (18.39)	-
12	-	-	-	-	5 (19.23)	-	17 (19.54)	-
13	-	-	-	3 (18.75)		4 (17.39)	1 (1.15)	8 (10.96)
14	-	-	-	2 (12.5)		6 (26.09)	-	19 (26.03)
15	-	-	-	3 (18.75)		4 (17.39)	-	15 (20.55)
16	-	7 (41.18)	-	2 (12.5)		4 (17.39)	-	14 (19.18)
17	-	8 (47.06)	-	3 (18.75)		5 (21.74)	-	15 (20.55)
18	-	1 (5.88)	-	3 (18.75)		-	-	2 (2.74)
19	-	1 (5.88)	-	-		-	-	-
Gender								
Male	8 (66.7)	10 (58.82)	8 (66.7)	8 (50)	16 (61.54)	13 (56.52)	36 (41.38)	39 (53.42)
Female	4 (33.3)	7 (41.18)	4 (33.3)	8 (50)	10 (38.46)	10 (43.48)	51 (58.62)	34 (46.58)
Ethnicity								
White UK majority (White British)	8 (66.7)	10 (58.82)	5 (41.7)	11 (68.75)	13 (50)	16 (69.57)	49 (56.32)	46 (63.01)
White other (e.g. African, Polish, Turkish)	-	1 (5.88)	2 (16.7)	1 (6.25)	4 (15.4)	3 (13.04)	5 (5.75)	4 (5.48)
Black (British, African, Caribbean)	1 (8.3)	-	1 (8.3)	-	-	-	9 (10.34)	3 (4.11)
Asian (Indian, Bangladeshi, Pakistani)	2 (16.7)	3 (17.65)	2 (16.7)	4 (25)	7 (26.9)	4 (17.39)	18 (20.69)	8 (10.96)
Asian other (Arabic)	-	1 (5.88)	-	-	-	-	3 (3.45)	2 (2.74)
Chinese	-	-	-	-	-	-	-	-
Mixed	1 (8.3)	2 (11.76)	2 (16.7)	-	-	-	3 (3.45)	2 (2.74)
Missing	-	-	-	-	2 (7.7)	-	-	8 (10.96)
Severity of visual impairment								
LV: logMAR ≤0.46	-	1 (5.88)	-	-	-	-	5 (5.75)	1 (1.37)
VI1: logMAR 0.48-0.70	4 (33.3)	8 (47.06)	4 (33.3)	9 (56.25)	13 (50)	9 (39.13)	37 (42.53)	20 (27.4)
VI2: logMAR 0.72-1.00	5 (41.7)	3 (17.65)	3 (25)	5 (31.25)	8 (30.8)	7 (30.43)	32 (36.78)	30 (41.1)
SVI: logMAR 1.02-1.30	-	2 (11.76)	1 (8.3)	1 (6.25)	3 (11.5)	4 (17.39)	5 (5.75)	8 (10.96)

Blind: logMAR ≥1.32	3 (25)	3 (17.65)	4 (33.3)	1 (6.25)	2 (7.7)	3 (13.04)	8 (9.2)	14 (19.18)
Timing of onset of visual impairment								
Early (≤2 years)	12 (100)	15 (88.24)	12 (100)	10 (62.5)	25 (96.1)	21 (91.3)	74 (85.06)	58 (79.45)
Late	-	2 (11.76)	-	6 (37.5)	1 (3.9)	2 (8.7)	13 (14.94)	15 (20.55)
Nature of deterioration of visual impairment								
Stable	9 (75)	12 (70.59)	6 (50)	5 (31.25)	18 (69.2)	21 (91.3)	56 (64.37)	60 (82.19)
Progressive	3 (25)	5 (29.41)	6 (50)	11 (68.75)	8 (30.8)	2 (8.7)	31 (35.63)	13 (17.81)
Diagnosis by site of visual impairment†								
Whole globe and anterior segment	-	1(5.88)	1 (8.3)	1 (6.25)	-	-	2 (2.3)	3 (4.11)
Glaucoma, primary or secondary	1 (8.3)	-	3 (25)	-	5 (19.23)	-	5 (5.75)	10 (13.7)
Cornea (sclerocornea and corneal opacities)	-	-	-	1 (6.25)	1 (3.85)	1 (4.35)	1 (1.15)	2 (2.74)
Lens (cataract and aphakia)	1 (8.3)	-	1 (8.3)	2 (12.5)	3 (11.54)	1 (4.35)	11 (12.64)	8 (10.96)
Uvea	-	-	-	-	2 (7.69)	1 (4.35)	4 (4.6)	7 (9.59)
Retina	9 (75)	12 (70.59)	8 (66.67)	9 (56.25)	15 (57.69)	18 (78.26)	56 (64.37)	50 (68.49)
Optic nerve	1 (8.3)	3 (17.65)	1 (8.3)	3 (18.75)	1 (3.85)	2 (8.7)	12 (13.79)	4 (5.48)
Cerebral/visual pathways	1 (8.3)	-	-	1 (6.25)	1 (3.85)	1 (4.35)	4 (4.6)	8 (10.96)
Other (idiopathic nystagmus, high refractive error)	-	6 (35.29)	1 (8.3)	-	3 (11.54)	3 (13.04)	16 (18.39)	13 (17.81)
Index of multiple deprivation quintile rank								
1: most deprived	2 (16.7)	1 (5.88)	1 (8.3)	2 (12.5)	1 (3.8)	1 (4.35)	21 (24.14)	17 (23.29)
2	1 (8.3)	2 (11.76)	5 (41.7)	-	9 (34.6)	5 (21.74)	14 (16.09)	14 (19.18)
3	3 (25)	4 (23.53)	2 (16.7)	4 (25)	8 (30.8)	4 (17.39)	17 (19.54)	11 (15.07)
4	2 (16.7)	8 (47.06)	3 (25)	3 (18.75)	4 (15.4)	5 (21.74)	15 (17.24)	12 (16.44)
5: least deprived	4 (33.3)	2 (11.76)	1 (8.3)	7 (43.75)	4 (15.4)	8 (34.78)	17 (19.54)	19 (26.03)
Missing	-	-	-	-	-	-	3 (3.45)****	-

*One child excluded from analysis due to incomplete child data (child having learning difficulties and parent proxy data provided instead).

**Four children excluded from analysis due to incomplete (n= 2, more than 25% data missing) or completely missing (n=2) child data (e.g. parent proxy report provided instead).

***Two young people excluded from analysis due to completely missing (n=1) young person data (e.g. parent proxy report provided instead) and failure to consent (n=1) to use of young person data.

****Data missing due to postcode data not provided by the managing clinical team, as per local governance approval at the patient identification centre.

† Does not add up to 100% because some children had visual impairment originating in multiple sites.

Table 2

Table 2. Rasch fit statistics, item measure and differential item functioning (DIF) contrasts for the 20-item and 22 item age-appropriate VQoL instrument extensions, and DIF contrasts for the overlapping items (overlapping items shown in bold).

VQoL_Child	VQoL_Young Person	VQoL_Child					VQoL_ Young Person					Core items
Item	**Item**	**Item measure (logits)**	**Infit MNSQ***	**Outfit MNSQ**	**DIF** contrast by age (logits)**	**DIF contrast by gender (logits)**	**Item measure (logits)**	**Infit MNSQ**	**Outfit MNSQ**	**DIF contrast by age (logits)**	**DIF contrast by gender (logits)**	**DIF contrast by sample (i.e. children v.s young people)**
I make new friends easily	**I make new friends easily**	0.44	0.98	0.96	-0.27	-0.16	0.47	0.91	0.86	-0.75	0.41	.25
I keep friends easily	**I keep friends easily**	-0.39	0.84	0.83	0.1	-0.11	-0.52	0.81	0.96	0	0.22	-.27
	I am happy with my social life						-0.25	0.89	0.83	0.44	-0.29	
	I spend enough time with my friends						0.06	1.19	1.13	0.48	0.16	
Other children pick on me because of my eyesight		-0.3	1.04	1.02	0.57	0.49						
I can stand up for myself if someone picks on me		0.01	1.28	1.24	-0.12	0.23						
My friends understand how things are for me because of my eyesight		-0.29	1.04	1.1	0.22	0.2						

	I get treated the same as everyone else						-0.22	1.18	1.19	-0.59	-0.1	
	I feel like I fit in						-0.25	1.01	0.9	0.08	-0.4	
My friends encourage me to join in their activities	**My friends encourage me to join in their activities**	0.26	1.28	1.45	0	0.42	-0.51	1.02	0.94	0	-0.18	-.29
I feel different from other children because of my eyesight	**I feel different from other young people because of my eyesight**	0.94	0.95	0.97	0.11	0.22	0.62	0.97	0.98	0.27	-0.57	-.16
I feel left out because of my eyesight	**I feel left out because of my eyesight**	-0.08	0.65	0.62	-0.08	0.09	-0.5	1.01	0.89	0.34	-0.33	-.14
I can decide things for myself		-0.78	1	1.2	0.77	0.24						
I am independent at home	**I am independent at home**	-0.44	0.94	0.95	0.14	0.17	-0.37	1.07	1.12	-0.1	-0.19	.00
I am independent at school	**I am independent at school/college**	-0.11	0.94	0.94	0	0.27	-0.03	0.8	0.83	0.06	0.22	-.11
	I can do most activities on my own						0.19	1	0.95	-0.18	0.54	
People give me a chance to do things for myself		-0.34	0.79	0.76	0.21	-0.1						
I am happy asking for help	**I am comfortable asking for help**	-0.52	1.13	1.02	-0.54	-0.11	-0.02	1.03	1.06	0.06	0.2	.06
I cope well with my eyesight problems	**I cope well with my eyesight problems**	-0.74	1.02	0.97	-0.7	-0.79	-0.49	0.89	0.83	-0.16	-0.22	.06

I feel tired because of my eyesight		0.74	1.28	1.35	0.39	-0.52						
I feel frustrated because of my eyesight	**I feel frustrated because of my eyesight**	0.51	0.96	1.05	0	-0.09	0.78	1.38	1.53	-0.06	-0.07	.00
	I feel confident						0.27	0.74	0.75	0	0.5	
Other people are fair to me		-0.13	0.67	0.65	0.05	0						
I worry what other people think of me because of my eyesight	**I worry what other people think of me because of my eyesight**	0.25	1.16	1.23	-0.53	0.17	0.45	1.13	1.02	-0.28	0.26	.00
	I am positive about the future						0.08	0.91	0.96	0	-0.11	
	I am confident I will be able to look after myself in the future						-0.03	0.93	0.83	-0.03	0	
	I worry about what job I will be able to do in the future						0.62	0.96	0.96	-0.03	0.53	
	I like to have a go at everything						-0.19	0.95	0.88	0.46	-0.27	
I like being at school	**I enjoy school/college**	-0.37	0.99	0.94	-0.33	-0.36	-0.16	1.19	1.21	0.06	-0.67	-.02
I have to work harder at school because of my eyesight		1.34	1.09	1.12	0	-0.33						

*MNSQ = Mean square standardized residual within the pre-defined interval (0.5, 1.5)[17] **DIF = Differential item functioning within a 1 logit threshold[24, 27]

Table 3

Table 3: Construct validity of VQoL_Child and VQoL_Young Person**

	VQoL_Child	VQoL_ Young Person	Scores from the VQoL_Child and VQoL_Young Person combined (representing the calibrated collection of instruments).
PedsQL Total Summary	.636*	.760	.698
	(.000)	(.000)	(.000)
PedsQL Psychosocial Health	.653	.804	.724
	(.000)	(.000)	(.000)
PedsQL Physical Health	.468	.563	.518
	(.000)	(.000)	(.000)
Visual acuity (categorized)	-.045	-.141	-.134
	(.351)	(0.129)	(.057)

*Spearman's Rank Coefficient *r* (*p* values)

** All observed correlations are within the pre-defined threshold.[17]

Table 4. Item reduction in Phase 4

Items removed – VQoL_Child		**Items removed – VQoL_Young Person**	
Item	**Removal criteria**	**Item**	**Removal criteria**
I have got some good friends	Item distribution	I have got some good friends	Item distribution
I am happy with how many friends I have	Item distribution		
I spend enough time with my friends	Rasch *- removed due to ordering of person abilities and response scales (not in the right order)*		
		Other young people my age pick on me because of my eyesight	Rasch *- removed because of DIF* by gender (more difficult for females to endorse as true)*
		I can stand up for myself if someone picks on me	Rasch *- removed because of DIF by age (more difficult for older age group to endorse as true)*
		My friends understand how things are for me because of my eyesight	Rasch *- removed due to item fit (OUTFIT MNSQ** = 1.56)*
My friends help me at school	Rasch *- removed due to item fit (OUTFIT MNSQ = 1.74)*	My friends help me when I need it	Item distribution
My teachers understand how things are for me because of my eyesight	Item distribution	My teachers and tutors understand how things are for me because of my eyesight	Rasch *- removed due to item fit (OUTFIT MNSQ = 2.23)*
I get along with my family	Item distribution		Item distribution
		I am comfortable going places on my own	Rasch *- removed because of DIF by gender (more difficult for females to endorse as true)*

Table 4. Item reduction in Phase 4

Items removed – VQoL_Child		**Items removed – VQoL_Young Person**	
Item	**Removal criteria**	**Item**	**Removal criteria**
		People give me a chance to do things on my own	Rasch *- removed because of ordering of person abilities and response scales (not in the right order)*
		People overprotect me because of my eyesight	Rasch *- removed due to item fit (OUTFIT MNSQ = 2.23)*
		I have enough private time to myself	Item distribution
		I feel tired because of my eyesight	Rasch *- removed due to item fit (OUTFIT MSQ = 1.62) and ordering of person abilities and response scales (not in the right order)*
I feel lonely because of my eyesight	Item distribution	I feel lonely because of my eyesight	Item distribution
I feel confident	Rasch *- removed due to ordering of person abilities and response scales (not in the right order)*		
		I am treated fairly by my friends	Rasch *- removed because of ordering of person abilities and response scales (not in the right order)*
I like to have a go at everything, although my eyesight isn't perfect	Item distribution		
I can do most activities on my own	Rasch *- removed due to ordering of person abilities and*		

Table 4. Item reduction in Phase 4

Items removed – VQoL_Child		**Items removed – VQoL_Young Person**	
Item	**Removal criteria**	**Item**	**Removal criteria**
	response scales (not in the right order)		
		I worry my eyesight will get worse	Rasch *- removed due to item fit (OUTFIT MNSQ = 1.53)*
		I can get around on my own	Rasch *- removed because of DIF by gender (more difficult for females to endorse as true)*
		I have to work harder at school/college because of my eyesight	Rasch *- removed due to item fit (OUTFIT MNSQ = 1.59)*

*DIF = Differential item functioning

**MNSQ = Mean squared standardized residuals

Table 5a. Conversion table for transforming raw scores on the 20-item VQoL_Child into comparable Rasch person measures.

Score	Measure	S.E.	Score	Measure	S.E.	Score	Measure	S.E.
0	0.00	16.92	21	44.19	2.57	42	58.41	2.64
1	11.26	9.34	22	44.90	2.55	43	59.17	2.69
2	17.88	6.68	23	45.59	2.52	44	59.97	2.73
3	21.84	5.52	24	46.28	2.50	45	60.80	2.79
4	24.71	4.83	25	46.95	2.49	46	61.66	2.85
5	26.99	4.37	26	47.62	2.47	47	62.56	2.93
6	28.90	4.04	27	48.28	2.46	48	63.52	3.01
7	30.55	3.78	28	48.94	2.46	49	64.53	3.11
8	32.01	3.58	29	49.59	2.45	50	65.62	3.23
9	33.33	3.41	30	50.24	2.45	51	66.80	3.37
10	34.54	3.27	31	50.89	2.45	52	68.09	3.54
11	35.66	3.16	32	51.54	2.45	53	69.52	3.75
12	36.70	3.06	33	52.19	2.46	54	71.15	4.01
13	37.68	2.97	34	52.84	2.46	55	73.03	4.35
14	38.61	2.90	35	53.50	2.47	56	75.30	4.82
15	39.50	2.83	36	54.17	2.49	57	78.16	5.51
16	40.35	2.77	37	54.84	2.50	58	82.11	6.68
17	41.17	2.72	38	55.53	2.52	59	88.73	9.34
18	41.96	2.68	39	56.22	2.55	60	100.00	16.92
19	42.72	2.64	40	56.93	2.57			
20	43.46	2.60	41	57.99	2.61			

*scores ranging from 1-4 must be re-scored into a scale of 0-3 (and negative items reversed) before conversion.

Table 5b. Conversion table for transforming raw scores on the 22-item VQoL_Young Person into comparable Rasch person measures.

Score	Measure	S.E.	Score	Measure	S.E.	Score	Measure	S.E.
0	0.00	16.39	23	41.91	2.34	46	56.31	2.59
1	10.82	8.99	24	42.52	2.33	47	57.08	2.63
2	17.08	6.38	25	43.12	2.32	48	57.86	2.68
3	20.77	5.23	26	43.72	2.31	49	58.68	2.73
4	23.41	4.55	27	44.31	2.30	50	59.52	2.78
5	25.48	4.10	28	44.90	2.30	51	60.40	2.84
6	27.20	3.77	29	45.49	2.29	52	61.33	2.91
7	28.68	3.52	30	46.07	2.30	53	62.30	2.99
8	29.98	3.32	31	46.66	2.30	54	63.32	3.07
9	31.14	3.16	32	47.25	2.30	55	64.41	3.17
10	32.21	3.02	33	47.84	2.31	56	65.57	3.29
11	33.19	2.91	34	48.44	2.32	57	66.82	3.42
12	34.10	2.82	35	49.04	2.33	58	68.18	3.58
13	34.96	2.74	36	49.65	2.34	59	69.69	3.78
14	35.78	2.67	37	50.26	2.35	60	71.38	4.02
15	36.55	2.61	38	50.88	2.37	61	73.32	4.34
16	37.29	2.56	39	51.51	2.39	62	75.63	4.78
17	38.01	2.51	40	52.15	2.41	63	78.52	5.44
18	38.70	2.47	41	52.81	2.43	64	82.49	6.56
19	39.37	2.44	42	53.48	2.46	65	88.98	9.12
20	40.03	2.41	43	54.16	2.49	66	100.00	16.47
21	40.67	2.38	44	54.86	2.52			
22	41.30	2.36	45	55.58	2.56			

*scores ranging from 1-4 must be re-scored into a scale of 0-3 (and negative items reversed) before conversion.