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A patient-reported outcome measure of functional vision for children and young people aged 8 to 18 years with visual impairment

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ABSTRACT

Purpose: To develop age-appropriate extensions of a patient-reported outcome measure for capturing the functional impact of visual impairment on daily activities of children and young people aged 8 up to 18 years.

Design: Questionnaire development and validation study.

Setting: Pediatric Ophthalmology departments at Great Ormond Street Hospital and Moorfields Eye Hospital, and, in the final study phase, 20 further UK hospitals.

Participants: Children and young people (aged 6-19 years) with visual impairment (acuity of the logarithm of the minimum angle of resolution (LogMAR) worse than 0.50 in the better eye) due to any cause but without significant non-ophthalmic impairments.

Methods: We used our prototype FVQ_CYP for 10-15 year olds as the foundation. Twenty-nine semi-structured interviews confirmed relevance of existing, and identified new, age-specific items. Twenty-eight cognitive interviews captured information regarding comprehensibility and format. The FVQ_Child (8-12 years) and FVQ_Young Person (13-18 years), were evaluated with a national sample of 113 children and 96 young people using Rasch analysis.

Results: Issues emerging from interviews with children and young people were largely congruent with those elicited originally with 10-15 year olds. The 28-item FVQ_Child and 38-item FVQ_Young Person versions have goodness-of-fit statistics within the interval 0.5, 1.5 and person separation values of 5.87 and 6.09 respectively. Twenty-four overlapping ‘core’ items enabled their calibration on the same measurement scale. Correlations with acuity (r = 0.47) demonstrated construct validity.

Conclusions: The FVQ_C and FVQ_Young Person are robust age-appropriate versions of the FVQ_CYP which can be used cross-sectionally or sequentially/longitudinally across the age-range of 8-18 years in clinical practice and research.

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Short title:

Measuring functional vision of children/young people

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Supplemental Material:

Supplementary Table 1 available at AJO.com

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INTRODUCTION

Visual impairment (VI) affects a child's ability to perform everyday tasks and activities, with cumulative effects on their educational, social and occupational prospects, and engagement in daily life.[1 2] In keeping with the international drive to use patient-reported outcome measures (PROMs)[3] to assess the impact of eye conditions and any treatment undertaken, the ability to accurately assess the affected child's perspective of their functional vision (FV) i.e. vision for everyday tasks, would complement clinical (objective) measures.

However, until recently, age-appropriate measures of FV for children and young people with VI have been lacking. Recently, instruments comprising a single measure applicable to the whole age-range of 8-18 years[4 5] have been reported but it is unclear whether their content is developmentally appropriate, given the significant differences in activities that are meaningful and relevant to children versus young people, for example an 8 year old versus an 18 year old, as well as the evolution of their abilities to self-assess and self-report.

In response to both the importance and the lack of age-appropriate, child-centred, psychometrically robust PROMs for use in Pediatric Ophthalmology[6] we developed and used a child-centred approach to generate our 'foundation' PROM for capturing FV of children and young people with VI aged 10-15 years (the FVQ_CYP).[7]

We now report the development of age-specific extensions of this instrument to allow for use with a broader age-range of children and young people with VI. This work forms part of our broader program of development of pediatric PROMs, in which we have developed age-appropriate versions of a PROM assessing the complementary but distinct construct of vision-related quality of life (the VQoL_CYP).[8-10]

METHODS

This instrument development study was approved by the National Health Service (NHS) Research Ethics Committee for East of England, United Kingdom (UK) and followed tenets of the Declaration of Helsinki. Participants >16 years consented and those aged <16 years assented alongside their parents' consent.

Sample

Participants were recruited from two patient populations between September 2014 and May 2017, comprising those attending the Department of Ophthalmology at Great Ormond Street Hospital, and the Pediatric Glaucoma Service and Genetic Eye Disease Service at Moorfields Eye Hospital, London UK supplemented (in the final phase only) by patients attending 20 other hospitals across the UK (see Acknowledgements). Children and young people aged 6-19 years (with final age boundaries for the instrument versions determined empirically later) were eligible if they were visually impaired, severely visually impaired or blind (corrected acuity in the better eye of LogMAR 0.50 or worse or Snellen worse than 6/18 or additional visual defects causing VI) due to any disorder, but without any other significant non-ophthalmic impairment. By sampling across multiple sources nationally in the final phase, where the largest sample was needed, we ensured our sample was as

representative as possible of the UK population of children and young people with VI with respect to ethnicity, socio-economic status, and disorder.

Procedures

Instrument development was undertaken in three standard phases using our foundation FVQ_CYP for 10-15 year olds[7] and its underpinning archived interview data as the springboard for adaptation.

Phase 1: Item development and adaptation

Individual in-depth, interviews were conducted with children younger than 10 and young people older than 15 years to investigate the relevance of issues covered by the FVQ_CYP items (from the 10-15 year olds' instrument[7]) to those outside the age-range of 10-15 years, and to identify any new age-specific issues. We used our existing data from the development of the original FVQ_CYP, involving 32 interviews with 10-15 year olds,[7] as the foundation for data collection, and reached data saturation after 12 interviews with children and 17 interviews with young people. Interviews were transcribed and coded using NVivo10.[11] Qualitative analysis revealed areas of overlap, discrepancy or omissions in the new data, compared to the issues covered by the existing FVQ_CYP instrument. New, age-appropriate items were developed to address any new issues not addressed in the foundation FVQ_CYP. To ensure existing FVQ_CYP items were developmentally appropriate for children younger than those for whom it was originally designed, participants <10 years completed the FVQ_CYP (10-15 years) with parental assistance. Feedback informed the early draft of the FVQ_CYP version for younger children. This was not considered necessary for participants older than 15 years, who were developmentally well placed to comprehend the existing FVQ_CYP (10-15 years) items.

Phase 2: Pre-testing

The upper and lower age boundary for each new age-appropriate FVQ instrument version was developed empirically throughout Phase 2. To ensure the new draft instrument versions would be comprehensible and age-appropriate to a broader age-range, recruitment in this phase was focused on participants younger than 10 years and older than 15 years. One-to-one cognitive interviews with 12 children aged 7-10 years and 16 young people aged 13-18 years were conducted. Items were evaluated for importance, comprehensibility, difficulty and response format. The original interviews with 10-15 year olds were re-read,[7] and 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 and 13-18 years.

Phase 3: Piloting and validation

The age-appropriate instrument versions were piloted with a national sample (UK) of 113 children aged 8-12 years and 96 young people aged 13-18 years to confirm their psychometric properties.

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

Data from the returned instrument versions were entered into IBM SPSS version 24,[12] and verified through double-checking, with no errors detected. Data from participants with >25% of item responses, and items with >60% of participant responses missing were excluded.[13]

Rasch analysis[14] and the Andrich Rasch Rating Scale model defined the item reduction. Criteria used to assess the appropriateness of the two instrument versions[13 15] are detailed in Table 2 and Figures 1 and 2. Prior to analysis, 1 – 4 responses were coded into a scale of 0 – 3.

Calibrating the FVQ_Child and FVQ_Young Person versions

We used the model resulting from equating both age-appropriate instrument versions (as outlined by Linacre[16]) to ensure that they measure the same construct in children and young people. This model utilizes the 'core' items common to both instrument versions and provides continuity of measurement across the age-range of 8-18 years. Thus the instrument versions can be used in cross-sectional studies and also at different time points with the same participants, to allow for longitudinal analysis. In this transformation, all items are assumed to have equal importance, and response categories are scaled accordingly to provide an equal value with uniform increments between consecutive categories. A final differential item functioning (DIF) analysis was conducted using these 'core' items common to both instrument versions, to investigate whether the equated Rasch person measures from the two age groups (8-12 and 13-18 years) were comparable.[17]

We assessed unidimensionality using infit and outfit statistics, following the criteria described in Table 2.[13] DIF statistics (Table 2) represent the effect size of the difference between the two classifications of persons, in logits.[18]

FVQ total summary scores were calculated by adding item scores across the scale and converted into Rasch person measures ranging from 0 (denoting lower difficulty and excellent FVQ) to 100 (denoting greater difficulty and severely reduced FVQ). This was done using the score-to-measure conversion tables for each version (Table 3). These conversion tables allow the derived measures to be compared between the two age-appropriate versions regardless of the differences in the number and wording of items.

For those participants with any missing items, Rasch person measures were imputed applying a procedure which is consistent with item response theory.[19 20] This approach uses adjusted score-to-measure conversion tables derived from Table 3.

Construct validity

Construct validity, assessing the instrument's ability to truly measure the underlying latent construct, was assessed through Spearman's rank correlation coefficients

between Rasch person measures on the FVQ_Child and FVQ_Young Person and objectively measured visual acuity.

Rasch analysis was conducted using Winsteps 4.0.1.[11] and all other analyses using SPSS.

RESULTS

Participants represented the overall "target" UK population of children and young people with VI able to self-report (i.e. without additional significant impairment) in terms of clinical and socio-demographic characteristics and ophthalmic diagnoses (Table 1).[7 9 21]

Phase 1: Item development and adaptation

The issues raised by children younger than 10 years and those older than 15 years overlapped significantly with those addressed by the original FVQ_CYP instrument for 10-15 year olds.[7] Nevertheless, domain-pertinent issues in the original instrument were not relevant to younger children and older participants reported engagement in additional activities (e.g. attending parties, and using mobile phones) different to those covered by the original FVQ_CYP.

The original FVQ_CYP instrument for 10-15 year olds has 36 items addressing activities at home, school and leisure, restrictions and limitations, levels of functioning, mobility, and communication. Of these, 28 were retained for the new extension for children <10 years i.e. the FVQ_Child, and one new item capturing outdoor/playground games was added. Thirty-one of the original 36 items were retained following minor linguistic adaptations (e.g. references to '*school*' were changed to '*school/college*') for the extension for those aged >15 years i.e. the FVQ_Young Person. We added 7 items that drew on our foundation research and 2 entirely new items related to maintaining physical appearance and using a mobile phone for social networking.

Item presentation was modified to calibrate the instrument versions by retaining a consistent format and structure across them. All items were presented as a question stem ('*Because of my eyesight, I find…*') followed by an activity (e.g. '*Watching TV*'), with four response options: '*1: Very easy*'; '*2: Easy*'; '*3: A bit difficult*' ('*Difficult*' in the FVQ_Young Person); and '*4: Very difficult or impossible*'.[7] The prompt: '*Remember to tell us how things are for you when wearing your glasses (if you wear them), with your low vision aids and other devices (if you use them for these activities) and with the best lighting and contrast for you*' was inserted between items.

Phase 2: Pre-testing of the 29-item FVQ_Child and 40-item FVQ_Young Person

One item '*Getting around outdoors by myself*' was divided into two items in both instrument versions to specify context ('*in daylight*' and '*when it's dark*'). Age-boundaries for the extensions were re-adjusted as 8-12 years and 13-18 years empirically, reflecting the minimum age for accurate self-reporting.[22]

Phase 3: Piloting and validation

Four children and two young people were excluded from Phase 3 because they had >25% missing data. These participants had visual acuity ranging from 0.48 to perception of light only. In the remaining children and young people, missing data per child (aged 8-12 years) was ≤7%, and ≤22% among young people (aged 13-18 years). A Poisson regression model revealed a non-significant relationship between the number of missing items and severity of visual impairment (p = 0.351).

Missing data per item was ≤20% in the child dataset and ≤17% for young people.

Following Rasch analysis, one item was removed from the FVQ_Child and 3 items were removed from the FVQ_Young Person based on outfit MNSQ statistics and notable DIF (see online Supplementary Table 1).

Calibrating the FVQ_Child and FVQ_Young Person instrument versions

Analysis of DIF between children and young people on the combined datasets for the overlapping 'core' items revealed that the item *'Reading small writing such as food packets, tickets, and labels'* was more difficult for children than young people. Results from the preliminary item reduction stage were re-visited and this item was removed from the FVQ_Child only, based on the finding that 57% of children (vs. 35.5% of young people) rated this item as *'Very difficult or impossible'*, confirming an age-related bias. All remaining overlapping 'core' items were productive for measurement of FV in both instrument versions.

The final 28-item FVQ_Child and 38-item FVQ_Young Person contain 24 overlapping 'core' items and 4 and 14 age-specific items, respectfully (Table 2). Both instrument versions showed fit statistics and DIF values within acceptable limits. Item probability plots showed good ordering and acceptable distinction between 4 response categories (Figure 1), and targeting of items to respondents (Figure 2). The FVQ_Child and FVQ_Young Person showed precision as indicated by the indices for person separation (5.87 and 6.09, respectively).

Score-to-measure transformation

Rasch person measures from the FVQ_Child and FVQ_Young Person may be compared on a linear scale ranging from 0 to 100. Table 3 shows the transformation of scores into person measures which enable easy and precise scoring, and direct comparison of scores from individuals of different ages, and scores over time.

Construct validity

In keeping with published criteria,[13] Rasch person measures on the FVQ_Child and FVQ_Young Person correlated positively with participants' latest recorded visual acuity (r = 0.48, p = <.001 for FVQ_Child, r = 0.43, p = <.001 for FVQ_Young Person, and r = 0.46, p <.001 for the combined FVQ_Child and FVQ_Young Person datasets), indicating, as hypothesized, that lower FV is reported by children with poorer acuity in both age-groups.

DISCUSSION

We report development of age/stage appropriate versions of a robust PROM assessing the functional impact of VI on children and young people. The novel equating approach we used to calibrate the two instrument versions means that Rasch person measures from either version can be compared using one linear scale representing FV, despite age-specific variation. This affords many advantages when used in practice, namely that the instrument can be used cross-sectionally and sequentially, with children and young people aged from 8 years up to 18 years, and without loss of continuity of measurement as subjects get older by using an alternative instrument. We provide log transformation tables, which can be used to convert summary scores into Rasch person measures, which are also accompanied by the model-based standard error of each measure, which should be used in future clinical research.

Our research adhered to best practice via independent self-report from children and young people themselves, through one-to-one individual interviews, expert consultations, and provision of age-appropriate materials. This rigor is reflected in the content, format and evidence of construct (convergent) validity of both instrument versions. By deliberately isolating activities on which VI can impact, we have avoided any conflation between FV and the psychosocial emotional impact of VI which is captured instead in our corresponding vision-related quality of life instrument.[8-10]

The relatively small sample size of our study (reflecting the rarity of childhood VI) has implications for Rasch analysis, particularly the stability of DIF analyses and item fit statistics. We addressed this in the analysis of DIF by age, by grouping participants by individual year groups to optimize use of the sample. We carefully considered the trade-off between retaining meaningful items which are productive for measurement and thus preserving content and face validity, versus removing those which did not fit the 'perfect' measurement scale. The broader criteria we used for assessing item fit reflects this.

Although FV is not formally defined in the extant literature, it bridges the gap between health conditions and associated symptoms (i.e. reduced visual function) and contextual factors (i.e. environmental and personal factors inherent to daily activities) specified by the International Classification of Functioning, Disability and Health.[23] We framed FV as the ability to complete meaningful daily activities in real everyday environments. Consequently, our instrument captures activities performed at home and in school, with age-appropriate items reflecting increasing independence and responsibility with age.

Our instrument differs from some other current vision-specific PROMs which capture some aspects of FV of children and young people, by being applicable to all/any cause of VI versus a single eye condition[24 25] and to an English speaking population.[26] The most direct comparators are the Cardiff Visual Ability Questionnaire for Children (CVAQC)[4] and the LV Prasad-Functional Questionnaire Second Version (LVP-FVQ II)[5] but neither has age-appropriate versions capable of capturing change in the nature of tasks of daily living over time. The recently reported PedEyeQ[27] addresses age-specificity through separate instruments for

different age-groups but lacks the calibration required to allow for valid comparisons of these measures.

The benefits of using PROMs within clinical practice include improvements in patient-clinician communication such as advice and diagnoses given by health professionals,[28] and increased 'patient centricity' within clinical care.[29] PROMs are also valuable at a higher institutional level, with potential to trigger changes in clinical practice and monitor the quality of healthcare provided.[30] The instrument versions we have developed enhance these uses by also affording the opportunity to compare scores meaningfully from individuals across the age-range of 8 up to 18 years whilst maintaining specificity to differences between the two age-groups. This makes them useful in assessments of key, age-related or vision-specific milestones or interventions without the need for clinicians to use and interpret multiple instruments; the latter a well-documented barrier to routine use of PROMs.[31 32]

The age-boundaries for our instrument versions are empirically-based and echo most child-centred, vision-specific PROMs.[5 28 33] However, given the specific developmental profile of the population of children and young people with VI, we advocate tailoring the choice of version[34] to the patient's developmental needs rather than just her/his age.

To ensure ability to self-report and focus on the impact of VI per se, we restricted our participant population to those without additional impairments. Further work is necessary to address the challenge of developing our FV measure to make it appropriate for children/young people in whom VI may be one of a number of co-existing impairments. Whilst parent or proxy reporting is not considered best practice due to the potential for discordance between proxies and those affected i.e. risk of misinterpreting the child's views,[35] this may nevertheless be required when complex health conditions preclude self-reporting by children/young people. This may be the way forward for our FVQ_CYP instrument as parents rate physical symptoms more accurately than subjective well-being or quality of life.[36]

Our child-centred and resource efficient approach has enabled development of a robust age- and stage-appropriate PROM allowing children and young people to self-assess and report on the functional impact of their VI. This instrument can be used cross-sectionally (e.g. in population burden of disease studies) or sequentially (e.g. moving from the FVQ_Child to the FVQ_Young Person over time in clinical trials) in clinical practice and research to provide a deeper understanding and alternative quantification of the impact of eye disease and its treatment than objective clinical measures alone can afford.

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FIGURE CAPTIONS

Figure 1. Category probability curves for the 28-item FVQ_Child (left), and 38-item FVQ_Young Person (right)

Figure 1: Category probability curves showing the probability of selecting response categories across the scale of item difficulty for age-appropriate extensions of the FVQ_CYP[37]

Figure 2. Item-Person map for the 28-item FVQ_Child (left), and 38-item FVQ_Young Person (right)

Figure 2: Item-person maps illustrating acceptable targeting of FVQ items (located on the right hand side of the dashed line) to responders (located on the left side of the dashed line and represented by X).[38] Participants with higher functional vision and items with higher difficulty are at the bottom half of the map. M = mean; S = 1 standard deviation from the mean; T = 2 standard deviations from the mean.

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TABLES

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

	Phase 1		Phase 2		Phase 3	
Demographic characteristic	**Children (*n* = 12)**	**Young People (*n* = 17)**	**Children (*n* = 12)**	**Young People (*n* = 16)**	**Children (*n* = 113[a])**	**Young People (*n* = 96[b])**
Age						
6	1 (8.3)	-	-	-	-	-
7	-	-	2 (16.7)	-	3 (2.65)	-
8	4 (33.3)	-	6 (50)	-	22 (19.47)	-
9	7 (58.3)	-	3 (25)	-	26 (23)	-
10	-	-	1 (8.3)	-	15 (13.27)	-
11	-	-	-	-	24 (21.24)	-
12	-	-	-	-	22 (19.47)	-
13	-	-	-	3 (18.75)	1 (0.88)	12 (12.5)
14	-	-	-	2 (12.5)		25 (26.04)
15	-	-	-	3 (18.75)		19 (19.79)
16	-	7 (41.18)	-	2 (12.5)		18 (18.75)
17	-	8 (47.06)	-	3 (18.75)		20 (20.83)
18	-	1 (5.88)	-	3 (18.75)		2 (2.08)
19	-	1 (5.88)	-	-		-
Gender						
Male	8 (66.7)	10 (58.82)	8 (66.7)	8 (50)	52 (46.02)	52 (54.17)
Female	4 (33.3)	7 (41.18)	4 (33.3)	8 (50)	61 (53.98)	44 (45.83)
Ethnicity						
White UK majority (White British)	8 (66.7)	10 (58.82)	5 (41.7)	11 (68.75)	62 (54.87)	62 (64.58)
White other (e.g. African, Polish, Turkish)	-	1 (5.88)	2 (16.7)	1 (6.25)	9 (7.96)	7 (7.29)
Black (British, African, Caribbean)	1 (8.3)	-	1 (8.3)	-	9 (7.96)	3 (3.13)
Asian (Indian, Bangladeshi, Pakistani)	2 (16.7)	3 (17.65)	2 (16.7)	4 (25)	25 (22.12)	12 (12.5)
Asian other (Arabic)	-	1 (5.88)	-	-	3 (2.65)	2 (2.08)
Chinese	-	-	-	-	-	-

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

	Phase 1		Phase 2		Phase 3	
Demographic characteristic	**Children (*n* = 12)**	**Young People (*n* = 17)**	**Children (*n* = 12)**	**Young People (*n* = 16)**	**Children (*n* = 113[a])**	**Young People (*n* = 96[b])**
Mixed	1 (8.3)	2 (11.76)	2 (16.7)	-	3 (2.65)	2 (2.08)
Missing		-		-	2 (1.77)	8 (8.33)
Severity of visual impairment						
LV: logMAR ≤0.46	-	1 (5.88)		-	5 (4.42)	1 (1.04)
VI1: logMAR 0.48-0.70	4 (33.3)	8 (47.06)	4 (33.3)	9 (56.25)	50 (44.25)	29 (30.21)
VI2: logMAR 0.72-1.00	5 (41.7)	3 (17.65)	3 (25)	5 (31.25)	40 (35.4)	37 (38.54)
SVI: logMAR 1.02-1.30	-	2 (11.76)	1 (8.3)	1 (6.25)	8 (7.08)	12 (12.5)
Blind: logMAR ≥1.32	3 (25)	3 (17.65)	4 (33.3)	1 (6.25)	10 (8.85)	17 (17.71)
Timing of onset of visual impairment						
Early (≤2 years)	12 (100)	15 (88.24)	12 (100)	10 (62.5)	99 (87.61)	79 (82.29)
Late	-	2 (11.76)	-	6 (37.5)	14 (12.39)	17 (17.71)
Nature of deterioration of visual impairment						
Stable	9 (75)	12 (70.59)	6 (50)	5 (31.25)	74 (65.49)	81 (84.38)
Progressive	3 (25)	5 (29.41)	6 (50)	11 (68.75)	39 (34.51)	15 (15.62)
Diagnosis by site of visual impairment[d]						
Whole globe and anterior segment	-	1 (5.88)	1 (8.3)	1 (6.25)	2 (1.77)	3 (3.13)
Glaucoma, primary or secondary	1 (8.3)	-	3 (25)	-	10 (8.85)	10 (10.42)
Cornea (sclerocornea and corneal capacities)	-	-	-	1 (6.25)	2 (1.77)	2 (2.08)
Lens (cataract and aphakia)	1 (8.3)	-	1 (8.3)	2 (12.5)	14 (12.39)	9 (9.38)
Uvea	-	-	-	-	6 (5.31)	8 (8.33)
Retina	9 (75)	12 (70.59)	8 (66.67)	9 (56.25)	71 (62.83)	68 (70.83)
Optic nerve	1 (8.3)	3 (17.65)	1 (8.3)	3 (18.75)	13 (11.5)	6 (6.25)
Cerebral/visual pathways	1 (8.3)	-	-	1 (6.25)	5 (4.42)	9 (9.38)

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

	Phase 1		Phase 2		Phase 3	
Demographic characteristic	**Children (*n* = 12)**	**Young People (*n* = 17)**	**Children (*n* = 12)**	**Young People (*n* = 16)**	**Children (*n* = 113[a])**	**Young People (*n* = 96[b])**
Other (idiopathic nystagmus, high refractive error)	-	6 (35.29)	1 (8.3)	-	19 (16.81)	16 (16.67)
Index of multiple deprivation quintile rank						
1: most deprived	2 (16.7)	1 (5.88)	1 (8.3)	2 (12.5)	22 (19.47)	18 (18.75)
2	1 (8.3)	2 (11.76)	5 (41.7)	-	23 (20.35)	19 (19.79)
3	3 (25)	4 (23.53)	2 (16.7)	4 (25)	25 (22.12)	15 (15.62)
4	2 (16.7)	8 (47.06)	3 (25)	3 (18.75)	19 (16.81)	17 (17.71)
5: least deprived	4 (33.3)	2 (11.76)	1 (8.3)	7 (43.75)	21 (18.58)	27 (28.13)
Missing		-		-	3 (2.65)[c]	-

[a] Four children excluded from analysis due to incomplete (more than 25% data missing) child data (e.g. parent proxy report provided instead).
[b] 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.
[c] Data missing due to postcode data not provided by the managing clinical team, as per local governance approval at the patient identification centre.
[d] Does not add up to 100% because some children had visual impairment originating in multiple sites.

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Table 2. Rasch Fit Statistics, item measure and differential item functioning (DIF) contrasts for the 28-item and 38-item age-appropriate FVQ instrument extensions, and DIF contrasts for the overlapping items (overlapping items shown in bold).

FVQ_Child	FVQ_Young Person	FVQ_Child					FVQ_Young Person					Core items
Item	Item	Item measure (logits)	Infit MNSQ[a]	Outfit MNSQ	DIF[b] 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 contrasts by sample (i.e. children vs. young people)
Watching TV	**Watching TV**	0.31	0.94	0.89	-0.26	0.05	0.33	0.87	0.96	-0.22	0.19	-0.19
Playing video and computer games	**Playing video and computer games**	0.27	0.98	0.99	-0.19	-0.35	-0.16	1.04	1.08	-0.60	0.23	0.22
Playing other indoor games, such as board games or card games	**Playing indoor games, such as board games or card games**	0.60	0.76	0.72	0.34	0	0.26	0.80	0.88	-0.07	0.32	0.22
Playing outdoor games, such as tag or hide and seek		0.03	0.97	0.94	-0.23	-0.06						-
Using the computer at home to do my school work	**Using the computer at home to do my homework**	0.37	1.32	1.29	-0.54	-0.24	0.62	1.24	1.33	0.77	0.21	-0.39
	Reading food packets, tickets, labels or recipes						-1.30	0.78	0.73	-0.07	0.28	-
Doing household jobs, for example, tidying up my toys	**Doing household chores, for example, washing up or tidying my bedroom**	1.33	1.07	1.04	0.02	0.33	0.99	0.79	0.80	-0.08	-0.07	0.31
	Looking after my appearance, for example, doing my hair, shaving, or putting on make-up						0.62	0.95	0.94	0.31	-0.44	-

Table 2. Rasch Fit Statistics, item measure and differential item functioning (DIF) contrasts for the 28-item and 38-item age-appropriate FVQ instrument extensions, and DIF contrasts for the overlapping items (overlapping items shown in bold).

FVQ_Child	FVQ_Young Person	FVQ_Child					FVQ_Young Person					Core items
Item	Item	Item measure (logits)	Infit MNSQ[a]	Outfit MNSQ	DIF[b] 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 contrasts by sample (i.e. children vs. young people)
	Making myself a snack at home						1.60	0.68	0.66	0.63	0.43	-
	Making myself a meal						0.37	0.92	0.90	0.84	0.34	-
	Finding objects I have dropped such as coins or glasses on a low contrast surface						-1.33	1.06	1.22	0	0.23	-
Using the computer in school lessons	**Using the computer at school or college to do schoolwork/ coursework**	0.16	0.89	0.87	-0.19	-0.22	0.43	1.01	1.02	0.30	-0.09	-0.45
Reading small print worksheets and textbooks like dictionaries	**Reading small print textbooks, worksheets and exam papers**	-1.93	0.99	0.92	-0.08	0.50	-2.21	0.88	0.91	-0.18	-0.44	-0.15
Reading enlarged worksheets and textbooks like dictionaries		1.53	1.20	1.40	-0.18	-0.14						-
Drawing or painting		0.90	1.18	1.23	-0.32	0.72						-
Reading other people's handwriting	**Reading other people's handwriting**	-1.23	0.60	0.60	0.30	0	-1.59	0.85	0.83	-0.20	0.08	0
Seeing the board in the classroom	**Seeing the board in the classroom when sitting at the**	-1.38	1.11	1.02	-0.49	0.29	-1.21	1.06	1.00	-0.47	0.23	-0.54

Table 2. Rasch Fit Statistics, item measure and differential item functioning (DIF) contrasts for the 28-item and 38-item age-appropriate FVQ instrument extensions, and DIF contrasts for the overlapping items (overlapping items shown in bold).

FVQ_Child	FVQ_Young Person	FVQ_Child					FVQ_Young Person					Core items
Item	Item	Item measure (logits)	Infit MNSQ[a]	Outfit MNSQ	DIF[b] 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 contrasts by sample (i.e. children vs. young people)
	front											
Recognising people, for example in school corridors	**Recognising people, for example, in corridors at school/college or shops**	-0.20	1.01	1.02	0.34	0.16	-0.89	1.31	1.35	-0.74	-0.10	0.41
Recognising other people's facial expressions	**Recognising other people's facial expressions when they are close to me/at arm's length**	0.25	1.06	1.02	0.40	0.31	0.16	1.34	1.27	-0.32	0.51	-0.11
Finding friends in the playground	**Finding friends in crowded areas**	-1.10	0.97	0.89	0.21	0	-1.77	0.90	1.17	0	-0.41	0.29
Doing maths in lessons	**Doing maths**	0.73	1.16	1.11	-0.24	-0.30	1.26	1.15	1.15	0.23	0.16	-0.56
Doing literacy in lessons		0.67	0.92	0.96	-0.21	-0.02						-
	Doing science						0.44	1.08	1.10	0.06	0.41	-
Doing PE	**Doing sports at school/college**	0.05	1.12	1.20	0	-0.52	-0.19	1.42	1.47	-0.19	-0.57	0
Keeping up with the teacher in lessons	**Keeping up with the teacher or tutor in lessons**	0.32	1.04	1.07	0	0	0.45	0.81	0.80	-0.14	0.41	-0.29
Keeping up with other children in lessons	**Keeping up with other students in lessons**	0.10	0.85	0.91	0.52	-0.10	0.51	0.71	0.71	-0.06	0	-0.59

Table 2. Rasch Fit Statistics, item measure and differential item functioning (DIF) contrasts for the 28-item and 38-item age-appropriate FVQ instrument extensions, and DIF contrasts for the overlapping items (overlapping items shown in bold).

FVQ_Child	FVQ_Young Person	FVQ_Child					FVQ_Young Person					Core items
Item	Item	Item measure (logits)	Infit MNSQ[a]	Outfit MNSQ	DIF[b] 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 contrasts by sample (i.e. children vs. young people)
Getting around school without someone helping me	**Getting around school/college by myself**	1.82	1.19	1.02	-0.39	0	1.71	0.76	0.72	-0.19	-0.09	0.17
Playing team sports without special balls	**Playing team sports, such as football, without adaptations such as special balls**	-0.31	1.25	1.18	0.41	-0.35	-0.68	1.24	1.17	-0.52	-0.91	0.09
Seeing small balls when playing games like tennis or cricket	**Seeing small balls when playing games, such as tennis or cricket**	-1.10	1.05	1.00	0.28	0	-2.35	0.92	0.89	0.26	0.16	0.87
Seeing big moving objects, such as bicycles passing by	**Seeing big moving objects, such as bikes passing, in daylight**	0.59	0.73	0.74	0.44	0.14	0.36	0.81	0.79	0	-0.51	0.09
Getting around outdoors in daytime	**Getting around outdoors e.g. shops or the park, by myself when it's daylight**	0.79	0.76	0.74	0.05	-0.13	0.74	0.54	0.52	0.57	-0.41	-0.05
	Getting around outdoors e.g. shops or the park, by						-0.71	1.08	1.02	0.31	-0.28	-

Table 2. Rasch Fit Statistics, item measure and differential item functioning (DIF) contrasts for the 28-item and 38-item age-appropriate FVQ instrument extensions, and DIF contrasts for the overlapping items (overlapping items shown in bold).

FVQ_Child	FVQ_Young Person	FVQ_Child					FVQ_Young Person					Core items
Item	Item	Item measure (logits)	Infit MNSQ[a]	Outfit MNSQ	DIF[b] 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 contrasts by sample (i.e. children vs. young people)
	myself when it's dark											
	Getting around in crowds by myself						-0.61	0.95	0.88	0.75	-0.53	-
	Finding my way around an unfamiliar house or a new building						-0.24	0.81	0.77	0.68	-0.44	-
Reading signs and posters at stations or shops	**Reading signs and posters at stations or shops**	-0.96	0.60	0.63	-0.07	0.10	-1.18	0.85	0.76	-0.23	-0.07	0.48
	Finding correct money to pay when shopping						0.75	0.97	1.00	0.09	0	-
Watching films in the cinema	**Watching films in the cinema**	1.04	1.01	0.95	0.35	0	0.69	0.74	0.72	0	-0.09	0.27
Watching shows at the theatre	**Watching shows, such as plays, at the theatre**	-0.26	1.09	1.07	-0.34	0.36	-0.65	0.98	1.00	-0.21	0.24	0.14
	Crossing the road by myself						0.28	0.97	0.95	0.46	-0.76	-
	Using public transport, such as trains, buses or the tube by myself						-0.22	1.02	1.02	0.40	-0.83	-
	Using a mobile phone to text people						1.34	1.27	1.15	0.15	0.70	-
	Using a mobile phone or tablet for						1.63	1.13	1.02	-0.21	-0.21	

Table 2. Rasch Fit Statistics, item measure and differential item functioning (DIF) contrasts for the 28-item and 38-item age-appropriate FVQ instrument extensions, and DIF contrasts for the overlapping items (overlapping items shown in bold).

FVQ_Child	FVQ_Young Person	FVQ_Child					FVQ_Young Person					Core items
Item	Item	Item measure (logits)	Infit MNSQ[a]	Outfit MNSQ	DIF[b] 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 contrasts by sample (i.e. children vs. young people)
	social networking, for example, Facebook, Twitter or MySpace											

[a] MNSQ = Mean-square standardized residual within the pre-defined interval (0.5, 1.5).[10]
[b] DIF = Differential item functioning within a 1 logit threshold.[11, 14]

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Table 3a. Conversion table for transforming raw scores on the 28-item FVQ_Child version) into comparable Rasch person measures[a]

Score	Measure	S.E.[b]	Score	Measure	S.E.	Score	Measure	S.E.
0	0.00	14.02	29	42.88	2.04	58	58.28	2.13
1	9.40	7.78	30	43.42	2.03	59	58.87	2.15
2	15.00	5.61	31	43.96	2.01	60	59.48	2.17
3	18.39	4.66	32	44.49	2.01	61	60.10	2.19
4	20.88	4.10	33	45.01	2.00	62	60.74	2.22
5	22.87	3.72	34	45.54	1.99	63	61.39	2.24
6	24.55	3.45	35	46.06	1.99	64	62.06	2.27
7	26.01	3.24	36	46.57	1.98	65	62.74	2.31
8	27.31	3.07	37	47.09	1.98	66	63.45	2.34
9	28.49	2.93	38	47.60	1.98	67	64.18	2.38
10	29.57	2.81	39	48.11	1.98	68	64.94	2.43
11	30.57	2.72	40	48.62	1.97	69	65.73	2.48
12	31.51	2.63	41	49.13	1.97	70	66.55	2.53
13	32.39	2.56	42	49.64	1.98	71	67.41	2.59
14	33.22	2.49	43	50.16	1.98	72	68.31	2.67
15	34.02	2.44	44	50.67	1.98	73	69.27	2.75
16	34.78	2.39	45	51.19	1.98	74	70.29	2.84
17	35.51	2.34	46	51.70	1.99	75	71.39	2.96
18	36.22	2.30	47	52.22	1.99	76	72.59	3.09
19	36.90	2.26	48	52.75	2.00	77	73.91	3.26
20	37.56	2.23	49	53.27	2.01	78	75.39	3.46
21	38.21	2.20	50	53.80	2.02	79	77.08	3.74
22	38.83	2.17	51	54.34	2.03	80	79.08	4.11
23	39.44	2.15	52	54.88	2.04	81	81.59	4.66
24	40.04	2.13	53	55.43	2.05	82	84.99	5.61
25	40.63	2.10	54	55.98	2.06	83	90.59	7.79
26	41.20	2.09	55	56.54	2.08	84	100.00	14.02
27	41.77	2.07	56	57.11	2.09			
28	42.33	2.05	57	57.69	2.11			

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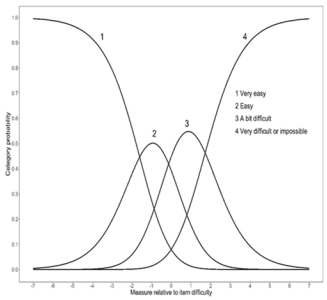
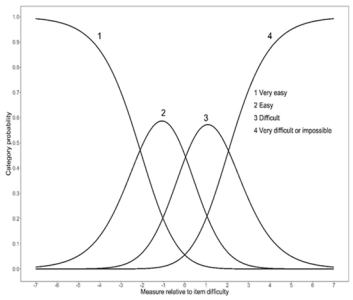
Table 3b. Conversion table for transforming raw scores on the 38-item FVQ_Young Person into comparable Rasch person measures[a]

Score	Measure	S.E.[b]	Score	Measure	S.E.	Score	Measure	S.E.
0	0.00	12.49	39	43.46	1.70	78	59.18	1.71
1	8.41	6.96	40	43.88	1.69	79	59.61	1.72
2	13.45	5.03	41	44.30	1.68	80	60.05	1.73
3	16.53	4.19	42	44.71	1.68	81	60.49	1.74
4	18.80	3.70	43	45.13	1.67	82	60.94	1.75
5	20.63	3.37	44	45.54	1.66	83	61.39	1.76
6	22.18	3.12	45	45.94	1.66	84	61.85	1.77
7	23.52	2.94	46	46.35	1.66	85	62.32	1.79
8	24.73	2.79	47	46.75	1.65	86	62.79	1.80
9	25.82	2.66	48	47.15	1.65	87	63.27	1.82
10	26.82	2.56	49	47.55	1.64	88	63.76	1.83
11	27.75	2.47	50	47.95	1.64	89	64.26	1.85
12	28.62	2.39	51	48.34	1.64	90	64.77	1.87
13	29.44	2.32	52	48.74	1.64	91	65.29	1.89
14	30.21	2.26	53	49.13	1.64	92	65.82	1.92
15	30.95	2.21	54	49.53	1.63	93	66.37	1.94
16	31.65	2.16	55	49.92	1.63	94	66.93	1.97
17	32.33	2.12	56	50.31	1.63	95	67.51	2.00
18	32.97	2.08	57	50.70	1.63	96	68.11	2.03
19	33.60	2.04	58	51.09	1.63	97	68.73	2.07
20	34.20	2.01	59	51.49	1.63	98	69.37	2.11
21	34.79	1.98	60	51.88	1.63	99	70.03	2.15
22	35.36	1.95	61	52.27	1.63	100	70.73	2.20
23	35.91	1.93	62	52.67	1.64	101	71.46	2.26
24	36.45	1.90	63	53.06	1.64	102	72.24	2.32
25	36.98	1.88	64	53.45	1.64	103	73.06	2.40
26	37.49	1.86	65	53.85	1.64	104	73.93	2.48
27	38.00	1.84	66	54.25	1.64	105	74.88	2.59
28	38.49	1.82	67	54.95	1.65	106	75.91	2.71
29	38.98	1.81	68	55.05	1.65	107	77.04	2.86
30	39.45	1.79	69	55.45	1.65	108	78.32	3.04
31	39.92	1.78	70	55.85	1.66	109	79.79	3.29
32	40.38	1.77	71	56.26	1.66	110	81.54	3.62
33	40.84	1.75	72	56.67	1.67	111	83.73	4.12
34	41.29	1.74	73	57.08	1.67	112	86.71	4.97
35	41.73	1.73	74	57.49	1.68	113	91.66	6.91
36	42.17	1.72	75	57.91	1.69	114	100.00	12.47
37	42.60	1.71	76	58.33	1.69			
38	43.03	1.70	77	58.75	1.70			

[a] Scores ranging from 1-4 must be re-scored into a scale of 0-3 before conversion.
[b] Model-based standard error of the measure.





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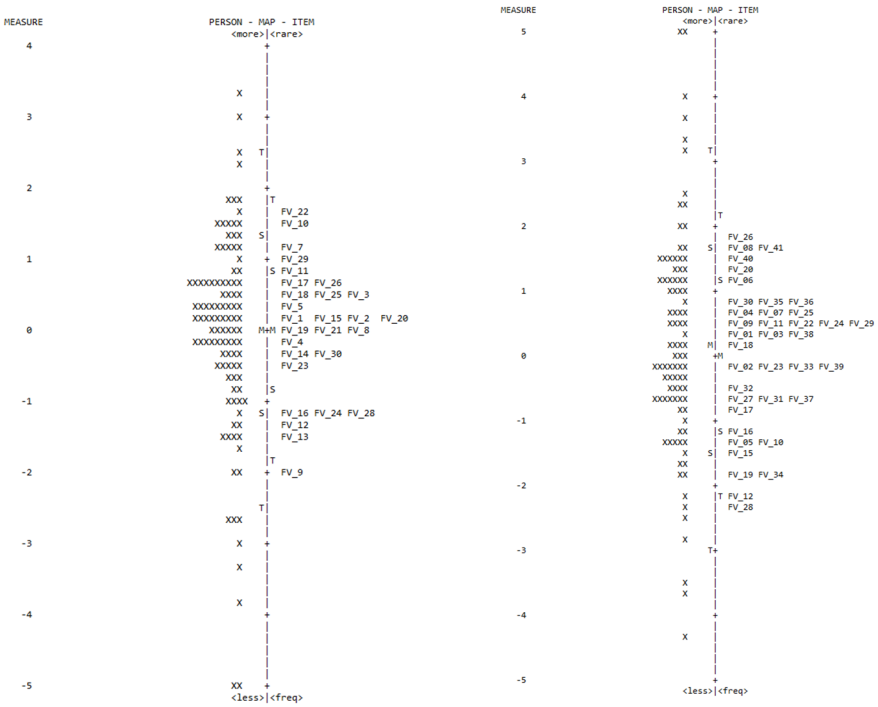

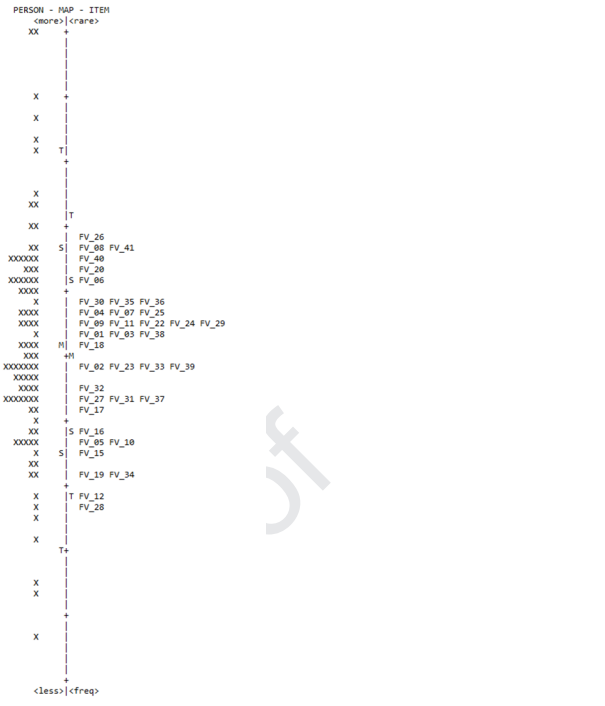

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Highlights

- Age-appropriate versions of a patient-reported outcome measure were developed.
- The FVQ_Child (8-12 years) and FVQ_Young Person (13-18 years) measure functional vision.
- Development comprised Rasch analysis and calibration on the same measurement scale.
- They can be used cross-sectionally or sequentially in practice and research.

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SUPPLEMENTARY TABLE

Supplementary Table 1. Item reduction in Phase 3

Items removed – FVQ_Child		Items removed – FVQ_Young Person	
Item	**Removal criteria**	**Item**	**Removal criteria**
Reading small writing such as food packets or instructions for toys	Rasch – *removed during calibration because of DIF*[a] *(more difficult for children (vs. young people))*		
		Reading enlarged textbooks, worksheets and exam papers	Rasch – *removed because of DIF by age (more difficult for older young people)*
		Drawing or painting	Rasch – *removed because of DIF by age (more difficult for older young people)*
		Doing English or literacy	Rasch – *removed because of DIF by gender (more difficult for males)*
Getting around outdoors when it is dark	Rasch – *removed due to item fit (OUTFIT MNSQ*[b] *= 1.71)*		

[a] DIF = Differential item functioning
[b] MNSQ = Mean squared standardized residuals

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Table of contents statement:

We report the development of age-specific extensions of the FVQ_CYP to allow for use with a broader age-range of children and young people with visual impairment. The FVQ_Child and FVQ_Young Person are psychometrically robust, age-appropriate versions of the FVQ_CYP, which can be used cross-sectionally or sequentially/longitudinally across the age-range of 8 up to 18 years in clinical practice and research.

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Alexandra O Robertson: Methodology, Validation, Formal Analysis, Investigation, Resources, Data Curation, Writing – Original Draft, Writing – Review & Editing, Visualization, Project administration. **Valerija Tadić:** Conceptualization, Methodology, Validation, Formal Analysis, Investigation, Resources, Data Curation, Writing – Review & Editing, Visualization, Supervision, Project administration, Funding acquisition. **Mario Cortina-Borja:** Methodology, Validation, Formal Analysis, Resources, Data Curation, Writing – Review & Editing, Visualization, Supervision. **Jugnoo S Rahi:** Conceptualization, Methodology, Resources, Writing – Review & Editing, Supervision, Project administration, Funding acquisition.

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