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.