A new instrument for measuring the impact of visual impairment following stroke on quality of life

Thesis submitted in accordance with the requirements of the University of Liverpool for the degree of Doctor of Philosophy by Lauren Rachel Hepworth.

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List of Abbreviations

ADL	- Activity of daily living
ADVS	- Activities of Daily Vision Scale
AI	- Activity Inventory
ANOVA	- Analysis of variance
AQLQ	- Asthma Quality of Life Questionnaire
ARMD	- Age-related macular degeneration
AS-20	- Adult Strabismus Quality of Life questionnaire
ASQE	- Amblyopia and Strabismus Questionnaire
AVL	- Adaptation to Age-related Vision Loss scale
BIT	- Behaviour Inattention Test
BIVI-QoL	- Brain Injury associated Visual Impairment questionnaire
BIVSS	- Brain Injury Vision Symptom Survey questionnaire
CAT-QoL	- Child Amblyopia Treatment Questionnaire
CENTRAL	- Cochrane Central Register of Controlled Trials
DIF	- Differential item functioning
df	- degrees of freedom
DLTV	- Daily Living Tasks Dependant on Vision
EQ-5D	- European Quality of Life Score
GQL-15	- Glaucoma Quality of Life - 15 questionnaire
HRA	- Health Research Authority
HVAT	- Houston Vision Assessment Test
ICC	- Item characteristic curves
IND-VFQ	- Indian Visual Function Questionnaire
IPHS	- Institute of Psychology, Health and Society (University of Liverpool)
IQR	- Inter-quartile range
IRT	- Item response theory
IVI	- Impact of Visual Impairment
IVIS	- Impact of Visual Impairment Scale
IVIS Study	- Impact of Visual Impairment after Stroke
LFVFS-39	- Long Form Visual Functioning Scale
LIFE-H	- Assessment of Life Habits
LVQoL	- Low Vision Quality of Life questionnaire

MDT - Multi-disciplinary team

MLVAI - Melbourne Low Vision Activities of Daily Living Index

MPAI - Mayo-Portland Adaptability Inventory

MS - Multiple sclerosis

MSQLI - Multiple Sclerosis Quality of Life Inventory

NEI RQL - National Eye Institute Refractive Error Correction Quality of Life questionnaire

NEI VFQ-25 - National Eye Institute Visual Functional Questionnaire

Neuro 10 - Neuro 10 supplement for NEI VFQ

NHS - National Health Service (UK)

NHVQoL - Nursing Home Vision Targeted Health-related Quality of Life questionnaire

NIHSS - National Institute of Health Stroke Scale

OT - Occupational Therapist

PCA - Principal component analysis

PGI - Patient Generated Index

PREM - Patient Reported Experience Measure

PRISMA - Preferred Reporting Items for Systematic Reviews and Meta-Analysis

PROM - Patient Reported Outcome Measure

PSI - Person separation index

OKN - Optokinetic nystagmus

QoL-VFQ - Quality of Life and Visual Function Questionnaire

QoV - Quality of Vision questionnaire

QVSFS - Questionnaire for Verifying Stroke-Free Status

RCT - Randomised controlled trial

REC - Research Ethics Committee

RNIB - Royal National Institute of Blind People

SD - Standard deviation

SEIQoL - Schedule for the Evaluation of Individual Quality of Life

SF-12 - Short Form Health Survey

SF-36 - Medical-Outcome-Study Short-Form-36 Health Survey

SRA-FVP - Self-Reported Assessment of Functional Visual Performance

STROBE - Strengthening the Reporting of Observational Studies in Epidemiology

TBI - Traumatic brain injury

VA LV VFQ - Veterans Affairs Low Visual Function Questionnaire

VAQ - Visual Activity Questionnaire

VCM1 - Vision-related Quality of Life Core Measure

VDA - Visual Disability Assessment

VDQ - Visual Disability Questionnaire

VF-14 - Visual Functioning 14-items

VFI - Visual Function Index

VF and QOL - Visual Function and Quality of Life questionnaires

VF Severity - Severity of visual field damage questionnaire

VIS Study - Vision in Stroke Study

VisQoL - Vision and Quality of Life Index

VOR - Vestibular ocular reflex

VQoL - Vision-related Quality of Life questionnaire

VSQ - Visual Symptom and Quality of Life questionnaire

WHO - World Health Organisation

95% CI - 95% confidence interval

Glossary

Conjugate deviation

A deviation of both eyes to the same side.

Constrast sensitivity

The ability of the eye to detect objects of varying contrast which can be tested using sinusoidal gratings of varying spatial frequency and varying luminance intensity.

Convergence retraction nystagmus

On attempted upgaze, the eyes are seen to converge and retract in nystagmoid type jerk movements.

Gaze-evoked nystagmus

An inability to maintain the eyes in a gaze position away from the primary position. The eyes drift back to the primary position then make a correction saccade to look in the position of defective gaze.

Gaze palsy

Partial or complete loss of conjugate gaze which may affect horizontal or vertical directions.

Homonymous hemianopia

A complete defect involving one half of the visual field involving the same side of the visual field in each eye.

Homonymous quadrantanopia

A complete defect involving a quadrant of each visual field involving the same side of the visual field in each eye and either superior or inferior quadrants.

Internuclear ophthalmoplegia (INO)

Characterised by a limitation of adduction with abducting jerky nystagmus of the other eye.

Multi-vector nystagmus

Repetitive oscillatory movements in a combination of directions; horizontal, vertical, or rotary.

One and a half syndrome

A combined ipsilateral horizontal gaze palsy and ipsilateral internuclear ophthalmoplegia (INO)

Optokinetic nystagmus

Normal oscillatory eye movements that occur with movement of the visual environment.

Oscillopsia

An illusion of oscillatory movement of the environment experienced in patients with nystagmus

Parinaud's syndrome

Also know as **Dorsal Midbrain syndrome**. Characterised by a bilateral upgaze paresis, convergence retraction nystagmus on attempted upgaze. Other associated features are mid-dilated pupils with light-near dissociation and lid retraction on downgaze.

Saccades

Rapid conjugate eye movements under both volitional and reflex control. Voluntary includes willed refixations and those in response to command. Reflex include saccades in the direction of a new stimulus and usually are accompanied by head movement in the same direction.

Scotoma

An area of partial or complete blindness surrounded by normal or relatively normal visual field. *See also Relative, Absolute, Central, paracentral and cecocentral Scotoma.*

Skew deviation

A hypertropia caused by prenuclear input which may be concomitant or may alternate. It is differentiated from a vertical muscle palsy by the co-existence of other signs of central neurologic dysfunction.

Stereopsis

Perception of the relative depth of objects on the basis of the slight difference in images presented to each eye.

Strabismus

A manifest or latent ocular deviation.

Temporal crescent

Monocular defect in the extreme temporal visual field

Upbeat nystagmus

Jerky nystagmus is seen with the fast phase beating in an upward direction and with increased amplitude on upgaze (the eyes drift down and beat up again).

Vestibular ocular reflex

A mechanism to maintain clear vision during rotation of the head.

Definitions courtesy of Rowe (2012) and British and Irish Orthoptic Society (2015) (1, 2).

Abstract

Introduction: The prevalence of post-stroke visual impairment has been recently reported at 72%. A systematic narrative review highlighted a reduction in quality of life as a result of visual impairment following stroke. The review also revealed a wide range of instruments currently being used to measure quality of life, some with significant flaws if used when assessing stroke survivors. A systematic narrative review of existing patient reported outcome measures revealed no instruments which were specifically targeted at visual impairment following stroke, or indeed instruments that had been specifically validated with stroke survivors. It was concluded that validation of a combination of instruments or the development of a new instrument was required. The overall aim of the project was identify patient reported outcome measures to assess the impact of stroke related visual impairment on quality of life. Methods/Results: The development process for the new instrument adopted two methods of instrument development in order to compare the outcomes; a Delphi process and Rasch analysis. The two methods were also used to inform each other, and consolidated using a nominal group process. Items were sourced from the systematic review of existing instruments and individual interviews with stroke survivors. The pilot instrument version one (102 items) was created using a database of items and input from clinicians and stroke survivors consisting of a ranking exercise. This version was piloted with short- and long-term stroke survivors across three hospital sites. Due to low recruitment numbers and poor return rate, analysis with the aim of item reduction was performed on version one to shorten the instrument. Version two (62 items) was generated from this analysis. A full pilot using version two was conducted across eleven hospital sites. This part of the study was powered to conduct Rasch analysis. Items from version two were also evaluated in a Delphi survey to assess their individual importance in measuring vision-related quality of life. The survey was completed by stroke survivors and clinicians. A nominal group process agreed decisions on the inclusion items based on the Delphi survey results and psychometrics from Rasch analysis. Conclusion: The main contribution of this thesis is the production of a 15-item instrument to measure quality of life in individuals with visual impairment related to stroke with a single value score. A validation study is now required to confirm the instrument's effectiveness in a wider target population (visual impairment related to neurological disease or brain injury) for use in both clinical and research settings.

Chapter 1
Background

1.1: Stroke

The World Health Organisation (WHO) defines stroke as "rapidly developed clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than of vascular origin" (3). Stroke is a complex condition; dependent on the location of the insult an individual can be affected by one or more of a wide range of problems; for example physical disability (hemiplegia), communication disability (aphasia), feeding disability (dysphagia), cognitive disability, and visual impairment (4).

Approximately 100,000 people experience a stroke every year in the United Kingdom (5). Globally, mortality due to stroke is declining, especially in high-income countries, however, the burden of stroke in terms of disability is increasing (6).

Until recently, the numbers of individuals who experience visual problems as a consequence of stroke were not accurately known. Visual impairment following stroke is defined as a new visual problem which has occurred as a result of a stroke event; this may be in addition to a pre-existing ocular pathology. The Impact of Visual Impairment after Stroke (IVIS) study has recently published the point prevalence of visual impairment following stroke as 72% (7). A systematic narrative review was conducted at the outset this project to investigate the reported prevalence of visual impairment following stroke (Chapter 2). This estimated the prevalence of post-stroke visual impairment to be around 60% (8). There are a wide variety of visual problems which can result from stroke: visual field loss, ocular motility defects, visual inattention, reduced visual acuity and visual perception problems (9-12).

A recent review reported no standardised visual screening tools are currently available to assess for all the potential post-stroke visual impairments (13). A survey conducted in 2013 investigated how visual impairment following stroke was investigated, treated and followed-up, in which 44% of participants reported a care pathway for visual problems was not in place (14). Visual assessments were carried out at a variety of time points with 41% seen within one week and 73% seen within one month. These assessments were conducted by a variety of professions from within both the stroke team and eye team. Occupational therapists and orthoptists used the widest range of tests; visual acuity, visual field, ocular alignment, ocular movement, binocular vision and functional vision (14). The gold standard for visual assessment following stroke was recommended as an orthoptic assessment within one week of stroke onset from best practice service interviews (8). In the most recent national clinical

guidelines for stroke, orthoptists are now listed as members of the core multi-disciplinary team (15).

A survey of clinicians revealed a wide range of treatment options are provided, from vision and functional advice to those specific to the type of visual impairment e.g. prisms for diplopia, patching and scanning for visual field loss (14). The majority of treatment options offered aim to aid compensation or encourage adaptation, rather than being curative (14). Three Cochrane reviews addressing visual field loss, eye movement and spatial neglect relating to stroke, report a lack of high quality evidence for treatment options (9, 10, 12). This is echoed in the national clinical guidelines, with no specific recommendations on treatment options (15). A systematic narrative review of treatment options for post-stroke visual impairment highlighted some treatment options have been assessed in broader populations and accepted as effective, for example prisms have been proven to be effective for the treatment of diplopia regardless of aetiology (16).

1.2: Quality of life

Quality of life is a concept now commonly used to measure the impact of disease on individuals and the effectiveness of management options within clinical and research circumstances (17, 18). The definition of quality of life varies across the literature, although it is agreed that it is a complex and multidimensional concept (17, 19). The WHO Quality of Life group define overall quality of life as an "individuals' perception of their position in life in the context of culture and value systems in which they live in relation to their goals, expectations, standards and concerns" (20). This definition highlights the importance of the subjective element of quality of life; an objective description of an individual's health provides insufficient information. Health-related quality of life is often broken down into three domains; physical, mental and social well-being stemming from the WHO's definition of health (18, 21). Felce *et al.* offer a definition of health-related quality of life; "an overall general well-being that comprises objective descriptors and subjective evaluations of physical, mental, social and emotional well-being together with the extent of personal development and purposeful activity, all weighted by a personal set of values" (22). This highlights that several individuals with the same level of disability may perceive themselves to have different levels of quality of life due to their personality and what they view as important. It is this 'subjectivity' which should be of central focus when measuring quality of life (19).

1.3: Patient reported outcome measures

A patient reported outcome measure (PROM) "addresses some aspect of the patient's subjective experience of health and the consequences of illness" (23). These measures can capture an individual's functionality and feelings related to either their general health or a specific condition. Different types of instruments exist, ranging from generic, to disease-specific, to individualised instruments (23). Generic instruments do not focus on a particular condition, and therefore can be applied to a wide range of population groups as they are broad in scope, e.g. Euro-QoL (EQ-5D), Short Form Health Survey (SF-12) (24, 25). Disease-specific instruments are tailored to the condition of interest and are more likely to contain items relevant to that disease, e.g. Asthma Quality of Life Questionnaire (AQLQ), Child Amblyopia Treatment Questionnaire (CAT-QoL) (26, 27). Individualised instruments allow the individual to select the items which are of most importance to them. Firstly, individuals are asked to rank tasks of importance to their lives, then subsequently the effect of their health condition on those specific tasks, e.g. Patient Generated Index (PGI), Schedule for the Evaluation of Individual Quality of Life (SEIQoL) (28, 29). It is possible for PROMs to cover more than one of these types.

Using self-reporting allows PROMs to capture concepts which would not be possible by any other method (30). PROMs are used for a wide range of purposes, from establishing the impact of a condition on an individual, assessing the effectiveness of a method of treatment, and as a utility index for health economic evaluation (31). A pilot randomised controlled trial of interventions for stroke induced visual field loss suggested vision-related PROMs assessing quality of life would be an appropriate primary outcome measure (32). A report by Devlin and Appleby demonstrates the wide potential for PROMs to inform decision-making at a variety of levels from clinicians to commissioners (33). Objective measures of health are important in both clinical settings and within research; these types of measures do not tell the whole story. PROMs provide a vehicle for the patient's voice, to inform clinicians and/or researchers with their views on the social, psychological and emotional impact of their health status (34, 35).

It is important to select a relevant, precise, reliable and valid instrument which is responsive to the changes which require detection (23, 36). The instrument should also be acceptable to the target population and provide interpretable results (37). Precision refers to the ability of the instrument to distinguish between individuals who have different levels of the construct being measured (23). The concept of reliability has two aspects: internal consistency and reproducibility (23). Internal consistency is closely associated with

unidimensionality. Unidimensionality is a key principle of measurement in which only one attribute is measured by the instrument. An instrument should be reproducible and produce the same result when completed by participants on separate occasions when there is no clinical change. This concept is assessed using a test-retest method (23, 34). Validity refers to an instruments ability to measure what it purports to measure. Validity is not a fixed property but is reliant on the specific purpose and setting in which an instrument is being used (23, 35). In reference to PROMs, it has been argued that the types of validity which are most relevant are face, content and construct validity (35). Face and content validity are assessed subjectively as to whether the contents of the instrument are suitable for its proposed application (23, 35). Construct validity is essential when measuring an unobservable construct e.g. disability, quality of life or depression. It is a corroboration that the instrument is measuring the intended underlying construct (34). PROMs are required to detect change in the underlying construct, especially if they are to be used as primary outcome measure in clinical research. Responsiveness refers to the ability to detect clinically important change when either improvement or deterioration has occurred (23, 35, 38). Acceptability has been argued as being a crucial feature of an instrument, and could potentially be strongly linked to face validity (23, 39). If an instrument is not acceptable to its target population, this could result in either non-return or partial completion.

1.4: Project overview

Overall, the aim of this project was to identify patient reported outcome measures to assess the impact of stroke related visual impairment on quality of life. This aim was achieved in several stages.

Systematic narrative literature reviews to investigate the prevalence and recovery of visual impairment following stroke (Chapter 2) and previous measurement of quality of life in this population (Chapter 3) were conducted.

A further systematic narrative review explored the literature with the aim of identifying suitable patient reported outcome measures for use in a population of stroke survivors experiencing visual impairment (Chapter 4).

The latter two reviews revealed no appropriate instruments were available to address a specific target population of stroke survivors with visual impairment, nor indeed instruments that had been specifically validated with stroke survivors. Three of the ten research priorities

set following an analysis of the gaps within the evidence supporting the National Stroke Strategy, support the rationale for the development of a new patient reported outcome measure (40, 41):

- To estimate the longer-term needs of stroke survivors including quality of life.
- To evaluate the effectiveness of rehabilitation interventions from the acute phase of stroke into the long-term.
- To develop comprehensive outcome measures.

The James Lind Alliance have set research priorities since 2004 using rigorous methodology involving patients and clinicians (42). Rehabilitation and treatment of stroke related visual impairment currently appears fourth on the neuro-ophthalmology and fifth on the stroke priority lists (43).

There is currently no widely accepted gold standard for the development of patient reported outcome measures (PROMs). The current movement is towards Rasch Models and Item Response Theory (IRT) and away from Classical Test Theory (44). The initial stage of development requires the generation of a pilot instrument. This is commonly achieved using a combination of knowledge from existing instruments and specialist opinion (45).

The development method for this new instrument adopted two common methods of instrument development, Rasch analysis and a Delphi process in order to compare the outcomes, as outlined in Figure 1.1. The two methods were also used to inform each other in the development of the instrument.

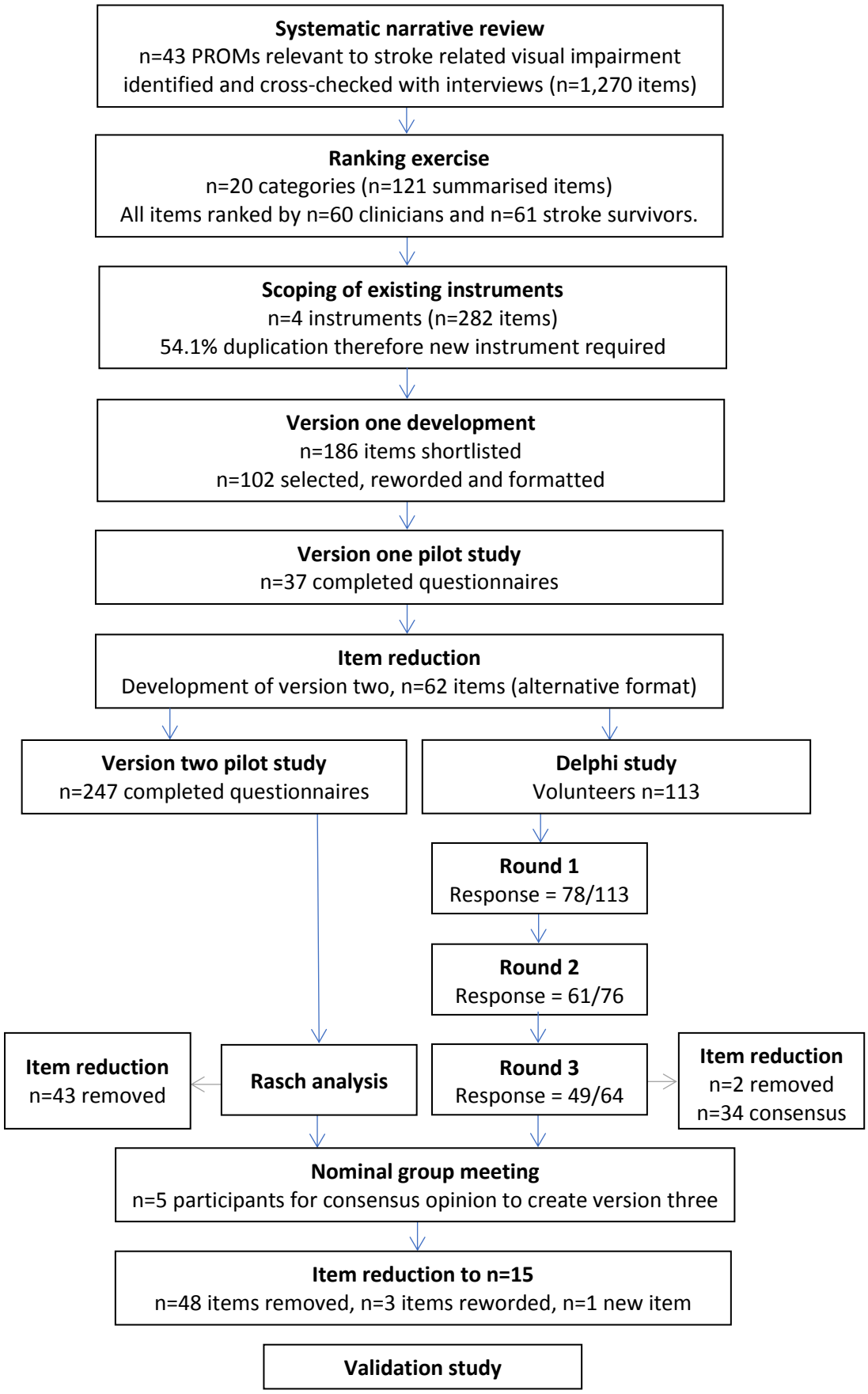

Figure 1.1: Flow chart of instrument development methods

Items were sourced from the systematic narrative review of existing instruments and individual interviews with stroke survivors with visual impairment. A ranking exercise with clinicians and stroke survivors helped to create the pilot instrument version one (Chapter 5). This instrument was then piloted with short- and long-term stroke survivors. Analysis with the aim of item reduction, was performed on version one to shorten the instrument due to difficulty with recruitment and questionnaire return, thereby creating version two (Chapter 6).

A full pilot was conducted using version two. This part of the study was powered for Rasch analysis (Chapter 7). Alongside the pilot of version two, the items were also used to create a three round Delphi survey (Chapter 8).

The outcomes of the Delphi survey (Chapter 8) and Rasch analysis (Chapter 9) were reviewed, comparing which items the instrument would contain if only one method had been used. The results of both methods were taken to a nominal group meeting for final item inclusion decisions based on the Delphi survey results, psychometrics (Rasch analysis), expert knowledge and semantics (Chapter 10). The participants at the nominal group meeting were also asked to make comment on the layout and formatting of the instrument, informing version three. Stroke survivors and frontline stroke clinicians were involved at every stage of the process in order to create an instrument which is primarily focused for stroke survivors.

Chapter 2

A systematic narrative review of types and recovery of post-stroke visual impairment

2.1: Introduction

There were no accurate estimates of prevalence or incidence of visual impairment for stroke survivors at the outset of this study. Determination of prevalence of visual impairment following stroke is important in enabling commissioning of specialist eye services and appropriate planning of efficacious referrals to an eye specialist for assessment, treatment and targeted advice (46-48).

The aim of this systematic narrative literature review was to provide a comprehensive synthesis and exploration of reported evidence relating to visual problems after stroke with specific attention to prevalence and recovery.

2.2: Methods

An integrative review was conducted, aiming to bring together all evidence relating to incidence, prevalence and recovery from stroke-related visual problems. This systematic review was conducted following the guidance of the Cochrane Handbook for Systematic Reviews and the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) checklist (49, 50).

2.2.1: Inclusion criteria for considering studies for this review

2.2.1.1*: Types of studies*

The following types of studies were included: randomised controlled trials (RCTs), controlled trials, prospective and retrospective cohort studies and observational studies. Case reports and case-controlled studies were excluded, as they specifically look at selected cases and are therefore unable to report incidence or prevalence. All languages were included and translations obtained when necessary.

2.2.1.2*: Types of participants*

Studies involving adult participants (aged 18 years or over) diagnosed with a visual impairment as a direct result of a stroke were included. Studies which included mixed populations were included if over 50% of the participants had a diagnosis of stroke and data were available for this subgroup.

2.2.1.3*: Types of outcome and data*

Incidence was defined as the number of new cases of any visual condition occurring during a certain period in a stroke survivor population. Prevalence was defined as the number of cases of any visual condition present in a stroke survivor population at a certain time. A measure of recovery was defined as being present if prevalence figures were available at more than one time point post-stroke for the same cohort. The visual impairments included are defined below.

2.2.2: Visual impairment definitions

Visual impairment is a deficit of visual function and includes abnormalities of peripheral vision, central vision, ocular motility and perception (9, 11, 12).

Visual field loss is the loss of a section of the field of vision and can be central, peripheral or both. Following stroke, visual field loss is frequently homonymous, with a loss on the same side of the visual field of both eyes. The types of visual field loss can include hemianopia, quadrantanopia, constriction and scotomas (11, 51).

Reduced central vision is a loss of clarity of sight and can occur to different degrees. It could include a reduction in visual acuity and/or contrast sensitivity. It may occur for many reasons following stroke, for example central scotomas or cortical blindness (52).

There are a wide range of ocular motility problems which can occur as a result of stroke including strabismus, cranial nerve palsies, gaze palsies, vergence abnormalities and nystagmus (53). Strabismus is the misalignment of the eyes, which can be longstanding from childhood or occur as a result of an insult to the extra-ocular muscles or the cranial nerves supplying them. Eye movement palsies or paresis following stroke can include cranial nerve palsy, horizontal gaze palsy and/or vertical gaze palsy. Nystagmus is a continuous oscillatory movement of the eyes and is frequently associated in which both eyes move symmetrically. It may occur in every position of gaze or only be present in certain gaze positions. A further consideration is that stroke survivors commonly have multiple defects concurrently (54).

There are a number of different visual perceptual problems that can occur after stroke. The most recognised is visual inattention/neglect, in which the individual does not respond or attend to visual stimuli on the affected side. Other perceptual problems are also reported such as visual agnosia, visual hallucinations and image movement problems (55).

2.2.3: Search methods for identification of studies

A systematic search strategy was used to search the following key electronic databases: Cochrane Stroke Group Trials Register, The Cochrane Eyes and Vision Group Trials Register, The Cochrane Central Register of Controlled Trials (CENTRAL), MEDLINE (1948 to April 2015), SCOPUS (1823 to April 2015), AMED (1985 to April 2015), CINAHL (1937 to April 2015) and PsycINFO (1887 to April 2015). In an effort to identify further published, unpublished and ongoing trials, registers of ongoing trials were searched, hand-searched journals and conference transactions were completed, citation tracking using Web of Science Cited Reference Search for all included studies was performed, and reference lists of included studies and review articles about vision after acquired brain injury were searched. Search terms included a comprehensive range of MeSH terms and alternatives in relation to stroke and associated visual conditions (Table 2.1).

2.2.4: Selection of studies

The titles and abstracts identified from the search were screened independently by two individuals (author and supervisor) using the pre-stated inclusion criteria (Section 2.1.1). The full papers of any studies considered potentially relevant were then considered and the selection criteria applied independently by two reviewers (author and supervisor). In the case of disagreement for inclusion of studies, an option was available to obtain a third opinion. In practice, this was not required as agreement was reached for all included or excluded studies.

Table 2.1: Search terms (MeSH terms indicated by /)

Cerebrovascular Disorders/ Brain Ischaemia/ Intracranial Arterial Disease Intracranial Arteriovenous Malformations/ Intracranial Embolism and Thrombosis/ Stroke/	Eye Movements/ Eye/ Eye Disease/ Visually Impaired Persons/ Vision Disorders/ Blindness/ Diplopia/ Vision, Binocular/ Vision, Monocular/ Visual Acuity/ Visual Fields/ Vision, Low/ Ocular Motility Disorders/ Blindness, Cortical/ Hemianopsia/ Abducens Nerve Diseases/ Abducens Nerve/ Oculomotor Nerve/ Trochlear Nerve/ Visual Perception/ Nystagmus/ strabismus smooth pursuits saccades depth perception stereopsis gaze disorder internuclear ophthalmoplegia Parinaud's syndrome skew deviation conjugate deviation oscillopsia visual tracking agnosia hallucinations
OR	OR
AND	

2.2.5: Data extraction

A pre-designed data extraction form was used which gathered information on sample size, study design, assessments undertaken, visual conditions reported, timing of assessment and population type. Data was extracted and documented by the author and verified by the primary supervisor.

2.2.6: Data analysis

Due to the heterogeneous nature of the studies, a narrative analysis was undertaken. The exception to this was a meta-analysis to estimate the prevalence of overall visual impairment following stroke. A strict criterion of only studies using consecutive recruitment from a stroke population was used for the mean and weighted mean prevalence calculations.

2.2.7: Quality assessment

To assess the quality of the studies included in this review, one checklist was considered relevant to the study designs included: the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) checklist (56, 57). The checklist was adapted as the original was designed to assess the quality of reporting rather than the potential for bias within a study. There is currently no 'gold standard' quality assessment tool for observational studies (58). The STROBE statement comprises 22 items covering the whole of the article from introduction, method, results and discussion, which are important to consider when assessing the quality of observation studies (including cohort, case-control and cross-sectional studies). The adapted version used in this review included 18 items; only the information pertinent to quality appraisal of the studies was included (Table 2.2). Using Boyle's recommendations for the evaluation of prevalence studies, the items excluded were not considered to be relevant information, such as the title, abstract, background, setting and funding (59).

Table 2.2: The items and recommendations used in quality analysis from the STROBE statement (56, 57)

Item	Recommendation
INTRODUCTION	
3. Objectives	State the specific objectives, including any pre-specified hypothesis.
METHODS	
4. Study design	Present key element of study design early in the paper.
6. Participants	(a) Give the eligibility criteria, and the sources and methods of selection of participants (controls). Describe methods of follow up or rationale for the choices of cases and controls.
7. Variables	Clearly define all outcomes, exposures, predictors, potential confounders and effect modifiers. Give diagnostic criteria, if applicable.
8. Data sources/ measurement	For each variable of interest, give sources of data and details of method of assessment (measurement). Describe comparability of assessment methods if there is more than one group.
9. Bias	Describe any efforts to address potential sources of bias.
10. Study size	Explain how the study size was arrived at.
11. Quantitative variables	Explain how quantitative variables were handled in the analysis. If applicable, describe which grouping were chosen and why.
12. Statistical methods	(a) Describe all statistical methods, (b) Describe any methods used to examine subgroups and interaction, (c) Explain how missing data were addressed, (d) Explain how follow-up or matching of cases and controls was addressed, or describe methods taking account of sampling, (e) Describe any sensitivity analysis.
RESULTS	
13. Participants	(a) Report number of individuals at each stage of the study, (b) Give reasons for non-participation at each stage.
14. Descriptive data	(a) Give characteristics of study participants and information on exposures and potential confounders, (b) Indicate the number of participants with missing data for each variable of interest, (c) Summarise follow-up time.
15. Outcome data	Report numbers of outcome events and summary measures or numbers in each exposure category or summary measures
16. Main results	(a) Give unadjusted estimates and if applicable confounder-adjusted estimates and their precision, (b) Report category boundaries when continuous variables are categorised.
17. Other analyses	Report any other analysis done.
DISCUSSION	
18. Key results	Summarise key results with reference to study objectives.
19. Limitations	Discuss limitations of the study, taking into account sources of potential bias or imprecision.
20. Interpretation	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results of similar studies and other relevant evidence.
21. Generalisability	Discuss the generalisability of the study results.

2.3: Results of the search

The search results are outlined in Figure 2.1. Sixty-four articles (26,321 participants) were included. Of the 64 included studies, 52 were prospective observational studies and 12 were retrospective analyses. Consequently, quality of study was assessed using the STROBE checklist. Although none of the studies were RCTs, one study was a retrospective analysis of data from an RCT archive (60). Quality appraisal using the adapted STROBE checklist is outlined in Table 2.3.

Seven studies (14,573 participants) reported on overall visual impairment. Nineteen studies (17,924 participants) reported on visual field defects; 22 studies (4,330 participants) reported on ocular alignment and motility defects; nine studies (2,097 participants) reported on central vision problems; and 13 studies (2,885 participants) reported on types of perceptual visual deficits following stroke (including visual neglect/inattention, visual hallucinations, agnosia and reduced stereopsis). Several studies reported on two or more of these categories.

None of the studies included had a specific primary aim to calculate either prevalence or incidence of visual impairment following stroke. Fifty-five studies specifically investigated visual impairment following stroke. This included studies looking at specific visual problems such as visual inattention. Ten studies investigated symptoms and signs of stroke, which included reporting visual impairment.

2.4: Quality of the evidence

Three papers reported 100% of the items requested by the adapted STROBE checklist (61). Sixteen papers reported 90% or more of the requested items, 51 papers reported 75% or more. Sixty-one reported 50% or more and three papers failed to reach 50%, achieving 17%, 33% and 39% (62-64). Only 36% of papers reported limitations of their studies. Results from all papers were reported and the individual results for each paper are outlined in Table 2.3.

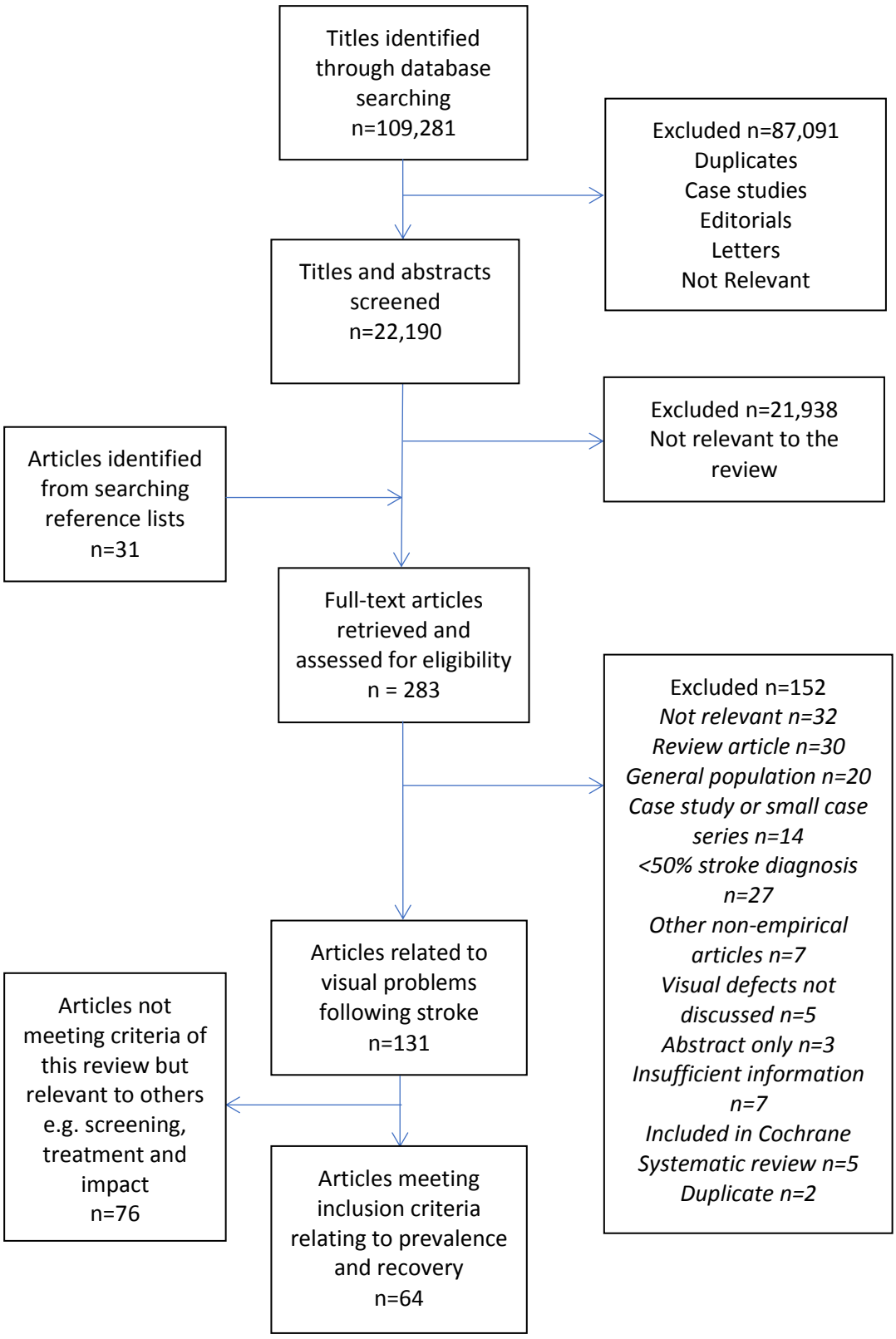

Figure 2.1: Flowchart of pathway for inclusion of articles

Table 2.3: Quality appraisal of papers using an adapted STROBE checklist

+ =Reported - = Not reported ? = Unclear

	Introduction	Methods								Results					Discussion			
	3	4	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21
Agrell et al., 1997 (65)	+	+	+	+	+	+	+	+	?	-	+	+	+	+	+	-	+	-
Akhtar et al., 2009 (66)	+	+	+	+	+	-	+	+	+	-	+	+	+	n/a	+	-	-	+
Ali et al., 2013 (60)	+	+	+	+	+	-	+	-	-	?	?	+	+	+	+	+	+	+
Appelros et al., 2002 (67)	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Baier and Dieterich, 2011 (68)	-	+	+	+	+	-	-	-	-	+	+	+	+	n/a	+	-	+	+
Barrett et al., 2007 (69)	+	+	+	+	-	-	-	+	+	+	+	+	+	+	+	+	+	-
Beaudoin et al., 2013(70)	+	+	+	+	+	+	-	+	-	+	+	+	+	+	+	+	+	+
Becker and Karnath, 2007 (71)	+	+	+	+	+	-	+	+	-	+	+	+	+	n/a	+	-	-	-
Benedetti et al., 1993 (72)	+	+	+	+	-	-	+	+	-	+	+	+	+	+	+	-	-	+
Bulens et al., 1989 (73)	-	+	+	+	+	-	-	+	-	+	+	+	+	+	+	-	-	-
Cassidy et al., 1998 (74)	+	+	+	+	+	-	+	+	-	-	+	+	+	n/a	+	+	+	-
Cassidy et al., 1999 (75)	+	+	+	+	+	-	-	+	-	+	-	+	+	n/a	+	-	+	-
Cassidy et al., 2001 (76)	+	+	+	+	+	+	+	+	-	+	-	+	+	+	+	+	+	-
Celesia et al., 1997 (77)	+	+	+	+	+	-	+	+	-	+	+	+	+	+	+	-	+	-
Chechlacz et al., 2014 (78)	-	+	-	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Clisby, 1995 (62)	+	-	-	-	-	-	-	-	-	+	-	+	-	-	-	-	-	-
De Renzi et al., 1982 (79)	-	+	+	+	+	+	+	+	-	+	+	+	+	n/a	+	-	+	-

	3	4	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21
dos Santos et al., 2012 (80)	+	-	+	+	+	+	-	+	+	+	+	+	+	n/a	+	+	+	+
Edwards et al., 2006 (81)	+	+	+	+	+	+	-	+	+	+	+	+	+	+	+	-	+	+
Farné et al., 2004 (82)	+	+	-	+	+	-	-	+	+	+	+	+	+	+	+	-	-	-
Fowler et al., 1996 (83)	+	+	+	+	+	-	+	+	-	+	+	+	+	n/a	+	-	+	-
Freeman and Rudge, 1987 (84)	+	+	+	+	+	-	+	+	-	+	+	+	+	n/a	+	-	-	-
Gall et al., 2010 (61)	+	+	+	+	+	+	+	+	+	+	+	+	+	n/a	+	+	+	+
Gray et al., 1989 (85)	+	+	+	+	+	+	+	+	-	+	+	+	+	n/a	+	-	-	-
Haerer, 1973 (86)	+	+	+	+	-	-	+	-	-	+	+	+	+	n/a	+	+	+	-
Isaeff et al., 1974 (63)	-	+	?	-	-	-	-	+	-	+	+	+	+	n/a	-	-	-	-
Jerath et al., 2011 (87)	+	+	+	+	+	-	+	+	-	+	+	+	+	n/a	+	+	+	+
Kedar et al., 2007 (88)	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	-
Lawrence et al., 2001 (89)	+	+	+	+	-	-	+	+	+	+	+	+	+	+	+	-	-	-
Lee et al., 2009 (90)	-	+	+	+	+	-	+	+	-	+	+	+	+	+	+	-	+	-
Linden et al., 2006 (91)	+	+	+	+	+	-	+	+	+	+	+	+	+	n/a	+	-	+	-
Lotery et al., 2000 (92)	+	+	+	+	-	-	-	+	-	+	+	+	+	n/a	+	-	-	-
Maeshima et al., 2012 (93)	-	+	+	+	+	-	+	+	+	+	+	+	+	n/a	+	-	-	-
Ng et al., 2005 (94)	+	+	+	+	+	-	+	+	+	+	+	+	+	+	+	+	+	+
Pedersen et al., 1997 (95)	+	+	+	+	+	-	+	+	+	+	+	+	+	+	+	-	-	-
Poggel et al., 2007 (96)	-	+	+	+	+	-	+	+	+	+	+	+	+	+	+	-	-	-
Rathore et al., 2002 (97)	-	-	+	+	-	-	+	+	+	+	+	+	+	+	+	+	+	-
Rowe, 2007 (98)	+	+	+	+	-	-	+	+	+	+	+	+	+	+	+	-	+	+
Rowe et al., 2008 (99)	+	+	+	+	-	-	+	+	-	+	+	+	+	+	+	-	+	+

	3	4	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21
Rowe et al., 2009a (55)	+	+	+	+	-	-	+	+	-	+	+	+	+	+	+	-	+	+
Rowe et al., 2009b (46)	+	+	+	+	+	-	+	+	-	+	+	+	+	+	+	+	+	+
Rowe et al., 2010 (54)	+	+	+	+	-	-	+	+	-	+	+	+	+	+	+	-	+	-
Rowe et al., 2011a (47)	+	+	+	+	+	-	+	+	+	+	+	+	+	+	+	+	+	+
Rowe et al., 2011b (48)	+	+	+	+	+	-	+	+	+	+	+	+	+	+	+	+	+	-
Rowe et al., 2013 (100)	+	+	+	+	+	-	+	+	+	+	+	+	+	+	+	-	+	+
Rowe et al., 2013 (53)	+	+	+	+	-	-	+	+	+	+	+	+	+	+	+	+	+	-
Rowe et al., 2013 (51)	+	+	+	+	+	-	+	+	+	+	+	+	+	+	+	+	+	+
Schmielau and Wong Jr, 2007 (101)	+	-	+	+	+	-	-	+	-	+	+	+	+	+	+	-	-	-
Searls et al., 2012 (102)	+	+	+	+	-	-	+	+	+	+	+	+	+	+	+	-	-	-
Shrestha et al., 2012 (103)	+	+	+	+	+	-	+	+	+	+	+	+	+	+	+	-	-	-
Siddique et al., 2009 (104)	-	+	+	-	-	-	+	+	-	+	+	+	+	+	+	-	+	+
Singer et al., 2006 (105)	-	+	+	+	-	-	+	+	+	+	+	+	+	+	+	+	+	+
Siong et al., 2014 (106)	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Stone et al., 1993 (107)	+	+	+	+	+	-	+	+	+	+	+	+	+	+	+	-	-	-
Su and Young, 2013 (108)	-	+	+	+	+	-	+	+	-	+	+	+	-	-	+	-	+	-
Tao et al., 2012 (109)	+	+	+	+	-	-	+	+	+	+	+	+	+	+	+	+	+	-
Tiel and Kölmel, 1991 (110)	-	+	+	+	-	-	+	+	-	+	+	+	-	n/a	+	-	-	-
Townsend et al., 2007 (111)	-	+	+	+	+	+	+	+	+	+	+	+	+	n/a	+	-	-	+
Trobe et al., 1973 (64)	-	+	+	-	-	-	+	-	-	+	+	+	-	-	+	-	-	-
van Nes et al., 2009 (112)	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	-	-	-
Yang et al., 2014 (113)	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	-	-	-

	3	4	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21
Yap et al., 1975 (114)	+	+	+	+	-	-	+	+	-	+	+	+	-	n/a	+	-	-	-
Zhang et al., 2006 (115)	+	+	+	+	+	+	+	+	-	+	+	+	+	+	+	-	+	+
Zhang et al., 2006 (116)	+	+	+	+	+	+	+	+	-	+	+	+	-	n/a	+	+	+	+

2.5: Prevalence and incidence

2.5.1: Visual impairment

The search of the literature did not reveal any studies that specifically aimed to assess the incidence of visual impairment following stroke. A number of the studies identified report an overall figure of prevalence for visual impairment. All of these studies, however, were judged to have limitations relating to the methods of recruitment or assessment. Thus, a calculation of incidence was not possible and estimates were instead calculated for prevalence.

Three prospective studies of stroke populations (n=709) were used to calculate a mean prevalence of visual impairment post-stroke of 65% and a weighted mean of 64%, with figures ranging from 62-71% (Table 2.4) (62, 63, 84). These studies evaluated a general stroke population including medical and orthoptic assessments undertaken during the hyperacute to subacute phases, ranging from within one week of onset to three months post-stroke onset. Further to these three studies of general stroke populations, one prospective study (n=915) recruited a sub-population of stroke survivors with suspected visual impairment who received full orthoptic assessment, typically within three weeks of stroke onset (46). They reported a prevalence of 92% with visual impairment. It is unknown what was missed from the general stroke population, as not all individuals can report visual symptoms and referrals were evaluated to be more accurate when visual symptoms were taken into consideration in addition to ocular signs, in comparison to ocular signs alone (100). Ali *et al*. analysed results from a database of stroke survivors recruited to a variety of stroke-related clinical trials and reported a baseline prevalence of 60% with visual impairment (60). This cohort would typically include those who are able and willing to participate in a clinical trial and are therefore not representative of the whole population. Cognitive impairment, aphasia and severe stroke in which visual impairment is more likely are factors which result in a reduced likelihood of recruitment to research (117).

Three studies (n=13,541) used a stroke assessment tool, the National Institute of Health Stroke Scale (NIHSS) ± status questionnaire, which only partly assesses visual function (60, 61, 69). The NIHSS is an assessment tool that only assesses for the presence of horizontal gaze problems, visual field loss and inattention, although the inattention section is not specific to vision. Therefore it would not be possible to differentiate visual inattention from sensory (118). Thus, it is not a full assessment of the possible visual problems which can manifest as a result of stroke. It can therefore be argued that the numbers presented by

these studies are not a true measure of overall incidence/prevalence of visual impairment following stroke. In addition to the NIHSS, the Questionnaire for Verifying Stroke-free Status (QVSFS) was used. However this questionnaire only asks the patient about painless complete or partial vision loss (119). The range of overall prevalence of visual problems was 19-25.9% from these studies, which was considerably less than was found in studies with more comprehensive vision assessment methods.

2.5.2: Visual field loss

The reported prevalence of visual field loss after stroke varied considerably in the literature from 5.5% to 57% (Table 2.5), most probably due to dependence on the type and affected area of a stroke, inclusion criteria, the timing of assessments and the method of testing used (85, 102, 109, 115).

Seven studies (n=1,210) recruited stroke patients consecutively, either as they were admitted to hospital acute stroke units or rehabilitation wards. Assessment of visual fields by confrontation and/or perimetry on admission after stroke onset detected visual field loss in up to 57% (62, 63, 65, 72, 76, 85, 86). The mean prevalence of visual field loss after stroke was calculated as 31% and the weighted mean as 33% (62, 63, 65, 72, 76, 85, 86). These studies typically assessed patients in the acute phase with homonymous hemianopia or quadrantanopia defects most frequently detected.

In addition to the above studies, seven prospective studies (n=15,388) of stroke sub-populations report prevalence of visual field loss (51, 60, 89, 94, 106, 109, 120). These sub-populations typically include only stroke survivors with hemianopic or quadrantanopic field loss, or with suspected visual impairment of any type, or do not recruit consecutively. Thus, reported prevalence is not representative of the full stroke population.

Prevalence of visual field loss has been described based on symptom reporting by patients in four studies (n=1,362) ranging from 14.6% to 22.7% (77, 87, 97, 102). These reports are considerably lower and likely reflect the poor reliability of detection by patient reported symptoms. In addition to those formally diagnosed with visual field loss following stroke, it is important to consider how many individuals are unaware of their visual loss. Celesia *et al.* conducted a prospective observation study (n=32) to investigate the presence of hemianopic anosognosia (77). From a sample of thirty-two patients with homonymous visual field loss, 62% were unaware of their visual deficit. Rowe *et al*. reported that only 45% of participants

with visual field loss reported symptoms of the visual field loss (100). It is important to note that not all participants had isolated visual field loss. Multiple visual impairments caused by stroke alongside visual field loss were reported such as visual acuity loss, eye movement abnormalities and perceptual difficulties. This discrepancy between those who do not complain of symptoms and have a diagnosis of visual field loss may highlight an under-estimation in the incidence in this and other studies.

For studies whose population samples have solely included participants with visual field loss post-stroke, it is not possible to establish prevalence. All three studies recruited participants with homonymous hemianopia consecutively, however they did not report the number screened for inclusion (64, 88, 115).

2.5.3: Ocular motility defects and strabismus

Three prospective studies (n=486) enabled a calculation of the mean prevalence of all ocular motility problems as 27% and a weighted mean as 24% (Table 2.6) with a range from 22% to 44%, (84, 114). Assessments were usually within the acute period and one study used detailed orthoptic evaluation of eye movements and binocular vision (84). Methods of ocular motility assessment are important to the accuracy of identification of eye movement abnormalities to ensure full detection of deficits in various gaze positions. In addition to the above studies, another prospective study (n=915) of a stroke sub-population with suspected visual impairment reported prevalence of ocular motility defects as 54% (47).

2.5.3.1*: Eye Alignment*

Strabismus may occur as an isolated finding or in association with ocular motility problems and is reported in 16.5% to 52% of stroke survivors recruited to three prospective observation studies (n=626), with a mean prevalence of 38% and a weighted mean of 35% (62, 83, 84). These studies used validated orthoptic assessments to detect the presence of strabismus, increasing the accuracy of detection. In a sub-population prospective multi-centre observational study, 19% of the sample were identified with strabismus (54). Pre-existing strabismus was acknowledged in 2.5%, thus 16.5% were considered to be a direct result of stroke. The cause of the strabismus in 70% of cases was an ocular motility defect. Only 36% were symptomatic with diplopia, which highlights an issue in relying purely

on symptoms alone. This study has a risk of underestimating the prevalence, as the sample is not representative of the whole stroke population.

Diplopia is reported as a symptom in many papers which is a result of a misalignment of the eyes and a disruption of binocular vision. Other studies have highlighted the discrepancy between patients who do or do not report diplopia in the presence of strabismus or ocular motility defects. There is a risk that a proportion are not captured if the symptom of diplopia is relied upon to identify ocular motility defects. The majority of studies reporting the incidence of diplopia limit recruitment to include strokes affecting specific areas of the brain (93, 108, 109), are retrospective (87, 102) or required informed consent (106). These studies cannot be generalised to the whole stroke population and also carry a risk of under estimating the true prevalence of strabismus.

2.5.3.2*: Eye movement palsy*

Eye movement palsy/paresis can include saccadic palsies, smooth pursuit palsies and gaze palsies (121).

Seven studies (n=2,783) report figures for gaze palsies including horizontal and/or vertical gaze positions and have a mean prevalence following stroke of 25% and a weighted mean of 18% (range 9-44%) (53, 62, 79, 84, 105, 109, 114). These defects may occur in isolation or in conjunction with other visual problems, and are the most common of all ocular motility abnormalities (53, 114). Horizontal gaze palsies are more prevalent than vertical and complete palsies more prevalent than partial (53, 62, 84, 105).

Cranial nerve palsies affecting the ocular motor muscles include third, fourth and sixth cranial nerves with a mean post-stroke prevalence of 15% and a weighted mean of 5% (range 1 to 39%) from three studies (n=1,414) (62, 109, 114). Third and sixth nerve palsies are reported as being more prevalent than fourth nerve palsies in these stroke populations (47, 62, 92).

Where ocular motility assessment only tests horizontal gaze, such as the NIHSS screening tool, the identification of all ocular cranial nerve palsies is limited. It is likely, therefore, that vertical gaze palsies, the more subtle horizontal nerve palsies and those involving the vertical muscles may be missed.

2.5.3.3*: Nystagmus*

Following stroke, nystagmus is reported in a mean of 9% and a weighted mean of 7% of cases (range 4 to 48%) across four studies (n=1,612) (79, 84, 104, 109). In most prospective and retrospective studies reporting nystagmus, the specific types of nystagmus are not reported. This, in addition to lack of information regarding the method of assessment, makes it difficult to assess if the more subtle types, or nystagmus absent in primary position, have been missed. These factors increase the risk of an underestimation of prevalence. When reported, common types of acquired nystagmus are gaze evoked, multi-vector and upbeat (99). The studies described to date, frequently report when the stroke has affected the posterior circulation, including the cerebellum (66, 68, 102, 108). No studies have reported the prevalence of nystagmus in anterior circulation strokes in isolation. It is, therefore not possible to estimate the proportion of cases which are potentially missed by restricting populations to posterior circulation strokes only.

2.5.3.4*: Vergence*

Clisby (n=140) reported 55% of participants to have reduced convergence and/or stereopsis (62). Rowe *et al.* (n=243) reported reduced convergence from the initial ten month data set of the Vision in Stroke (VIS) study (98). Using the gold standard 'normal' attainment for convergence of 6cm, 54% were judged to have reduced convergence. However, they also reported that 26% had convergence reduced less than 10cm, which could be judged to be a more appropriate standard for an older group of individuals. Siong *et al.* reported 21% of the recruited population to have convergence reduced to less than 15cm (106).

2.5.4: Visual acuity and central vision deficit

Clinical assessment of visual acuity has been used to identify those with reduced vision and up to 70% of stroke survivors (Table 2.7) have been noted to have poor central vision (62, 81, 92, 100). The mean prevalence of reduced visual acuity post-stroke was calculated from three studies (n=270) as 53% and a weighted mean as 52% (62, 81, 92). Methods included visual acuity assessment at near and at three or six metre distances. Further retrospective studies (n=447) provide information on the prevalence of patients reporting symptoms associated with a reduction of visual acuity (87, 102). A key issue identified by three studies

(n=1,045) related to patients' glasses (81, 92, 100). These were frequently reported as missing, or the glasses present were dirty, broken or the wrong prescription.

An important component of central visual function is contrast sensitivity, the reduction of which can deform image perception. Contrast sensitivity function has been reported to be abnormal in 62% of stroke survivors (n=16) (73). Different areas of the spectrum are impaired depending on the lesion site. For example, participants with parietal and temporal lesions have been reported to have reduced detection of low spatial frequencies whereas those with occipital and occipito-temporal lesions had difficulty with medium to high spatial frequencies (73). Furthermore, reduced contrast sensitivity in stroke survivors, particularly those with severe functional difficulties, has been found to be associated with reduced activities of daily living (80).

Central vision is key to activities such as reading. However, reading difficulties may be caused by a wide range of visual impairments in addition to reduced visual acuity. Rowe *et al.* (n=915) reported difficulties with reading occurred in 19.3% of the sample (48). The three largest associations with reading difficulties were visual field loss (61.6%, the majority of which were complete homonymous hemianopia), reduced convergence of less than 6cm (45.8%) and saccadic abnormalities (45.0%). Other visual impairments associated with reading difficulties included reduced visual acuity (22.5%), perceptual deficits (22.0%), including 16.5% with visual inattention, nystagmus (12.4%) and diplopia (8.5%) (48).

2.5.5: Visual perception abnormalities

The most common form of visual perception disorder following stroke is visual neglect or inattention. The literature reporting the prevalence of visual neglect/inattention can be difficult to interpret. Often the different types of inattention (e.g. auditory, visual, and spatial) are not separated, so it is not always possible to isolate visual inattention.

Visual inattention has been calculated to occur in a mean of 32% and weighted mean of 25% (range 14% to 82%) (Table 2.8) of stroke survivors from five studies (n=1,800) (67, 71, 91, 95, 107). These studies have recruited participants consecutively and have used a range of tests or tools to assess visual inattention including cancellation tests and the Behavioural Inattention Test (BIT). Studies (n=1,335) using cancellation tests alone reported prevalence of 15% to 26% (91, 95, 112). Those using a variety of assessments (n=991) for visual inattention reported a prevalence of 14% to 82% (55, 67, 74, 75, 90, 107). Discrepancies in

the wide range of prevalence figures typically related to the timing of assessment plus inclusion/exclusion criteria of left versus right sided stroke lesions and severe cognitive and/or communication deficits. As expected, there was a greater prevalence of left versus right sided inattention.

In addition to visual neglect/inattention, the prevalence of other perceptual deficits are reported in the literature. Perceptual deficits, such as object agnosia and colour detection difficulties have been reported in very small numbers (48, 54, 55, 103). The literature search found four studies reporting an estimated prevalence for different visual perceptual deficits following stroke (55). Beaudoin *et al.* (n=189) reported an overall prevalence of visual perception deficits as 49.2% (70). Rowe *et al.* (n=323) estimated the prevalence as 20%, of which the prevalence of visual hallucinations after stroke was 4% and visual agnosia was 2.5% (55). It was reported that patients with visual hallucinations and other perceptual deficits frequently do not disclose these symptoms. This, in addition to the method of recruitment could result in an under-estimation of the true prevalence. Yang *et al*. (n=82) reported 50% of participants had pathologic (>3^{o}) subjective visual vertical tilt following brainstem stroke (113). Chechlacz *et al.* (n=454) reported 28% of participants with right hemisphere stroke showed left visual extinction versus 6.8% of participants with left hemisphere stroke showed right visual extinction (78).

Freeman and Rudge reported 79% of participants to have defective stereopsis (84). Stereopsis was only tested in the pilot study (n=26), therefore the number of participants tested was limited to 19. It was also purposely not tested on participants with manifest strabismus even those which were a direct result of the stroke. The majority of those with strabismus would not demonstrate any stereopsis. This would result in an underestimation of those suffering reduced or absent stereopsis as a direct result of stroke.

Table 2.4: Overall visual impairment prevalence

Study	Design	Population	Time of vision assessment	Sample size (n)	Prevalence of visual issue (%)	Co-existent ocular condition	Method of visual assessment
1974; Isaeff *et al*. (63)	Prospective observation	General stroke	Median within 3 months of onset	322	62	Yes	Medical
1987; Freeman and Rudge (84)	Prospective observation	General stroke	Median within 1 week of onset	247	63	Yes	Medical Orthoptic
1995; Clisby (62)	Prospective observation	General stroke	Acute period on stroke unit	140	71	Yes	Orthoptic
2007; Barrett *et al*. (69)	Prospective observation	General stroke	Unknown	505	19	Unknown	NIHSS and QVSFS
2009; Rowe *et al*. (46)	Prospective observation	Stroke survivors with suspected visual issues	Median within 3 weeks of onset	323	92	Yes	Orthoptic
2013; Ali *et al*. (60)	Trial data	Acute stroke	Median within 1 week of stroke onset	11,900	60	Unknown	NIHSS
2010; Gall *et al*. (61)	Retrospective	General stroke	Unknown	1,136	25.9 23 – male 29 – female	Unknown	NIHSS

Table 2.5: Visual field loss prevalence

Study	Design	Population	Time of vision assessment	Sample size (n=)	Prevalence of visual issue (%)	Co-existent ocular condition	Method of assessment
1973; Haerer *et al.* (86)	Prospective observation	General stroke	Unknown	265	25 – homonymous hemianopia / quadrantanopia	Unknown	Confrontation
1974; Isaeff *et al.* (63)	Prospective observation	General stroke	Median within 3 months of onset	322	17 – visual field loss	Ocular pathology	Confrontation
1989; Gray et al. (85)	Prospective observation	General stroke	Every 24 hours for 4 days and 28 days	174	46.6 – complete homonymous hemianopia 10.3 – partial homonymous hemianopia	Ocular pathology	Confrontation
1993; Benedetti *et al*. (72)	Prospective observation	General stroke	Median within 48 hours of admission	94	19.1 – homonymous hemianopia	Unknown	Unknown
1995; Clisby (62)	Prospective observation	General stroke	Acute period on stroke unit	140	47 – visual field loss	Ocular pathology	Confrontation Campimetry
1997; Agrell *et al*. (65)	Prospective observation	General stroke	Median within 3 months of onset	67	30 – homonymous hemianopia	Visual inattention	Confrontation
1997; Celesia *et al.* (77)	Prospective observation	Stroke survivors with hemianopia	Median within 24 hours of onset	32	100 – homonymous hemianopia 62 – asymptomatic	Unknown	Kinetic perimetry
2000; Lotery *et al.* (92)	Prospective observation	General stroke	Median within 3 months of onset	77	19.5 – visual field loss (73.3 – hemianopia)	Ocular pathology	Unknown
2001; Cassidy *et al.* (76)	Prospective observation	General stroke	Median within 3 months of onset	148	50.6 – visual field loss	Ocular pathology	Confrontation Perimetry

Study	Design	Population	Time of vision assessment	Sample size (n=)	Prevalence of visual issue (%)	Co-existent ocular condition	Method of assessment
2007; Townend *et al.* (120)	Prospective observation	General stroke excl. receptive aphasia cognitive impairment	Within 9 months of onset	61	16 – homonymous hemianopia	Unknown	Static perimetry
2009; Rowe *et al.* (46)	Prospective observation	Stroke survivors with suspected visual issues	Median within 3 weeks of onset	915	49.5 – visual field loss 29.4 – complete hemianopia	Ocular pathology Visual inattention	Confrontation Kinetic perimetry Static perimetry
2012; Tao *et al.* (109)	Prospective observation	General stroke: anterior vs posterior circulation	Median within 3 months of onset	1,174	6.9 – visual field loss Hemianopia: 4.3 – posterior circulation 1.3 – anterior circulation Quadrantanopia: 1.3 – posterior circulation	Unknown	NIHSS Confrontation
2013; Ali *et al.* (60)	Prospective trial data	General stroke	Median within 1 week of stroke onset	11,900	51 – visual field loss: majority hemianopia	Unknown	NIHSS Confrontation
2013; Rowe *et al*. (51)	Prospective observation	Stroke survivors with suspected visual impairment	Variable over 2 weeks to 6 months	915	52.3 – visual field loss 54 – complete homonymous hemianopia 19.5 – partial homonymous hemianopia	Yes	Confrontation Static perimetry Kinetic perimetry

Study	Design	Population	Time of vision assessment	Sample size (n=)	Prevalence of visual issue (%)	Co-existent ocular condition	Method of assessment
					15.2 – homonymous quadrantaopia 0.2 – temporal crescent 9.2 – constricted fields 5.1 – scotomas 1.7 – bilateral hemianopia		
2014; Siong *et al.* (106)	Prospective observation	General stroke	10 days to 26 years post-stroke onset	113	26.5 – monocular defects 11.5 – binocular defect	Ocular pathology	Confrontation
2001; Lawrence *et al.* (89)	Retrospective	Stroke register	Median within 3 months of onset	1,136	26.1 – visual field loss	Unknown	Unknown
2002; Rathore *et al.* (97)	Retrospective	Database stroke cohort	Unknown	474	14.6 – homonymous hemianopia	Unknown	Unknown
2005; Ng *et al.* (94)	Retrospective	Posterior circulation strokes	Unknown	89	53 – visual field loss	Unknown	Unknown
2011; Jerath *et al.* (87)	Retrospective	General stroke Male vs female	Unknown	449	22.7 – visual field loss (female) 20.9 – visual field loss (male)	Unknown	Neurology Accident & Emergency assessment non-standardised

Study	Design	Population	Time of vision assessment	Sample size (n=)	Prevalence of visual issue (%)	Co-existent ocular condition	Method of assessment
2012; Searls *et al.* (102)	Retrospective	Posterior circulation stroke	Unknown	407	22 – visual field loss	Unknown	Neurology assessment of signs and symptoms

Table 2.6: Eye movement disorder prevalence

Study	Design	Population	Time of vision assessment	Sample size (n=)	Prevalence of visual issue (%)	Co-existent ocular condition	Method of assessment
1975; Yap *et al.* (114)	Prospective observation	General stroke	Median within 2 days of onset	100	44 – ocular motility disorders 28 – gaze palsy 11 – impaired vestibular ocular reflex (VOR) 6 – cranial nerve palsy	Unknown	Unknown
1982; De Renzi *et al.* (79)	Prospective observation	General stroke	Follow-up every 3-4 days for 2 weeks post onset	91	28 – horizontal gaze palsy 7 – nystagmus	Unknown	NIHSS
1987; Freeman & Rudge (84)	Prospective observation	General stroke	Median within 1 week of onset	247	22 – ocular motility disorders 35 – strabismus (additional 6% pre-existent) 18 – palsies 3 – skew deviation 6 – one and a half syndrome 57 – horizontal gaze palsy 20 – vertical gaze palsy 23 – nystagmus	Yes	Medical Orthoptic
1995; Clisby (62)	Prospective observation	General stroke	Acute period on stroke unit	140	52 – strabismus 44 – gaze palsy: (Right sided lesion, limitation to: 56 – left, 29 – bilateral, 6 – right, 10 – upgaze. Left sided lesion, limitation to: 31 – right, 27 – bilateral, 27 – upgaze, 15 – left)	Ocular pathology	Orthoptic

Study	Design	Population	Time of vision assessment	Sample size (n=)	Prevalence of visual issue (%)	Co-existent ocular condition	Method of assessment
					39 – cranial nerve palsy 55 – reduced vergence and stereoacuity		
1996; Fowler *et al.* (83)	Prospective observation	Mixed neurological on rehabilitation unit	Median within 2 months of admission	239 (54% stroke)	26 – acquired strabismus	Unknown	Orthoptic
2000; Lotery *et al.* (92)	Prospective observation	General stroke	Median within 2 weeks of onset	77	2.6 – third nerve palsy	Yes	Ophthalmology and optometric
2006; Singer *et al.* (105)	Prospective observation	Acute stroke excluding haemorrhagic stroke and posterior circulation ischaemia	Within 6 hours of onset	116	26.7 – complete gaze palsy 0.6 – partial gaze palsy	Unknown	NIHSS
2007; Rowe *et al.* (98)	Prospective observation	Stroke with suspected visual impairment	Median within 3 weeks of onset	243	54 – reduced convergence <6cms. 26 – reduced convergence <10cms.	Yes	Orthoptic
2008; Rowe *et al.* (99)	Prospective observation	Stroke with suspected visual impairment	Median within 3 weeks of onset	323	12 – nystagmus (5 – pre-existent 18 – oscillopsia/vertigo symptoms)	Yes	Orthoptic

Study	Design	Population	Time of vision assessment	Sample size (n=)	Prevalence of visual issue (%)	Co-existent ocular condition	Method of assessment
2009; Siddique *et al.* (104)	Prospective observation	General stroke	Acute period	100	4 – nystagmus	Unknown	Unspecified protocol
2009; Akhtar *et al.* (66)	Prospective observation	Posterior circulation stroke only	Acute period	116	48 – nystagmus	Unknown	Unknown
2009; Rowe *et al.* (46)	Prospective observation	Stroke survivors with suspected visual impairment	Median within 3 weeks of onset	323	54 – reduced convergence <6cms 26 – reduced convergence <10cms	Yes	Orthoptic
2010; Rowe *et al.* (54)	Prospective observation	Stroke survivors with suspected visual impairment	Median within 3 weeks of onset	512	19 – strabismus 16.5 – new onset 2.5 – pre-existent	Yes	Orthoptic
2011; Rowe *et al.* (47, 48)	Prospective observation	Stroke survivors with suspected visual impairment	Median within 3 weeks of onset	915	54 – ocular motility disorders (61 – diplopia) 19 – strabismus (2.5% pre-existent) 10 – cranial nerve palsy (VI>III>IV) 58 – VIth 26 – IIIrd	Yes	Orthoptic
2011; Baier & Dieterich (68)	Prospective observation	Cerebellar stroke	Mean within 6 days	21	33 – nystagmus	Unknown	Eye movement recording

Study	Design	Population	Time of vision assessment	Sample size (n=)	Prevalence of visual issue (%)	Co-existent ocular condition	Method of assessment
2012; Maeshima *et al.* (93)	Prospective observation	Pontine stroke	Unknown	68	15.9 – diplopia	Unknown	Unknown
2012; Tao *et al.* (109)	Prospective observation	General stroke: anterior vs posterior circulation stroke	Acute period	1,174	0.2 – diplopia: 7.3 – posterior circulation 0.7 – anterior circulation 9 – gaze palsy: 11 – anterior circulation 2.6 – posterior circulation 1 – cranial nerve palsy: 4 – posterior circulation 3.7 – nystagmus: 0.8 – anterior circulation 11.9 – posterior circulation	Unknown	NIHSS
2013; Su & Young (108)	Prospective observation	Posterior fossa stroke: vertigo clinic	Unknown	70	31 – ocular motility disorders 45 – diplopia 31 – nystagmus (45.5 – multidirectional, 54.5 – unidirectional, 86 – reduced OKN)	Unknown	Nystagmus – eye movement recordings
2013; Rowe *et al.* (53)	Prospective observation	Stroke survivors with suspected visual impairment	Median within 3 weeks of onset	915	23 – gaze defect: 15.9 – horizontal and vertical gaze palsy 69.7 – complete 13.5 – saccadic palsy 22.2 – smooth pursuit palsy 22.2 – impaired gaze holding 3.9 – Parinaud's syndrome	Yes	Orthoptic

Study	Design	Population	Time of vision assessment	Sample size (n=)	Prevalence of visual issue (%)	Co-existent ocular condition	Method of assessment
					9.7 – internuclear ophthalmoplegia (INO) 1.4 – one and a half syndrome		
2014; Siong *et al.* (106)	Prospective observation	General stroke	10 days to 26 years post-stroke onset	113	53.1 – jerky eye movements 11.5 – restricted ocular motility 20 – reduced convergence (<15cm)	Yes	Optometrist
2011; Jerath *et al.* (87)	Retrospective	General stroke Male vs female	Unknown	449	7.8 – diplopia (7.1 male, 0.7 female) 17.5 – nystagmus (4.6 male, 12.9 female)	Unknown	Neurology Accident & Emergency assessment non-standardised
2012; Searls *et al.* (102)	Retrospective	Posterior circulation stroke	Unknown	407	20 – ocular motility disorders 15 – diplopia 25 – nystagmus	Unknown	Neurology assessment of signs and symptoms

Table 2.7: Central visual deficit prevalence

Study	Design	Population	Time of vision assessment	Sample size (n=)	Prevalence of visual issue (%)	Co-existent ocular condition	Method of assessment
1989; Bulens *et al.* (73)	Prospective observation	General stroke	Days to years post onset	16	62 – reduced contrast sensitivity	No	Ophthalmology
1995; Clisby (62)	Prospective observation	General stroke	Acute period on stroke unit	140	58 – reduced visual acuity	Excluded ocular pathology	Orthoptic with adapted visual acuity assessment for dysphasia
2000; Lotery *et al.* (92)	Prospective observation	General stroke	Median within 2 weeks of onset	77	30 – visual acuity ≤6/12 27 – no glasses available, dirty or damaged lenses	Yes	Ophthalmology and optometric
2006; Edwards *et al.* (81)	Prospective observation	General stroke with exclusions if unable to hold a pencil or severe motor or language deficits	Median within 15 days of onset	53	70 – reduced visual acuity (30 – 6/7.5-6/15 4 – 6/21-6/30 36 – 6/60-6/120) 54 – no glasses available	Unknown	Near visual acuity
2011; Rowe *et al.* (48)	Prospective observation	Stroke survivors with suspected visual impairment	Median within 3 weeks of onset	915	19.3 – reading impairment: 61.6 – field loss 45.8 – reduced convergence 45 – saccadic defects 22.5 – reduced visual acuity 22 – perceptual defect	Yes	Orthoptic

Study	Design	Population	Time of vision assessment	Sample size (n=)	Prevalence of visual issue (%)	Co-existent ocular condition	Method of assessment
2013; Rowe *et al.* (100)	Prospective observation	Stroke survivors with suspected visual impairment	Median within 3 weeks of onset	915	31 – reduced visual acuity	Yes	Orthoptic
2011; Jerath *et al.* (87)	Retrospective	General stroke Male vs female	Unknown	449	27 – loss of vision reported: (15.8 – male, 10.3 – female) 19 – visual disturbance reported: blurred vision, focus difficulty, photophobia, visual hallucinations	Unknown	Neurology Accident & Emergency assessment non-standardised
2012; Searls *et al.* (102)	Retrospective	Posterior circulation stroke	Unknown	407	20 – blurred vision	Unknown	Neurology assessment of signs and symptoms
2012; dos Santos & Andrade (80)	Retrospective	General stroke with haemorrhagic stroke excluded	Unknown	40	100 – reduced contrast in comparison to controls	Excluded ocular pathology	Ophthalmology
2014; Siong *et al.* (106)	Prospective observation	General stroke	10 days to 26 years post-stroke onset	113	29.8 – vision worse than 0.3 LogMAR 11.5 – mild reduced vision (worse than 0.5 LogMAR) 1.8 – moderate reduced vision (worse than 1.0 LogMAR)	Yes	Optometrist

Table 2.8: Visual perception impairment prevalence

Study	Design	Population	Time of vision assessment	Sample size (n=)	Prevalence of visual issue (%)	Co-existent ocular condition	Method of assessment
1987; Freeman & Rudge (84)	Prospective observation	General stroke	Median within 1 week of onset	247	79 – reduced stereoacuity	Yes	Orthoptic
1993; Stone *et al.* (107)	Prospective observation	General stroke	Median within 3 days of onset	171	57.3 – visual neglect: Of those assessed 82 – right hemisphere stroke 65 – left hemisphere stroke 11.7 – anosognosia: Of those assessed 28 – right hemisphere stroke 5 – left hemisphere stroke	Unknown	Modified BIT
1997; Pedersen *et al.* (95)	Prospective observation	General stroke	At admission	1,014	23 – visual neglect [42 – right hemisphere, 8 – left hemisphere]	Unknown	Cancellation tasks
1998; Cassidy *et al.* (74)	Prospective observation	General stroke with left hemisphere lesions excluded	Within 7 days and monthly follow-up	66	40.9 – visual neglect 74 – visual field loss	Unknown	BIT
1999; Cassidy *et al.* (75)	Prospective observation	General stroke with left hemisphere lesions excluded	Within 7 days and monthly follow-up	44	61.4 – visual neglect	Unknown	BIT

Study	Design	Population	Time of vision assessment	Sample size (n=)	Prevalence of visual issue (%)	Co-existent ocular condition	Method of assessment
2002; Appleros *et al.* (67)	Prospective retrospective cases	General stroke	Unknown	279	23 – visual neglect [62 – right hemisphere] 74 – anosognosia	Unknown	Test battery
2005; Linden *et al.* (91)	Prospective observation	General stroke	At 20 months of onset	243	15 – visual neglect	Unknown	Star cancellation
2007; Becker & Karnath (71)	Prospective observation	General stroke	Median within 3 days of onset	93	26.2 – visual neglect [right hemisphere] 24.3 – visual extinction 2.4 – visual neglect [left hemisphere] 4.9 – visual extinction	Unknown	Cancellation tasks
2009; Lee *et al.* (90)	Prospective observation	General stroke Left hemisphere excluded	Median within 2 months of onset	138	58 – visual neglect 22.5 – neglect dyslexia	Unknown	Test battery
2009; van Nes *et al.* (112)	Prospective observation	General stroke Excluding aphasia, gaze palsy, cognitive issues	Median within 2 weeks of onset	78	21.8 – visual neglect 88 – right hemisphere	Gaze paresis excluded	Cancellation tasks
2009; Rowe *et al.* (46, 55)	Prospective observation	Stroke survivors with suspected visual defect	Median within 3 weeks of onset	323	14 – visual neglect 4 – visual hallucinations 2.5 – visual agnosia	Yes	Test battery

Study	Design	Population	Time of vision assessment	Sample size (n=)	Prevalence of visual issue (%)	Co-existent ocular condition	Method of assessment
2013; Beaudoin *et al.* (70)	Prospective longitudinal	General stroke	At discharge to home	189	49.2 – visual perceptual defect	Unknown	Motor-free visual perceptual test-vertical version
2014; Chechlacz *et al.* (78)	Prospective observational	Sub-acute stroke	2.5 – 27.3 days	454	9.1 – left visual extinction 4.6 – right visual extinction	Unknown	Confrontation extinction
2014; Siong *et al.* (106)	Prospective observational	General stroke	10 days to 26 years post-stroke onset	113	5.3 – visual neglect	Yes	Line bisection
2014; Yang *et al.* (113)	Prospective observational	Brainstem infarction	Less than 10 days post symptom onset	82	50 – pathologic subjective visual vertical tilt (>3º) 76 – ipsiversive 24 – contraversive 54.7 – abnormal torsion	Unknown	Computerised assessment

2.6: Recovery of visual function

This literature search identified one study that appeared to report the recovery of overall visual problems following stroke (Table 2.9). The majority that report recovery do so only for visual field loss (Table 2.10). Ali *et al*. had the largest sample for tracking recovery of multiple visual problems following stroke (60). However, not all visual problems were included due to the use of the NIHSS which limits assessment to visual field loss, horizontal gaze paresis and inattention. There was a variable sample size at the three time points used (baseline, 30 days and 90 days post-stroke). The authors reported a reduction of visual problems to 28.2% at 30 days and a further reduction to 20.5% at 90 days, compared to the initial 60.5% at baseline. The sample size considerably decreased between baseline (n=11,900) to 30 days post-stroke (n=4,965).

2.6.1: Visual field loss

Recovery of visual field loss is reported by a number of studies but across variable time periods (Table 2.10). The percentage of patients recovering from visual field loss ranges from 0% to 44% for complete recovery and up to 72.2% for partial recovery (n=6,656) (60, 76, 84, 85, 88, 101, 110, 116). Variability in recovery rates appears to be dependent on the timing of baseline assessment, length of follow-up, accuracy and sensitivity to detection of change of visual field assessment methods, prospective versus retrospective studies and exclusions of severe neurological and communication defects.

Gray *et al.* (n=174) documented recovery in 47.8% of their sample, with a slightly higher proportion of 56.5% who had been diagnosed with a right hemianopia (85). The macula was involved in 56.3% of the sample; 72.2% saw an improvement of the central loss and surrounding areas. They noted four different patterns of recovery, the most common (34.4%) of which was recovery of the lower quadrant. This was followed by complete recovery (25%), recovery of the upper quadrant (21.9%) and finally improvement in both quadrants with some residual defect (18.7%). They found that most improvement occurred between six and 25 days post-stroke. Cassidy *et al.* (n=19) reported that of those patients who demonstrated some recovery, only 15.8% achieved complete recovery at four weeks (76). Others had either central (macular) recovery (42.1%) or quadrantic recovery (5.3%). For an individual with a complete homonymous hemianopia the recovery of the macula area can appear to be only a small recovery. However, this can have a considerable functional impact, such as with

reading ability. They were also able to demonstrate the reduced sensitivity of the confrontation method at detecting areas of recovery. Variances in reports related to whether the baseline visual field loss was complete or partial, and/or congruous versus incongruous loss along with stroke-specific or mixed populations.

2.6.2: Ocular motility defects and strabismus

Little has been reported on the recovery of ocular alignment and motility problems following stroke (Table 2.11). The percentage of participants which were reported to recover ranged from 7% to 28.5% for full recovery, and up to 92% for partial recovery (n=6,047) (47, 53, 60, 79, 84, 99). The greatest recovery was seen in reduced stereoacuity at 92% (84). Sixth nerve palsies were reported to have the highest incidence of complete recovery of cranial nerve palsies at 28.5% (47). At least one third showed no recovery across ocular motility conditions of gaze palsy, nystagmus, cranial nerve palsy and strabismus (47, 48, 84, 99).

2.6.3: Visual acuity and central vision deficit

Few studies have reported on the recovery of central vision following stroke (Table 2.12). One study (n=247) was found that outlined the recovery of reduced vision following stroke (84). The majority (71%) showed some recovery. It was not clear from this study what extent of recovery was made and whether this had been achieved at the one or six month follow-up.

Rowe *et al.* (n=915) reported the recovery rates for a group of participants with reading difficulties (48). The data from follow-up visits was available for 42.9% of the participants. Of these, 10.5% had complete resolution of their symptoms, and 43.4% showed some improvement. A similar proportion of 44.7% saw no change in their symptoms and 1.3% experienced a deterioration in their condition.

2.6.4: Visual perception abnormalities

2.6.4.1*: Visual inattention*

Four studies (n=5,286) have reported recovery of visual neglect/inattention (60, 74, 82, 84). The percentage of recovery reported in the literature ranges from 29% to 78% (Table 2.13). In contrast to other visual impairments, participants with visual inattention were more likely to require a longer stay in hospital and have a poorer prognosis for recovering function (95). Recovery is mostly seen within three months of onset (60, 74, 84) with approximately 10% full recovery within the first two weeks (82).

2.6.4.2*: Other perceptual deficits*

One study (n=140) reported the recovery of visual hallucinations (96). Visual hallucinations (Charles Bonnet syndrome) persisted for several days or weeks after the onset of stroke before gradually subsiding. The median duration of visual hallucinations was 28 days, and they stated that the first 90 days is when spontaneous recovery was most likely to occur.

Table 2.9: Recovery of visual impairment

Study	Design	Population	Time of vision assessment	Sample size (n=)	Prevalence of visual issue (%)	Assessment
2013; Ali *et al.* (60)	Prospective observation	Stroke trial database	Baseline, 30 days and 90 days	11,900 at baseline 4,965 at follow-up	28.2 – visual impairment at 30 days 20.5 – visual impairment at 90 days versus 60.6 at baseline	NIHSS

Table 2.10: Recovery of visual field loss

Study	Design	Population	Time of vision assessment	Sample size (n=)	Prevalence of visual issue (%)	Assessment
1987; Freeman & Rudge (84)	Prospective observation	General stroke	Mean 73 day follow-up 1 week to 6 months	247	33 – improvement (22 – full, 11 – partial) 25 – stable field	Confrontation
1989; Gray *et al.* (85)	Prospective observation	General stroke	Followed every 24 hours for 4 days and max to 28 days	174	Complete hemianopia: 17 – full resolution within 2-10 days 27 – partial improvement 39 – stable field Partial hemianopia: 44 – full resolution within 48 hours 28 – full resolution within 14 days 17 – stable field	Confrontation
1991; Tiel & Kolmel (110)	Prospective observation	Posterior circulation stroke excluding communication difficulty and	Daily follow-up within 3 weeks of onset	125	47.8 – improvement within 6-25 days (34.4 – recovery of lower quadrant 25 – full recovery 21.9 – recovery of upper quadrant 18.7 – partial recovery of both quadrants)	Confrontation

Study	Design	Population	Time of vision assessment	Sample size (n=)	Prevalence of visual issue (%)	Assessment
		severe neurological deficits			56.5 – recovery for right hemianopia 41.3 – recovery for left hemianopia 72.2 – recovery for macular splitting	
2001; Cassidy *et al*. (76)	Prospective observation	General stroke	4 week intervals up to 12 weeks	19	15.8 – full recovery at 4 weeks 42.1 – central recovery at 4 weeks 5.3 – quadradratic recovery at 4 weeks 11.1 – stable	Perimetry
2007; Schmielau & Wong (101)	Prospective observation	Mixed population	Change at 1 through to 105 months post onset	20	61.5 – improvement	Kinetic perimetry
2013; Ali *et al.* (60)	Prospective observation	Stroke trial database	Baseline, 30 days and 90 days	11,900 at baseline 4,965 at follow-up	Complete hemianopia: 13 at 30 days, 10 at 90 days versus 35 at baseline Partial hemianopia: 11 at 90 days versus 14.5 at baseline	NIHSS Confrontation
2013; Rowe *et al.* (51)	Prospective observation	Stroke survivors with suspected visual impairment	Variable over 2 weeks to 6 months	915	7.5 – full recovery 39.2 – partial recovery 1 – deterioration 52.3 – static	Confrontation Static and Kinetic perimetry
2006; Zhang *et al.* (116)	Retrospective	Mixed population	Median 3 months of onset, change at 3 and 6 months	254	3 – full recovery 34 – partial recovery 63 – stable field	Perimetry – central 30 or 24 degrees
2007; Kedar *et al.* (88)	Retrospective	Mixed population	Median 3 days post onset	852	Congruous hemianopia: 38.1 – improvement, 58.5 – stable field 3.4 – deteriorated Incongruous hemianopia: 39.6 – improvement, 41.5 – stable field 18.9 – deteriorated	Perimetry – central 30 or 24 degrees

Table 2.11: Recovery of eye movement deficits

Study	Design	Population	Time of vision assessment	Sample size (n=)	Prevalence of visual issue (%)	Assessment
1982; De Renzi *et al.* (79)	Prospective observation	General stroke	Follow-up every 3-4 days for 2 weeks post onset	91	8.6 days – mean duration to improvement with left stroke 14.9 days – mean duration to improvement with right stroke	NIHSS
1987; Freeman & Rudge (84)	Prospective observation	General stroke	Up to 12 months post onset	76	7 – full recovery 50 – partial recovery 43 – stable 92 – improvement in stereoacuity within 1 month	Orthoptic
2011; Rowe *et al.* (47)	Prospective observation	Stroke survivors with suspected visual impairment	Variable over 2 weeks to 6 months	915	Cranial nerve palsy: 22.5 – full recovery 43 – partial recovery 3.5 – deterioration Nystagmus: 42 – partial recovery 24 – stable Gaze palsy: 4 – full recovery 66 – partial recovery 30 – stable	Orthoptic
2013; Ali *et al.* (60)	Prospective observation	Stroke trial database	Baseline, 30 days and 90 days	11,900 at baseline 4,965 at follow-up	Complete gaze palsy: 1.1 – at 30 days versus 14.5% at baseline Partial gaze palsy: 9 – at 30 days versus 31% at baseline	NIHSS Confrontation

Table 2.12: Recovery of central vision deficit

Study	Design	Population	Time of vision assessment	Sample size (n=)	Prevalence of visual issue (%)	Assessment
1987; Freeman & Rudge (84)	Prospective observation	General stroke	Median within 1 week of onset	247	71 – improvement	Medical Orthoptic
2011; Rowe *et al.* (48)	Prospective observation	Stroke survivors with suspected visual impairment	Variable over 2 weeks to 6 months	915	10.5 – full recovery 43.4 – partial recovery 44.7 – stable 1.3 – deteriorated	Orthoptic

Table 2.13: Recovery of visual perceptual impairment

Study	Design	Population	Time of vision assessment	Sample size (n=)	Prevalence of visual issue (%)	Assessment
1987; Freeman & Rudge (84)	Prospective observation	General stroke	Up to 4 months post onset	247	Visual neglect: 29 – complete recovery 57 – stable	Medical Orthoptic
1998; Cassidy *et al*.(74)	Prospective observation	General stroke with left hemisphere lesions excluded	Monthly follow-up	66	9.1 – visual neglect at 3 months versus 40.9 at baseline	BIT
2004; Farne *et al*. (82)	Prospective observation	Right hemisphere only	Follow-up at 2 weeks and 3 months post onset	33 at baseline 8 at 3 months	43 – recovery at 2 weeks (9 – full) 63 – recovery at 3 months	BIT
2007; Poggel *et al.* (96)	Prospective observation	Post-geniculate lesions	Mean 36 months (7-189 months), up to 6 months follow-up.	19	Visual hallucinations persisted for several days/weeks and then gradually subsided	Interview
	Retrospective questionnaire	Mixed population	Up to 6 months follow-up	121	Mean duration of 28 days	Questionnaire
2013; Ali *et al*. (60)	Prospective observation	Stroke trial database	Baseline, 30 days and 90 days	11,900 at baseline 4,965 at follow-up	0.6 – visual neglect at 90 days versus 27.7 at baseline	NIHSS Confrontation

2.7: Limitations and recommendations for future incidence, prevalence and recovery studies

None of the studies provided information about stroke survivors who were not admitted to a stroke unit, ward or rehabilitation unit. It is acknowledged that a proportion of stroke survivors can present as outpatients with an isolated visual impairment (usually occipital infarcts), but the numbers of these remain unknown.

The timing of the visual examination post-stroke has a direct effect on the estimate of prevalence of visual impairment that occurs due to stroke. As recovery of visual impairment can occur rapidly in some cases during the first weeks post-stroke, studies that assess visual function later than the initial two week period are likely to detect those with persistent visual impairment. The extent of visual impairment for those with persistent visual conditions may also be misrepresented as these individuals may have had substantial improvement with only partial deficits remaining. Thus, there is considerable potential for an underestimation of stroke related visual impairment.

Accuracy of non-specialist vision assessments and accuracy of screening tools and scores are also likely to impact on reported prevalence figures. Where basic screening is undertaken, it is possible to miss subtle visual problems whose ocular signs are not included in the screening assessment. Thus, there is the potential for underdiagnoses when the assessment is performed by the emergency or stroke team, rather than an eye team specialist or where screening tools are used which only measure specific features of vision, e.g. detection of hemianopia, horizontal gaze defects or inattention only as with the NIHSS, or reliance on basic confrontation assessment, rather than detailed confrontation or perimetry assessment.

Studies that report sub-populations of stroke survivors are also prone to reporting bias for visual impairment. Despite large sample sizes in studies that have included sub-populations of stroke survivors, such as those already suspected of having visual impairment or studies of clinical trial databases, these studies are unlikely to be representative of the general stroke population (46, 60). These estimates are potential under- or over-representations of the true prevalence of visual problems across all stroke survivors.

The timing of the baseline assessment is crucial for studies tracking the recovery of visual impairment. If the baseline assessment is delayed, complete or partial recovery may have already taken place. Furthermore, it has not yet been accurately established at what time

point recovery of each visual problem following stroke can be expected. If a study only has a short period of follow-up, recovery could continue after the participant has completed the study. Both factors result in underestimation of recovery of stroke related visual impairment.

Future studies are required to establish the incidence for post-stroke visual impairment in the hyperacute period. Such studies should involve a full stroke cohort with no exclusions so that visual impairment rates are comprehensively evaluated. Follow-up would be required at regular time intervals to plot change in visual impairment over the first weeks and months, longer term after stroke onset, to provide information on trajectory of improvement, if any, and rates for full, partial or no recovery. At baseline and follow-up visits, full specialist assessment is required such that subtle visual deficits are not missed.

2.8: Conclusion

The literature currently available for review does not include any studies whose primary aim was to determine the incidence or prevalence of visual impairment post-stroke. Thus, this review can only provide estimates of prevalence for individual stroke related visual problems. The estimation of the overall prevalence of visual impairment was approximately 64% at baseline assessment. A reduction to approximately 20% is seen by three months post-stroke, due to factors such as recovery, adaptation and death. The figures reported cover a wide range of prevalence for each visual problem. A variety of factors may be the cause of this wide range of figures including: the different study aims, research methods used, baseline assessments being conducted at different time points and different methods of assessment. The prevalence is reported as being highest for eye movement defects, visual field loss and visual inattention. The existing literature regarding the recovery of visual problems following stroke is scarce for both individual deficits and overall visual impairment. Further prospective studies are required to establish the incidence of post-stroke visual impairment, the prevalence at various time periods post-stroke and trajectory of improvement.

This work has been published in Ophthalmology Research (122)

Chapter 3

A systematic narrative review of the impact of visual impairment following stroke on quality of life

3.1: Background

Visual impairments following stroke have the potential to affect the ability of an individual to perform activities of daily living (ADLs), for example mobility, social interaction and self-care. An individual with visual impairment may also have a reduced level of independence. A combination of disabilities has the potential to adversely affect an individual's mood and motivation. These effects have been reported in populations with visual impairment (123-126).

The World Health Organisation (WHO) defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (127). The assessment of quality of life could be seen as a measurement of the subjective perceptions of an individual of how they are affected by their health state (123).

The analysis of utility values of diabetic retinopathy and age-related macular degeneration revealed the impact on quality of life was associated with the severity of impairment rather than the cause (128). However, it has also been shown that there is not a consistent trend between severity of symptoms and reduction in quality of life. The individuals with the most severe visual impairment may not report the poorest quality of life but those with a slight impairment may (129). This highlights the importance of patient reported outcome measures (PROMs) as part of clinical and research assessments.

The aim of this review was to summarise the impact of stroke related visual impairment on quality of life.

3.2: Methods

This systematic review was conducted following the guidance of the Cochrane Handbook for Systematic Reviews and the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) checklist (49, 50).

3.2.1: Inclusion criteria for considering studies for this review

3.2.1.1: *Types of studies*

The following types of studies were included: randomised controlled trials (RCTs), controlled trials, prospective and retrospective cohort studies and observational studies. Case reports were excluded. All languages were included and translations obtained when necessary.

3.2.1.2: *Types of participants*

Studies involving adult participants (aged 18 years or over) diagnosed with a visual impairment as a direct result of a stroke were included. Studies which included mixed populations were included if over 50% of the participants had a diagnosis of stroke and data were available for this subgroup.

3.2.1.3: *Types of outcome and data*

Studies using a formal quality of life assessment using a PROM were included. Studies which assessed an intervention and used a PROM before and after, were included if the results prior to treatment were available for comparison to other studies.

3.2.2: Search methods for identification of studies

A systematic search strategy was used to search the following key electronic databases: Cochrane Stroke Group Trials Register, The Cochrane Eyes and Vision Group Trials Register, The Cochrane Central Register of Controlled Trials (CENTRAL), MEDLINE (1948 to May 2015), SCOPUS (1823 to May 2015), AMED (1985 to May 2015), CINAHL (1937 to May 2015) and PsycINFO (1887 to May 2015). In an effort to identify further published, unpublished and ongoing trials, registers of ongoing trials were searched, hand-searched journals and conference transactions were completed, citation tracking using Web of Science Cited Reference Search for all included studies was performed, reference lists of included trials and review articles about vision after acquired brain injury were searched. Search terms included a comprehensive range of MeSH terms and alternatives in relation to stroke and associated visual conditions (Table 3.1).

3.2.3: Selection of studies

The titles and abstracts identified from the search were independently screened by two individuals (author and supervisor) using the pre-stated inclusion criteria. The full papers of any studies considered potentially relevant were then considered and the selection criteria applied independently by two individuals (author and supervisor).

3.2.4: Data extraction

A pre-designed data extraction form was used which gathered information on sample size, study design, quality of life instrument used, visual conditions reported and population type. Data was extracted and documented by the author and verified by the primary supervisor.

3.2.5: Quality assessment

To assess the quality of the studies included in this review, an adapted version of a checklist was used: the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) checklist (56, 57). This adapted checklist was devised originally for used in the previous review (Chapter 2), a more detailed description is outlined in Section 2.2.7.

Table 3.1: Search Terms (MeSH terms indicated by /)

Cerebrovascular Disorders/ Brain Ischaemia/ Intracranial Arterial Disease Intracranial Arteriovenous Malformations/ Intracranial Embolism and Thrombosis/ Stroke/	Eye Movements/ Eye/ Eye Disease/ Visually Impaired Persons/ Vision Disorders/ Blindness/ Diplopia/ Vision, Binocular/ Vision, Monocular/ Visual Acuity/ Visual Fields/ Vision, Low/ Ocular Motility Disorders/ Blindness, Cortical/ Hemianopsia/ Abducens Nerve Diseases/ Abducens Nerve/ Oculomotor Nerve/ Trochlear Nerve/ Visual Perception/ Nystagmus/ strabismus smooth pursuits saccades depth perception stereopsis gaze disorder internuclear ophthalmoplegia Parinaud's syndrome skew deviation conjugate deviation oscillopsia visual tracking agnosia hallucinations	Quality of Life/ Impact/
OR	OR	OR
AND		

3.3: Results and discussion

3.3.1: Results of the search

The search results are outlined in Figure 3.1. Eleven studies (5,646 participants) were included. Of the 11 included studies, ten were prospective observational studies and one was a retrospective analysis. Seven different instruments were used in the included studies to report quality of life in stroke survivors with visual impairment.

3.3.2: Quality of the evidence

Two of the eleven papers reported 100% of the items requested by the STROBE checklist (130). Eight of the eleven papers reported 90% or more of the requested items, ten of the eleven papers reported 75% or more. All eleven papers reported 73% or more. The majority of papers (81%) reported limitations of their studies. The quality assessment of all papers was reported and the individual results for each paper are outlined in Table 3.2.

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3.3.3: Quality of life assessment for stroke survivors with visual impairment

Eight studies investigating quality of life following stroke were focused on stroke survivors with visual field loss (51, 130-136). Homonymous hemianopia is the most common type of visual field loss following stroke (60). Other types of defect are possible including homonymous quadrantanopia, general constriction and scotomas (51). Of the remaining studies, Ali *et al.* and Rowe *et al.* addressed a combination of visual impairments following stroke while Beaudoin *et al.* focused on visual perception problems (60, 70, 100).

The included studies used both generic health-related instruments and/or vision specific instruments which were administered to stroke survivors.

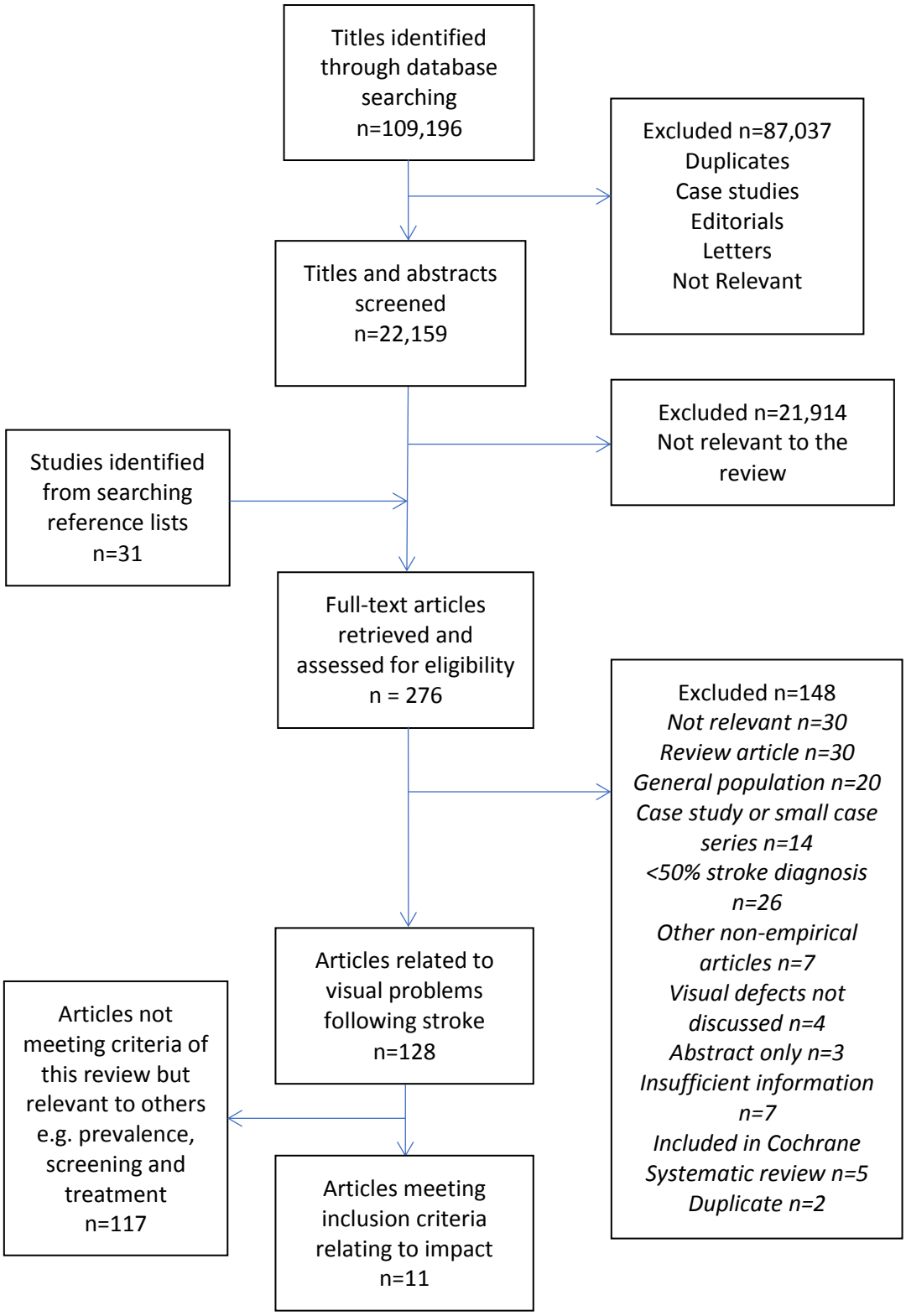


Figure 3.1: Flowchart of the pathway for inclusion of articles

Table 3.2: Quality appraisal of papers using the adapted STROBE checklist

+	=Reported	-	= Not reported	?	= Unclear

	Introduction	Methods								Results					Discussion			
	3	4	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21
Ali et al. 2013 (60)	+	+	+	+	+	-	+	-	-	?	?	+	+	+	+	+	+	+
Beaudoin et al., 2013 (70)	+	+	+	+	+	+	-	+	-	+	+	+	+	+	+	+	+	+
Chen et al., 2009 (133)	+	+	+	+	+	-	-	+	+	+	+	+	+	n/a	+	-	+	+
Gall et al., 2008 (135)	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+
Gall et al., 2009 (134)	+	+	+	+	+	+	+	+	+	+	+	+	+	+	+	-	+	+
Gall et al., 2010 (130)	+	+	+	+	+	+	+	+	+	+	+	+	+	n/a	+	+	+	+
George et al., 2011 (132)	+	+	+	+	+	-	-	+	+	+	+	+	+	+	+	+	+	+
Mennem et al., 2012 (131)	+	+	+	+	+	+	-	+	+	?	+	+	+	n/a	+	+	+	+
Papageorgiou et al., 2007 (136)	+	+	+	+	+	-	-	+	+	-	+	+	+	+	+	+	+	+
Rowe et al., 2013 (100)	+	+	+	+	+	-	+	+	+	+	+	+	+	n/a	+	-	+	+
Rowe et al., 2013 (51)	+	+	+	+	+	-	+	+	+	+	+	+	+	+	+	+	+	+

3.3.3.1*: Generic Health-related Instruments*

The European Quality of Life Score (EQ-5D), the Medical Outcome Study Short-Form-36 Health Survey (SF-36) and the Assessment of Life Habits (LIFE-H) have been used to assess quality of life in individuals with visual impairment post-stroke. More details about these instruments can be viewed in Table 3.3. They are generic health-related instruments and are not specific to visual impairment. Generic instruments include items which are relevant to a broad definition of health 'physical, mental and social well-being' (127). This allows comparisons to be made not only within a disease group but across difference disease groups; for example the EQ-5D is currently used in the NHS PROMs programme before and after four common surgeries (hip replacement, knee replacement, hernia repair and varicose vein surgery) (31). However, these instruments may not be sensitive to specific symptoms caused by visual impairment.

The EQ-5D was reported to show that participants (n=3,859) with visual impairment following stroke had a poorer quality of life at baseline assessment after adjustment for age, thrombolysis treatment, other stroke non-visual related impairment and other medical conditions (60). Visual impairment was assessed by using the National Institute of Health Stroke Scale (NIHSS), which only tests for homonymous visual field loss and horizontal gaze defects. Therefore, it potentially misses many other forms of visual impairment. Thus, it is not possible for this study to give an overview of the impact of visual impairment following stroke. It was reported that participants with conjugate deviations had reduced scores in all domains with the exception of anxiety/depression. Participants with hemianopia were reported to have reduced scores in self-care and usual activities. If the visual impairment was persistent to 90 days post-stroke onset, those participants had poorer outcomes in all domains for participants with hemianopia and three out of five for participants with gaze palsies with the exception of pain/discomfort and anxiety/depression (60).

The LIFE-H reported the participants' (n=93) quality of life to be persistently reduced in the presence of perceptual difficulties post-stroke compared to a group (n=96) without visuo-perceptual deficits (70). This difference was still present when controlling for the use of a walking aid and previous stroke events. The greatest difference was in socialisation rather than activities of daily living. This was shown at all three time points (n=57), 18-24 days following discharge (baseline), three months and six months following baseline (70). The domains relating to employment and education were not included as part of this study,

however, with the increasing number stroke survivors of working age, these areas are critical to examining how visual impairment impacts the different areas of life.

The SF-36 has been used by three studies in conjunction with the NEI VFQ-25 and compared against healthy controls (130, 134, 135). In each study stroke survivors with visual field defects were reported to have reduced scores in seven out of eight subscales (the exception being role limitation due to emotional problems). Participants with visual field defects were also reported to have better quality of life than general stroke survivors one month post-stroke without visual field defects (134). However, when compared to general stroke survivors six months post-stroke without visual field defects, the participants with visual field defects had a reduced health-related quality of life (130, 134). This delay in impact was reflected in a qualitative study which interviewed stroke survivors with visual impairment (8). When the composite scores of participants were compared with stroke survivors with different lesion ages (3, 6 and 12 months post-stroke onset), those with visual field defects scored better in the physical composite score and worse in the mental composite score (130). Individuals with visual field defects in combination with reduced visual acuity are reported to have a further reduction of scores across four subscales: physical functioning, vitality, social functioning and emotional well-being (130). The comparison groups used by these studies were from previously published data and therefore were not matched.

3.3.3.2*: Vision-specific instruments*

Four different vision specific instruments; the National Eye Institute Visual Function Questionnaire (NEI VFQ-25), the Veterans Low Vision Visual Function Questionnaire (VA LV VFQ-48), the Self-Reported Assessment of Functional Visual Performance (SRA-FVP) and the Daily Living Tasks Dependent on Vision (DLTV) have been used to assess quality of life in individuals with visual impairment post-stroke. More details about these instruments can be viewed in Table 3.3. Vision-specific instruments come under the wider disease-specific instruments umbrella and are tailored to assess quality of life in individuals with visual impairment. They can be more clinically sensitive to changes in visual impairment than generic instruments (137).

The most commonly used instrument was the NEI VFQ-25, and it is regarded to have good sensitivity to changes in visual impairment (138). The six studies which used the NEI VFQ-25 concentrated on visual field loss post-stroke (130, 132-136). Five studies compared the

scores from the NEI VFQ-25 of individuals with visual field loss post-stroke and a reference healthy population, and reported a reduced quality of life for those with visual field loss (130, 133-136). Gall *et al.* also compared the scores of individuals with visual field loss post-stroke to individuals diagnosed with glaucoma and reported the former group to have a poorer quality of life (135).

The studies reported reduction in several subscales in addition to the composite score. The number of affected subscales varied from seven up to all 12 subscales. Six subscales showed a significant difference between individuals with visual field loss post-stroke and healthy individuals: general health, general vision, near activities, vision-specific mental health, driving, and peripheral vision (130, 133-136). These six subscales were found to be commonly affected in all six studies. Chen *et al.* performed a multivariate analysis, adjusting for visual acuity, reading ability, contrast sensitivity and any pre-existing ocular conditions, which changed the subscales affected and were deemed significantly different between the hemianopia and control group (133). Considering that the study had a very small sample size (n=10), following the multivariate analysis both the NEI VFQ-25 and VA LVQ-48 had a decrease in the number of subscales which were significantly affected, to five and one respectively. The factors adjusted for would not all be considered confounding factors but instead could also be a result of stroke and homonymous hemianopia, for example reduced reading ability (100). The results following this multivariate analysis should be viewed as an assessment of quality of life with an isolated factor of hemianopia rather than visual impairment following stroke.

Five studies used a combination of instruments; two studies used the NEI VFQ-25 in conjunction with the VA LV VFQ-48 (132, 133). A further three studies used the NEI VFQ-25 in conjunction with the SF-36 (130, 134, 135).

Two studies investigated the effect of varying degrees of visual field loss post-stroke (130, 135). They reported that those with a greater area of spared central visual field had a better composite score and the following subscales: distance vision, social functioning and colour vision (130). Individuals with a quadrantanopia had similar scores to individuals diagnosed with glaucoma, and therefore were less affected than those with hemianopia (135).

Table 3.3: Patient Reported Outcome Measures (PROMs) used with stroke survivors

Questionnaire	Type of instrument	Overview	References
EQ-5D	Generic	5-item instrument, comprising of 5 dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression with an additional health analogue scale.	Ali *et al*., 2013 (60)
LIFE-H	Generic	77-item instrument comprising of 12 domains split equally between daily activities and social roles.	Beaudoin *et al*., 2013 (70)
SF-36	Generic	36-item general health instrument consisting of 8 domains. Widely used in health research.	Gall *et al*., 2010 (130)
NEI VFQ-25	Vision-specific	25-item short version instrument, composed of 11 vision-related subscales with an additional question for general health rating. Used to assess many different ocular conditions.	Chen *et al*., 2009 (133) Gall *et al*., 2008; 2009; 2010 (130, 134, 135) George *et al*., 2011 (132) Papageorgiou *et al*., 2007 (136)
SRA-FVP	Vision-specific	38-item instrument covering a range of activities of daily living.	Mennem *et al*., 2012 (131)
VA LV VFQ	Vision-specific	48-item instrument, composed of five domains: visual ability, reading, mobility, visual motor and visual information. Originally developed and validated with patients with ophthalmic pathology such as glaucoma, macular degeneration and diabetic retinopathy	Chen *et al.,* 2009 (133) George *et al*., 2011 (132)
DLTV	Vision-specific	24-item instrument which are not categorised under named domains, but covers topics such as reading, mobility, self-care and recognition. Originally developed for individuals with macular degeneration.	Rowe *et al*., 2013 (51, 100)

Several visual conditions can co-exist post-stroke, creating the potential to have a larger impact on quality of life (46). The presence of visual neglect has been shown to have a negative effect on the general health and mental health domains of the NEI VFQ-25 (134). However, in the majority of domains participants with combined neglect and visual field loss were reported to have better quality of life than those with visual field loss without neglect. An explanation for this may be that those with visual neglect are less aware of their defect than those with visual field loss alone (100).

Two studies compared and reported the quality of life impact in individuals with visual field loss post-stroke with good visual acuity versus reduced visual acuity (130, 134). Individuals with reduced visual acuity in addition to visual field loss had lower scores (reduced quality of life) in the majority of domains with the exception of ocular pain, the following domains showed a significant reduction; general vision, near vision, distance vision, social functioning, mental health, role difficulties, and dependency (130). Furthermore, Gall *et al.* reported a link between reduced scores for both reduced visual acuity and slower reading speeds (134).

George *et al.* reported correlations between the objective assessments of the Behaviour Inattention Test (BIT) and the Mayo-Portland Adaptability Inventory (MPAI) and the subjective NEI VFQ-25 in participants with homonymous hemianopia (132). The BIT demonstrated the participants did not have attention deficits and it correlated well with eight out of twelve domains of the NEI VFQ-25. The instrument had a good association with both the participation and ability/adjustment scales of the MPAI. The participants (n=24) involved in this study performed well on objective testing, however the details of the PROM were not discussed (132). The raw composite score of the NEI VFQ-25 in this study are comparable with those reported by Chen *et al.,* Papageorgiou *et al.* and Gall *et al.* all of which recruited participants with homonymous hemianopia (130, 133-136).

The Veterans Low Vision Visual Function Questionnaire (VA LV VFQ-48) has been used by two studies investigating quality of life post-stroke in stroke survivors with homonymous hemianopia (132, 133). Chen *et al.* reported that initially the scores showed individuals with hemianopia (n=10) had more difficulty with visual ability, mobility and visual motor functioning when compared to healthy controls (133). The differences for the reading and visual information subscales were found to be much smaller. When visual acuity, contrast sensitivity and the presence of pre-existing ocular conditions were controlled for, the only

remaining significant difference was mobility. George *et al.* reported the correlations between the objective assessments of the BIT and the MPAI and the subjective VA LV VFQ-48 for participants with homonymous hemianopia without any attention deficits (132). The BIT correlated well with four out of five domains of the VA LV VFQ-48. The instrument had a good association with both the participation and ability/adjustment scales of the MPAI (132). The raw scores for the VA LV VFQ-48 in this study are comparable with those reported by Chen *et al.* (133).

The Self-Reported Assessment of Functional Visual Performance (SRA-FVP) was used in a preliminary prospective observational study with the aim of validating the instrument with individuals with homonymous hemianopia (n=30) (131). They reported that functional mobility tasks were less difficult to perform than reading and eye-hand co-ordination tasks. Participants without macular sparing had significantly more problems with reading. This study reported good reliability and validity of the SRA-FVP (131). However, the study had several limitations including a small sample size, the majority of the sample were male (29:1) and individuals with inattention, aphasia and other ocular pathology were excluded.

The Daily Living Tasks Dependent on Vision (DLTV) was used in a large cohort study involving individuals with a wide variety of different visual impairments following stroke (100). Not all participants within the study completed the questionnaire as it was not a compulsory assessment. Two papers relating to visual symptoms and visual field loss report the findings from the DLTV (51, 100). No significant difference in scores was found between those with visual impairment that reported symptoms and those that did not. Across all the symptom types and an asymptomatic group, a wide range of scores were noted. Scores were reported to be reduced in individuals with visual impairment following stroke irrespective if any symptoms were reported (100). Quality of life was shown to be reduced in individuals with multiple visual impairments when compared to individuals without visual impairment. The reduced score with multiple visual impairments was not significantly different to those diagnosed only with visual field loss (51).

3.4: Conclusion

Issues exist when extracting the specific impact of visual impairment following stroke from the impact of other sequelae of stroke, such as physical and cognitive impairments (4). The wording of the NEI VFQ-25 aids this task. All questions ask the participant specifically about the impact of vision. However, the generic PROMs ask about the impact of their current health state on a particular aspect of health-related quality of life. Consequently, the individual's current health state could include other sequelae of stroke. This renders it impossible to establish how much of the impact on quality of life is as a result of visual impairment. Studies which adjust for multiple factors have shown that when adjusting for confounding factors that participants have a poorer quality of life. This is an important consideration for researchers when choosing PROMs for future studies in this area.

Regardless of the instrument used, all studies similarly report that visual impairment following stroke negatively impacts on quality of life. There are some differences in the areas of quality of life affected, relating in part to the range of instruments used and the subscales of these.

Eight of the eleven included studies focused on visual field loss following stroke. One of the eleven was found to assess the impact of a specific ocular motility defect (horizontal gaze palsy) occurring following stroke. There is currently no literature reporting the impact of a wider range of ocular motility defects following stroke. Due to this skew towards visual field loss and lack of studies investigating the impact ocular motility, it was not possible to compare the effects on quality of life due to different visual impairments caused by stroke.

This review highlights the need for further research into the impact on quality of life of visual impairment following stroke using appropriate vision-specific outcome measures.

This work has been published in Ophthalmology Research (139).

Chapter 4

A systematic narrative review of existing patient reported outcome measures

4.1: Introduction

Many patient reported outcome measures (PROMs) are currently available (140, 141). The selection of which instrument to use is dependent on the study design and the population involved. It is important to select a relevant, precise, reliable and valid instrument which is responsive to the changes which require detection. The instrument should also be acceptable to the target population and provide interpretable results (37).

Literature reviews of PROMs for ocular conditions causing visual impairment, such as glaucoma and cataract, have been conducted, some of which give recommendations for which instrument to use for different disease specific populations (140, 142, 143).

The aim of this review was to identify PROMs available for use in research and clinical practice involving individuals with visual impairment following stroke, and to evaluate their content validity against quality assessment criteria. This review will focus on high quality instruments which have previously been validated with stroke survivors. A secondary aim is to highlight suitable high quality alternative instruments which have not yet been validated for stroke survivors. This review will focus on disease-specific and individualised instruments, which are either tailored to the condition of interest or allows the individual to select items which are of most importance to them.

4.2: Methods

4.2.1: Search strategy

A systematic search strategy was used to search the following key electronic databases: MEDLINE (1948 to August 2014), SCOPUS (1823 to August 2014), AMED (1985 to August 2014), CINAHL (1937 to August 2014) and PsycINFO (1887 to August 2014). Citation tracking was performed using Web of Science Cited Reference Search for all included studies, and reference lists of included articles were searched. Search terms included a variety of MESH terms and alternatives in relation to patient reported outcome measures, visual impairments and quality of life (Table 4.1).

4.2.2: Inclusion and exclusion criteria

Articles related to the development and/or validation of PROMs for adult stroke survivors were included. Some of the visual problems experienced following a stroke are also

experienced by other population groups, for example visual field loss is also experienced in glaucoma and blurred reduced vision is experienced with cataracts. Therefore, articles related to the development and/or validation of PROMs for individuals with visual impairment which could be experienced following other ocular conditions were also included. Studies evaluating questionnaires in languages other than English were excluded, unless the questionnaire was originally developed in another language and later translated to English. PROMs which were not accessible, for example if they required payment to view, were excluded.

4.2.3: Selection of studies

The titles and abstracts identified from the search were screened using the pre-stated inclusion criteria. The full papers of any studies considered potentially relevant were then considered and the selection criteria applied.

4.2.4: Quality assessment

All included PROMs were quality assessed using a modified version of a published quality assessment tool (45, 142). The modified quality assessment tool is shown in Table 4.2. The original tool is made up of two parts, the first evaluates the development of the instrument and the second evaluates the performance of the instrument in terms of validity and reliability (45). For the purposes of this review, six items from part one were relevant, focusing on evaluating the development of the instrument. Two additional items were added to make the quality assessment specific to a stroke survivor population. The first assessed if stroke survivors were involved in the item identification process of development. The second assessed if the instrument had ever been validated for stroke survivors. Both these additional items were ranked higher if a greater proportion of stroke survivors were involved. For each of the quality assessment items the instruments were judged against specific criteria to have a positive rating (√√), a minimal acceptable rating (√) or a negative rating (X), and if information relating to the criteria was not reported 'NR' was recorded (45).

4.2.5: Data synthesis

Descriptive analysis tables (Appendix 1) were completed from the included articles with the following data: initial aim of the PROM, the intended population, how items were identified, whether stroke survivors were involved in the development process, the process for selecting items included in the instrument and the scale, and the validation processes including populations for which the instrument has been validated. The quality assessment data was synthesised using a graphical representation for each rating.

Table 4.1: Search terms

Eye/ Eye Disease/ Eye Abnormalities Vision, Ocular/ Vision Disorders/ Visually Impaired Persons/ Blindness/ Vision, Low/ Visual Acuity/ Eye Movements/ Diplopia/ Ocular Motility Disorders/ Strabismus/ Vision, Binocular/ Vision, Monocular/ Nystagmus, Pathologic/ Visual Fields/ Visual Perception/	Quality of Life/ Value of Life/ Activities of Daily Living/ Questionnaires/ daily life activity rating scale visual function questionnaire vision related quality of life visual function questionnaire studies	Psychometrics/ Rasch analysis/ Validation Studies/ validation item response theory reliability validity development
OR	OR	OR
AND		

Table 4.2: Modified quality assessment tool for evaluation of PROMs based on Pesudovs *et al.* (45), Hamzah *et al.* (142).

If not reported, scored as 'NR'; **√√** positive rating; **√** minimal acceptable rating; **X** negative rating.

Quality criteria	**Definition**	**Quality criteria**
Pre-study hypothesis	The pre-study specification of the aim of the instrument and the intended population	**√√** A clear description is provided of the aim of the instrument and the intended population **√** Only one of the above **X** Neither reported
Intended population	The extent to which the instrument has been studied in the intended population	**√√** Intended population studied **√** Partly studied only or sample size was small (less than 50 patients) **X** Not studied in the intended population, only generic
Actual content area	The extent to which the content meets the pre-study hypothesis specifications	**√√** Content is intended and is relevant to the intended population **√** Some of the intended content areas are missing **X** Content areas are not relevant to the intended population
Item identification	Selection of the items relevant to the target population for inclusion in the pilot instrument	**√√** Comprehensive consulting with patients (focus groups or in-depth interviews) and a literature review **√** Minimal consultation with patients and expert opinion and literature review **X** No consultation with patients
Item selection	Determining the items included in the final instrument	**√√** A pilot instrument was developed and tested with Rasch or factor analysis and statistical justification provided for removing items, plus items with floor and ceiling effects removed and the amount of missing data considered **√** Only one of the above techniques were used **X** No pilot instrument OR no statistical justification of items included in the final instrument
Scoring	A description of how the instrument should be scored	**√√** Rasch scoring of a statistically justified response scale **√** Summary scoring of a statistically justified response scale **X** Scoring system not described or scoring of a statistically unjustified or faulty scale

Quality criteria	Definition	Quality criteria
Views of stroke patients considered	The percentage of stroke patients involved in item identification during the development of PROMs	**√√** At least 50% of stroke patients were involved in the consultation with patients in the item identification **√** Less than 50% of stroke patients were involved in the consultation with patients in the item identification **X** No stroke patients were involved in the consultation with patients in item identification
Stroke population	The extent to which the instrument has been studied in a stroke population	**√√** Stroke population studied **√** Partly studied only or sample size was small (less than 50 patients) **X** Not studied in a stroke population

4.3: Results

The search revealed 142 PROMs of which 43 vision-specific instruments were identified as being relevant. However, nine of these instruments were excluded as they were not accessible. Lack of accessibility was due to requiring payment or no development or validation papers could be found for an instrument. A total of 34 vision-specific PROMs were analysed for this review. Specific details of all PROMs included are shown in Appendix 1.

4.3.1: Target condition

None of the instruments reviewed had been specifically targeted at visual impairment following stroke. Eighteen of the instruments were developed for populations with visual impairment with no specific condition targeted. As this group of instruments was aimed generally at visual impairment, it was difficult to establish if stroke survivors were included in the populations recruited by studies reporting the use of these instruments. Of the remaining instruments, eight were cataract-specific, three were strabismus/amblyopia-specific, two were glaucoma-specific, two were retinal disease-specific and one was refractive error-specific.

None of the PROMs included in the review sought the views of stroke survivors during the item identification process. The Neuro 10 supplement was created to adapt the National Eye Institute Visual Functional Questionnaire (NEI-VFQ) to be better targeted to a population experiencing visual impairment due to neuro-ophthalmic disorders (144). Of note, however, the item identification process of the Neuro 10 supplement only involved individuals with multiple sclerosis (145).

4.3.2: Administration

The methods of administration varied between interview, self-administration and a combination of both. Details of the administration methods used by each instrument are outlined in Appendix 1. A study into the most appropriate method of administration of vision-related quality of life instruments concluded postal administration to be the most reliable, valid and cost-effective (146). However, depending on the severity of visual impairment it may not be possible for an individual to complete a self-administration of an

instrument (147). It is important to consider the method which best suits the population group and/or the individual (148).

4.3.3: Instrument content

The instruments had a broad range in the number of items per instrument, the smallest being the Vision and Quality of Life Index (VisQoL) with six items, and the largest being the Activity Inventory (AI) with up to 337 items (149, 150). The mean number of items was 39 (SD 57.7) across the instruments reviewed and the median number of items was 25 (IQR 17 to 38).

4.3.4: Instrument development and quality

4.3.4.1*: Instruments validated with stroke survivors*

Content validity assesses if the instrument and individual items are relevant to the target population and are able to measure the area of interest (151). A summary of the descriptive analysis of the development and content validity for each instrument is provided in Appendix 1 and the quality assessment is available in Table 4.3. Five instruments were found to have been previously used with stroke survivors: NEI VFQ-25 (Neuro 10), AI, DLTV, (Daily Living Tasks Dependant on Vision), VA LV VFQ (Veteran Affairs Low Visual Function Questionnaire) and SRA-FVP (Self-Reported Assessment of Functional Visual Performance). The remainder of this review will concentrate mainly on the analysis of these instruments (131, 144, 150, 152-154).

The instrument found to have the highest number of positive ratings in the quality assessment was the NEI VFQ-25 (Neuro 10). The NEI VFQ-25 is composed of 11 vision-related subscales: vision rating, near vision activities, distance vision activities, social functioning, role limitation, dependency, mental health, driving, peripheral vision, colour vision and ocular pain with an additional question for general health rating (152). There is also the option to add items to specific subscales (13 items). The instrument provides an overall composite score (155). It is unclear if any stroke survivors were involved in the item identification of the NEI-VFQ 25 or Neuro 10 supplement as the population had a variety of causes of visual impairment including neurological aetiologies. This instrument has been subsequently used to assess quality of life in individuals with visual impairment following stroke, especially in individuals with homonymous hemianopia (130, 133)

Two instruments were ranked as joint second with regard to quality assessment. These were the AI and the VA LV VFQ. During the development stages of these instruments, stroke survivors were not involved in item identification.

The validation process for the AI involved a population with visual impairment due to a variety of aetiologies. This population included a small proportion (3%) with stroke or traumatic brain injury (156). The AI uses a theoretical framework called Activity Breakdown Structure to allow the questionnaire to be adapted for each individual. At the highest level of this structure are three 'objectives': daily living, social interaction and recreation (150). Under these headings are 41 'goals', for example cooking a meal, which would be required to achieve the 'objective' of daily living. The 'goals' are then divided into the specific 'tasks' of which there are 337, for example reading a recipe, measuring ingredients and reading oven dials, which must be achieved to successfully complete the 'goal'. The importance of each 'goal' is initially rated by the individual, and if it is not considered important, the next 'goal' is considered. If it is deemed important the individual is asked to rate the difficulty of the 'tasks' that make up that 'goal' (150). The design of this instrument allows the number of items to vary depending on the number of goals important to the individual.

The VA LV VFQ was originally validated with individuals with ophthalmic pathology such as glaucoma, macular degeneration and diabetic retinopathy (153, 157, 158). It was later used with a small group (n=24) of stroke survivors with homonymous hemianopia (132). The VA LV VFQ is composed of five domains: visual ability, reading, mobility, visual motor and visual information. The instrument consists of a total of 48 items, with each item made up of four questions: for example: "Is it difficult to read menus?". If the answer to the first question is yes, the following questions are subsequently asked "Is it because of your vision?", "Do you want training to read menus?" and finally "How do you usually read menus?" (158).

The instrument ranked next with regard to quality assessment was the DLTV. The DLTV was originally developed for use with individuals with macular degeneration. It was later used with a group of stroke survivors with visual impairment. The total study population was large (n=915), however only 63 participants were reported to have completed the questionnaire (51). It comprises 24 items which are not categorised under named domains, but covers topics such as reading, mobility, self-care and recognition (154). Fifteen of the items use the following question format; "How much difficulty do you have pouring yourself a drink?". Two mobility questions use format; "How confident are you in your ability to walk around in your immediate neighbourhood?". Five questions on reading use the following question format;

“With your near glasses on, how much difficulty do you have reading normal sized newspaper print?”. The final two questions use the following format; “How would you rate your overall distance vision?” (154).

The other instrument which has previously been used with stroke survivors is the SRA-FVP, however this was limited to individuals with homonymous hemianopia (131). This instrument consists of 38 items covering a range of activities of daily living: reading, clothing care, meal preparation, leisure participation, financial management, shopping, writing, communication, health management, social participation, functional mobility, personal hygiene, feeding and dressing. The individual completing the instrument is asked to rate their ability to perform each task. This instrument scored a lower rating on quality assessment than the NEI VFQ-25 (Neuro 10), AI, VA LV VFQ and DLTV, as it only utilised expert opinion rather than consulting patients on the item selection process.

Table 4.3: Quality appraisal of the included instruments

If not reported, scored as 'NR'; **√√** positive rating; **√** minimal acceptable rating; **X** negative rating

Used with stroke survivors

Instrument	Pre-study hypothesis	Intended population	Actual content area	Item identification	Item selection	Scoring	Views of stroke patients considered	Stroke population
Activities of daily vision scale (ADVS)	√√	√√	√√	√	√	√√	X	X
Activity Inventory (AI)	√√	√√	√√	√√	√√	√√	X	√
Adaptation to age-related vision loss scale (AVL)	√√	√√	√√	X	√√	√	NR	NR
Adult Strabismus Quality of Life questionnaire (AS-20)	√√	√√	√√	√	√	√√	NR	NR
Amblyopia and strabismus questionnaire (ASQE)	√√	√√	√√	√	√√	√√	X	NR
Catquest	√√	√√	√√	√√	√	√√	X	X
Daily living tasks dependent on vision (DLTV)	√√	√√	√√	√	√√	√√	X	√√
Diplopia questionnaire	√√	√√	√√	X	X	√	NR	NR
Glaucoma quality of life -15 questionnaire (GQL-15)	√	√√	√	X	√	√	X	X
Houston vision assessment test (HVAT)	√√	√√	√√	√√	√	X	X	X
Impact of vision impairment (IVI)	√√	√√	√√	√√	√√	√√	X	X
Indian visual function questionnaire (IND-VFQ)	√	√	√	√√	√√	√√	X	X

Instrument	Pre-study hypothesis	Intended population	Actual content area	Item identification	Item selection	Scoring	Views of stroke patients considered	Stroke population
Low vision quality of life questionnaire (LVQoL)	√	√√	√	√	√	√	X	NR
Melbourne low vision ADL index (MLVAI)	√√	√	√√	X	√√	√	NR	NR
Mobility questionnaire	√√	√√	√√	X	√	√	X	X
National Eye Institute Refractive Error Correction quality of life Questionnaire (NEI RQL)	√√	√√	√√	√√	√√	√√	X	NR
National Eye Institute Visual Functioning Questionnaire (NEI VFQ-25) **and** Long form visual functioning scale (LFVFS-39)	√√	√√	√√	√√	√√	√√	NR	√√
Nursing home vision targeted health related quality of life questionnaire (NHVQoL)	√√	√√	√√	X	√	√	NR	NR
Quality of life and visual function questionnaire (QoL-VFQ)	√√	√√	√	√	√	√√	X	X
Quality of vision (QoV)	√√	√√	√√	√√	√√	√√	X	X
Self-report assessment of functional visual performance (SRA-FVP)	√√	√√	√√	X	√	√√	X	√√
Severity of visual field damage	√√	√√	√	√	√	√	X	X

Instrument	Pre-study hypothesis	Intended population	Actual content area	Item identification	Item selection	Scoring	Views of stroke patients considered	Stroke population
Veterans affairs low vision visual functioning questionnaire (VA LV VFQ)	√√	√√	√√	√√	√√	√√	X	√
Vision and quality of life index (VisQoL)	√√	√√	√√	√√	√	√	X	NR
Vision function and quality of life questionnaires (VF and QOL)	√√	√√	√√	X	√	√	X	X
Vision related quality of life (VQoL) **or** Vision-related quality of life core measure (VCM1)	√√	√√	√√	√√	√√	√√	X	X
Visual activity questionnaire (VAQ)	√	√	√√	X	√√	√√	X	NR
Visual disability assessment (VDA)	√√	√√	√	X	√	√	X	X
Visual disability questionnaire (VDQ)	√√	√	NR	√√	√	√√	X	NR
Visual function index (VFI)	√√	√√	√	X	√	√	X	X
Visual functioning 14 items (VF-14)	√√	√√	√	√	√	√√	X	NR
Visual symptom and quality of life questionnaire (VSQ)	√√	√√	√√	√√	√√	√√	X	X

4.3.4.2*: Instruments not yet validated with stroke survivors*

Of the other instruments not previously tested with stroke survivor populations, a number achieved high positive ratings in quality appraisal and may be appropriate for use with a specific visual condition or symptom arising due to stroke. For instance, the Diplopia questionnaire or the Adult Strabismus Quality of Life questionnaire (AS-20) could potentially be used with stroke survivors experiencing ocular motility problems (159, 160). None of the high positive rating instruments in the quality assessment were found to be specific for visual field loss. The instruments for specific visual conditions or symptoms (Diplopia questionnaire and AS-20) are unlikely to be suitable for use with stroke populations experiencing varied and mixed visual impairment post-stroke.

The AS-20 is comprised of 20 items originally divided equally into two domains: psychological and function. The domains were later divided further into self-perception, interactions, reading function and general function (159, 161). The questions involve statements for which the individual is asked to record the frequency of occurrence.

The Diplopia Questionnaire consists of eight items. The first question is a filter question asking if diplopia has been noticed in the past week. If yes, the following items record the frequency of diplopia in seven positions of gaze, simply asking if “During the last week, did you have double vision when reading (in a normal reading position)?” (160). This is an instrument with the aim of assessing the presence of symptoms rather than their impact on quality of life.

An alternative to using these instruments for specific visual conditions is to use a vision-specific instrument which has no target condition. Three such instruments achieved the highest positive rating in quality assessment after the stroke population criteria were discounted: the Impact of Vision Impairment (IVI), the Vision Related Quality of Life (VQoL) and the Visual Symptom and Quality of Life Questionnaire (VSQ) (162-164).

The IVI consists of 28 items within six domains: emotional reaction to vision loss, household care, personal care, leisure and work, mobility and social and consumer interactions. The question focuses on the last month and the frequency of impairment, for example “In the past month, how much has your eyesight interfered with visiting friends or family?” (165).

The VQoL is a parent questionnaire which can contain up to 139 items. This instrument has a modular approach to enable it to meet the requirements of different population groups. The questions focus on the past month , for example “In the past month, how much has your

eyesight interfered with seeing food on the plate?" or "In the past month, how often have you felt anxiety because of your eyesight?" (164). A core set of ten items were identified which became the Vision-related quality of life Core Measure (VCM1). All items within the VCM1 relate to emotional feelings and concerns, such as embarrassment, frustration and worry (166). There is no method reported on how to decide if additional items are required, but it has the flexibility for the clinician or researcher to decide, dependant on the individual or population completing the questionnaire.

The VSQ has the option of either a long or a short version. The long version consists of 26 items and the short form is made up of 14 items across two domains, symptoms/dysfunction and vision-specific quality of life. There is no standardised question wording, but examples include "When you are watching television, do you find it difficult to see the picture clearly?" and "How often does your eyesight prevent you from doing the things you would like to do?" (162).

The IVI, VQoL and VSQ have been validated for use with many different types of visual impairment, and therefore may be suitable for use with a whole stroke population (162, 164-174).

4.4: Discussion

This review quality appraised existing vision-specific PROMs to identify those which could be used for individuals with visual impairment following stroke. All instruments included in the review could potentially be relevant for use when assessing the impact of visual impairment following stroke, due to the wide variety of visual problems which may occur as a result of the stroke. No instruments were clearly identified as involving stroke survivors in item identification. As a consequence, none of the currently available instruments have been influenced during their development by stroke survivors. This limitation potentially results in instruments having irrelevant items or not containing pertinent items for visual impairment following stroke. Five instruments (AI, NEI VFQ-25 (Neuro 10), VA LV VFQ, DLTV and SRA-FVP) have been administered with a stroke population embedded within larger mixed population studies or a relatively small sample (51, 131, 132, 150, 152).

The SRA-FVP is not discussed in detail in this review. It did not achieve a high number of positive ratings in quality assessment. Instruments achieving high positive ratings included the NEI VFQ-25 (Neuro 10), DLTV, VA LV VFQ and AI.

The NEI VFQ-25 (Neuro 10) was found to have the highest number of positive ratings in quality appraisal and has previously been validated for stroke survivors with homonymous hemianopia by five studies (608 participants) (130, 133). However, a stroke population has a much wider variety of potential visual impairments, for example ocular motility defects and visual perception defects which this instrument has not, to our knowledge, been validated for. Therefore, although this instrument has been used with stroke survivors, this use was restricted to a sub-population and if the instrument is to be used with stroke survivors with all forms of visual impairment, it requires further validation.

The next best alternatives were the AI or the VA LV VFQ which also scored highly with positive ratings. However, these instruments have only been used with a small number of stroke survivors, n=18 and n=24 respectively (132, 156). The details of the type of visual impairment following stroke was not reported by Massof *et al*. when using the AI, however, the VA LV VFQ was used in a stroke population with homonymous hemianopia (132, 156).

The question phrasing in the AI does not include a reference to vision or eyesight, but simply "How difficult is it for you to take care of your health needs without anyone else's assistance?" (156). Stroke survivors commonly have other new physical and cognitive deficits in addition to visual impairment. It would not be clear from the AI which deficit (visual/physical/cognitive) was causing, either fully or partially, the difficulty experienced.

The VA LV VFQ has the potential to include up to 192 questions depending on the number of goals the individual judges to be important, this is a high task burden considering the individual completing the instrument has visual impairment (158). This instrument also has only been used with stroke survivors with homonymous hemianopia (n=24) and, as with the NEI VFQ-25, would need further validation for use with stroke survivors with other forms of visual impairment (132).

The DLTV was ranked as the next best in terms of quality assessment. It could be regarded as being more suitable for completion by patients with regard to the fewer number of items. This instrument has previously been used with a population of stroke survivors who had a wide range of visual impairments (100). The question phasing of this instrument does not include a reference to vision or eyesight, but simply "How much difficulty do you have cutting up food on your plate?" (175). As with the AI, it would be difficult to establish if the impairment is due to visual impairment or physical/cognitive impairment.

Some alternative instruments were identified during the review. These were vision-specific instruments with no target condition (IVI, VQoL and VSQ) with the potential for use with stroke populations and other instruments for specific visual impairments following stroke (AS-20 and Diplopia questionnaire). It is important to acknowledge that none of these instruments have previously been validated for use within a stroke population. The vision-specific instruments without a target condition were of higher ranking in the quality assessment than the specific visual impairment instruments. None met the stroke specific quality assessment criteria of this review. If these were to be used for assessing vision-related quality of life in a stroke population, further validation would be recommended.

4.5: Conclusion

In this review, no instruments were developed specifically for visual impairment following stroke or involved stroke survivors in the item identification phase of instrument development. Five instruments have subsequently been used with stroke survivors. Four of these instruments (AI, NEI VFQ-25, DLTV and VA LV VFQ) scored highly on positive ratings in the quality appraisal. Three are vision-specific questionnaires without a target condition and intended for a broad population of individuals with visual impairment. The exception is the DLTV which was originally developed for individuals with macular degeneration. Other instruments (IVI, VQoL and VSQ) were identified in this review as having a potential application with stroke survivors with visual impairment. A combination of instruments may be required to cover areas relevant to specific forms of visual impairment which are important for the population of stroke survivors with visual impairment. Further research is required to (a) consult a stroke population with different forms of visual impairment regarding the items that they judge to be important, and (b) to develop or validate appropriate instruments for use with this population.

This work has been published in Health and Quality of Life Outcomes (176).

Chapter 5

Item generation and instrument development

5.1: Introduction

It is clear from the systematic narrative review of existing instruments (Chapter 4), that there is a need for the development of a new patient reported outcome measure (PROM) with a specific focus on the impact of the wide variety of visual impairments following stroke (176).

The literature reports a variety of methods in which to initiate the development of a new PROM (45, 177, 178). A tool to assess quality of PROMs awards the highest quality grade to instruments which have completed a "comprehensive consultation with patients and a literature review" (140). It was therefore important that development of the new PROM was carried out in collaboration with stroke survivors with visual impairment. The aim of this part of the process was to identify what are considered the most important issues for stroke survivors to aid the development of a new instrument.

5.2: Database construction

A database of items was created from the instruments found to be relevant to this population in a systematic narrative review of PROMs (Chapter 4) (176). The initial item pool included 1,277 items. Any instrument formed from this database would be vision-specific, as the sources of all items were vision-related quality of life measures.

These items were coded into themes using a method similar to qualitative coding. The themes evolving from the coding process resulted in 23 categories: walking, near vision, distance vision, reading, driving, travelling, television, peripheral vision, self-care, lighting, general health, general vision, well-being, colour, ocular pain, social function, role limitations, dependency, binocular vision, service provision of treatment, accuracy of answers, symptoms and satisfaction.

A review of the face validity of the categories to determine whether they should be included in a new instrument for stroke survivors with visual impairment was completed. The service provision of treatment category included items asking, for example, "How well has your eye condition been explained to you?" (179). The aim of the instrument was to measure quality of life, not evaluate services. The items within the service provision of treatment would be more suited to a patient reported experience measure (PREM). The accuracy of answers category was formed from one item, which asked "How certain do you feel about all the answers you gave?" (180). The satisfaction category included items which would again be more suited to a PREM, asking about individuals' satisfaction levels regarding aspects of care.

For the purpose of the new instrument these categories were not considered relevant and a consensus team decision was taken to discard these three categories from the process. This reduced the total item pool by seven to 1,270 items.

The process of coding the items and formation of categories resulted in some items being linked to more than one category, for example “Because of your eyesight how much difficulty do you have going down steps, stairs or curbs in dim light or at night?”- this item was listed under both the walking and lighting categories. In total 460 items were linked to two or more categories. The numbers of items sharing multiple categories are shown in **Error! Not a valid bookmark self-reference.**.

Lists of items were created by summarising the focus of the items within each category with the removal of duplications. This resulted in the following number of items in each category: walking (n=9), near vision (n=7), distance vision (n=5), reading (n=5), driving (n=8), travelling (n=4), television (n=5), peripheral vision (n=4), self-care (n=8), lighting (n=5), general vision (n=6), well-being (n=11), colour (n=3), ocular pain (n=3), social function (n=9), role limitations (n=8), dependency (n=4), binocular vision (n=5) and symptoms (n=11). General health did not have any sub-items therefore this was placed on the category list as a single item category. The details of the categories and their associated summarised items are outlined in Figure 5.1 and Figure 5.2.

These lists of items were cross-checked for any missing topics against comments regarding impact made by stroke survivors with visual impairment, in individual interviews conducted prior to the start of this project (8). No additional items needed to be added.

Table 5.1: Number of items in each category and number of items shared with other categories

	Binocular vision	Colour	Dependency	Distance vision	Driving	General health	General vision	Lighting	Near vision	Ocular pain	Peripheral vision	Reading	Role limitation	Self-care	Social function	Symptoms	Travelling	TV	Walking	Well-being
Binocular vision	38				1								1			16				3
Colour		21		8										6						
Dependency			37	2					3								2			5
Distance vision		8	2	105	4			5					28	19	29		2	11	14	
Driving	1			4	49			8			3									
General health						5														
General vision							53						1			25				
Lighting				5	8			63	3			3								5
Near vision			3					3	172			109	24	51	11			5	1	
Ocular pain										14						14				
Peripheral vision					3						20					1			9	
Reading								3	109			109						5		
Role limitations	1			28			1		24				83	8	5					1
Self-care		6		19					51				8	121						2
Social function				29					11				5		82			2		3
Symptoms	16						25			14	1					52				
Travelling			2	2													16			1
TV				11					5			5			2			36		
Walking	1			14				5	1		9						1		122	
Well-being	3		5										1	2	3					72

5.3: Ranking exercise

5.3.1: Method

The next stage of development was to rank the items in each category to identify key items versus items not considered important to a new PROM. The ranking exercises consisted of the 20 categories identified from the database construction and their respective individual items (Figure 5.1 and Figure 5.2).

The ranking exercise was undertaken by both stroke survivors and stroke clinicians. Participants were requested to rank the categories and items in their perceived order from most important to least important. In addition to ranking the items produced by the database construction, clinicians were also given the opportunity to add items which they felt were missing.

Convenience sampling was used to recruit clinicians at the 2014 annual orthoptic stroke and neuro-rehabilitation specialist interest group meeting. This meeting was attended primarily by orthoptists who have an interest and specialise in the care of stroke survivors with visual impairment. This provided a target clinical audience for the ranking exercise. For this sample the survey was paper-based. The list of 20 categories was presented first, followed by individual pages for the items within each category. The items did not have any question wording but rather a summarisation of the item's focus e.g. 'walking indoors', 'using public transport' and 'adjusting to darkness'.

Stroke survivors were recruited using an advertisement through the Stroke Association Talk Stroke forum. Interested individuals were asked to contact the research team. The survey was presented in the same way to that completed by clinicians, other than it took the form of an online questionnaire which was divided into two parts. Participants were asked to complete both parts. The first part included the category ranking, followed by nine item rankings. The nine item rankings were those which clinicians had ranked the highest. The second part included the remaining ten item rankings.

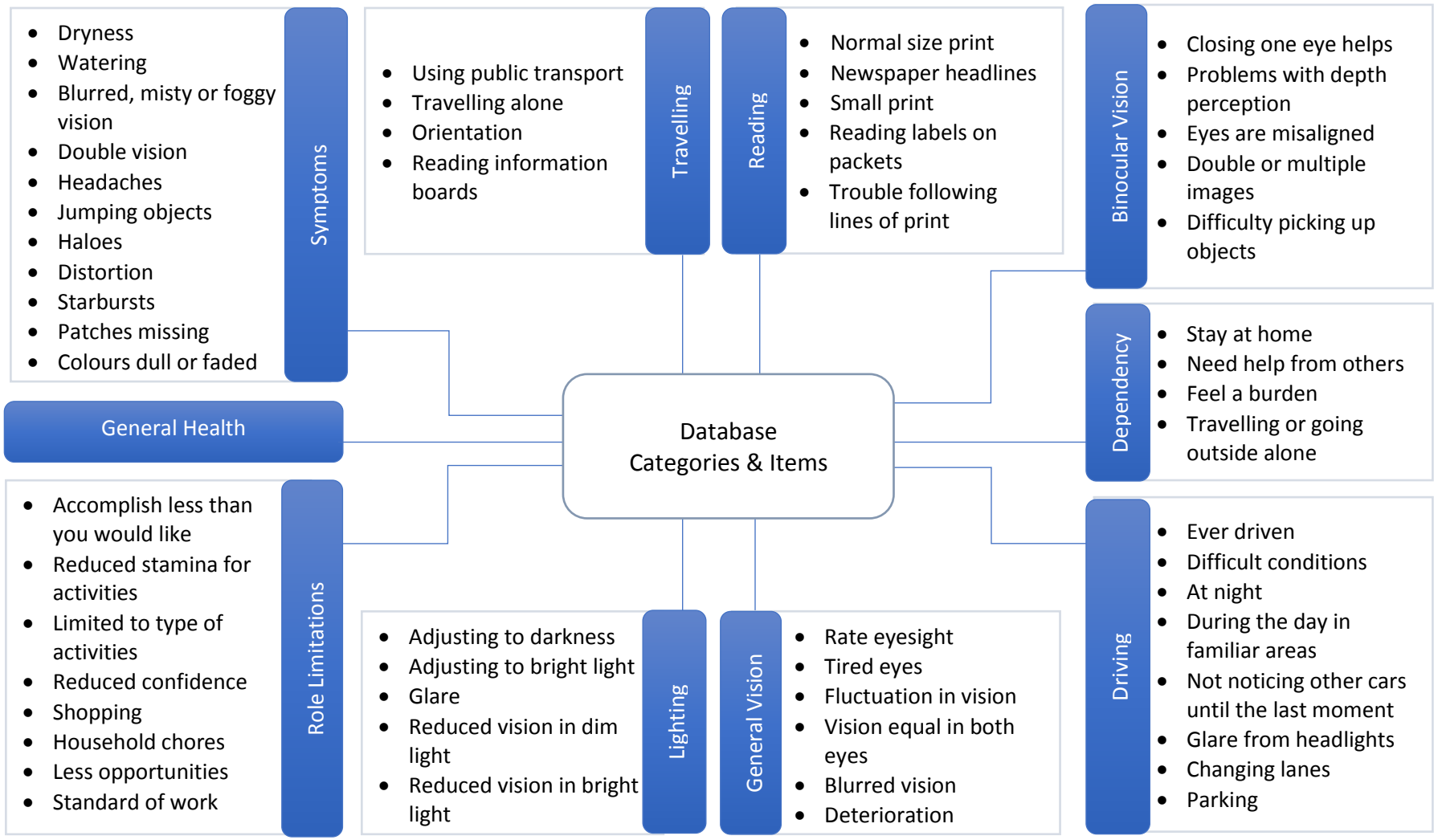


Figure 5.1: Diagram of half of the categories and associated summarised items with the database

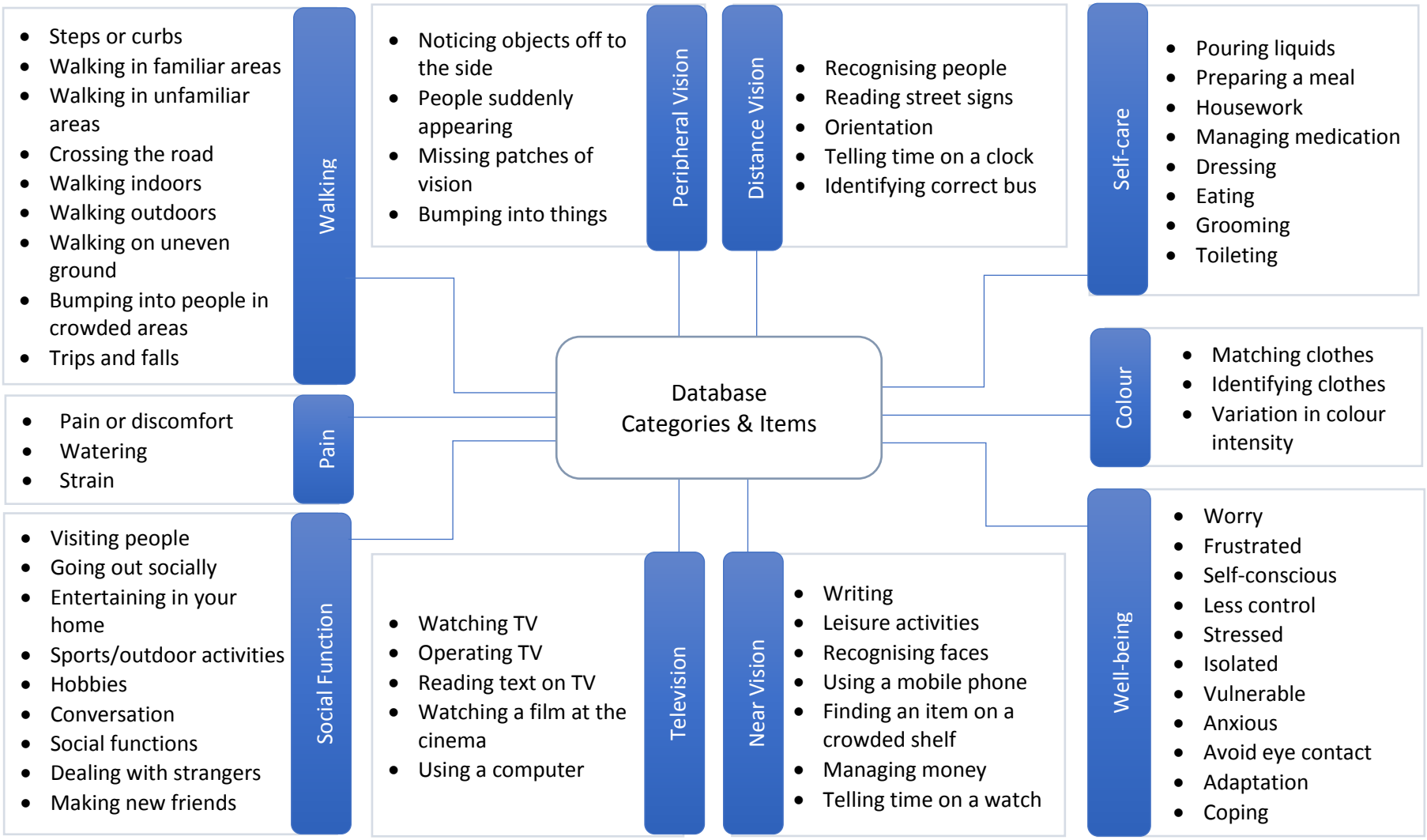


Figure 5.2: Diagram of half of the categories and associated summarised items with the database

5.3.2: Results

Fifty-nine orthoptists and one ophthalmologist completed the ranking exercise. Of those who completed the ranking, 88.3% were female. Thirty-nine participants offered more detailed demographic information; years of experience within orthoptics and within stroke care. The mean number of years' orthoptic experience was 16.63 (SD 9.19) and a mean number of years' experience specialising in stroke care of 7.80 (SD 6.61). These figures, although only for 65.0% of participants, support the choice of target group as experienced in stroke related visual impairment care.

Sixty-one stroke survivors participated in the ranking exercise. Due to the division of the survey only 21 participants completed the whole ranking exercise. Fifty-nine responded to part one, of which 18 were incomplete, and 25 responded to part two, of which four were incomplete. All complete and incomplete responses were used.

The ranking results of the categories from both stroke survivors and clinicians are outlined in Table 5.2. The categories which were deemed to be the most important by stroke survivors and clinicians and had the highest mean rank were walking (4.49, SD 4.17) and dependency (5.57, SD 4.00) respectively. The clinicians were in close agreement with stroke survivors with regard to walking, which was ranked second (6.16, SD 4.16). However, stroke survivors ranked dependency as 19th (13.73, SD 5.95). The categories deemed to be least important by stroke survivors and clinicians and had the lowest mean rank were symptoms (17.78, SD 4.60) and colour (17.85, SD 2.74) respectively. Clinicians ranked symptoms to be more important with a rank of 10th (10.22, SD 5.25). Stroke survivors agreed that colour was of lower importance with a rank of 15th (14.10, SD 2.73). With the exception of three categories (peripheral vision, dependency and symptoms), stroke survivors and clinicians agreed on whether categories were positioned in the top or bottom ten rankings. All categories had a wide range of rank; 15% of categories spanned from the absolute minimum of one to the absolute maximum of 20 for stroke survivors and 25% for clinicians.

Table 5.2: Mean rank, standard deviation, minimum and maximum position for each category

Category	Stroke survivors (n=59)					Clinicians (n=61)				
	Mean rank	SD	Min	Max	Rank	Mean rank	SD	Min	Max	Rank
Walking	4.49	4.17	1	19	1	6.16	4.16	1	18	2
Near Vision	5.56	4.05	1	15	2	8.33	4.08	1	16	9
Reading	6.03	2.85	1	14	3	7.26	3.64	2	17	5
Distance Vision	6.83	4.01	1	17	4	8.15	4.04	1	17	8
Self-Care	7.07	3.75	1	15	5	6.38	4.74	1	18	3
Peripheral Vision	7.56	4.52	1	17	6	10.30	4.67	1	19	13
Driving	7.76	5.60	1	20	7	7.34	4.90	1	19	6
General Health	7.92	4.79	1	19	8	7.12	5.96	1	18	4
General vision	8.93	4.85	1	20	9	8.07	5.06	1	20	7
Well being	9.20	4.83	1	18	10	10.26	5.76	1	20	11
Travelling	9.22	3.85	4	19	11	14.52	4.20	4	20	17
Television	10.05	3.81	2	20	12	12.56	4.28	3	19	15
Lighting	11.58	3.12	3	18	13	15.91	4.24	1	20	19
Dependency	13.73	5.95	1	19	14	5.57	4.00	1	16	1
Colour	14.10	2.73	6	20	15	17.85	2.74	9	20	20
Social Function	14.47	3.81	3	19	16	10.28	5.15	1	19	12
Ocular Pain	15.39	2.81	6	20	17	14.44	3.73	7	20	16
Binocular Vision	16.05	5.09	3	20	18	15.60	3.65	5	20	18
Role Limitations	16.34	3.13	2	20	19	11.30	4.98	1	20	14
Symptoms	17.78	4.60	1	20	20	10.22	5.25	1	20	10

5.3.2.1*: Walking*

The ranking results for the items in the walking category from both stroke survivors and clinicians are outlined in Table 5.3. The item which was deemed to be the most important by stroke survivors and clinicians and had the highest mean rank was 'steps and curbs': (3.35, SD 1.78) and (3.73, SD 1.91) respectively. The item deemed to be least important by stroke survivors and clinicians and had the lowest mean rank was 'walking on uneven ground': (5.47, SD 2.41) and (6.33, SD 2.12) respectively. In this case stroke survivors and clinicians agreed on the most and least important items in this category but all items had a wide range of rank. One hundred percent of items spanned from the absolute minimum of one to the absolute maximum of nine for both stroke survivors and clinicians.

5.3.2.2*: Near vision*

The ranking results for the items in the near vision category from both stroke survivors and clinicians are outlined in Table 5.4. The items which were deemed to be the most important by stroke survivors and clinicians and had the highest mean rank were 'writing': (2.54, SD 1.62) and 'recognising faces' (2.15, SD 1.78) respectively. Both groups were in close agreement for both these items, the item ranked as first by one group was ranked second by the other in both cases. Five clinicians added reading as an item to this category and ranked it as highly important. Reading would normally be classed as a near vision activity. However, in this exercise it was a separate category. The items deemed to be least important by stroke survivors and clinicians and had the lowest mean rank were 'telling time on a watch' (5.41, SD 1.90) and 'using a mobile phone' (5.34, SD 1.55) respectively. The clinicians were in close agreement with stroke survivors with regard to 'telling time on a watch', which was ranked sixth (mean rank 4.93, SD 1.73). Conversely, stroke survivors ranked 'using a mobile phone' as more important at fourth (mean rank 4.04, SD 1.43). All items had a wide range of rank; 100% of item spanned from the absolute minimum of one to the absolute maximum of seven for stroke survivors and 86% for clinicians.

5.3.2.3*: Distance vision*

The ranking results for the items in the distance vision category from both stroke survivors and clinicians are outlined in Table 5.5. The items which were deemed to be the most important by stroke survivors and clinicians and had the highest mean rank were 'recognising people' (2.15, SD 1.15) and 'orientation' (2.02, SD 1.09) respectively. The items deemed to

be least important by stroke survivors and clinicians and had the lowest mean rank were 'identifying the correct bus' (4.13, SD 1.28) and 'telling time on a clock' (4.51, SD 0.70) respectively. Both groups were in close agreement for both these items: the item ranked as fifth by one group was ranked fourth by the other in both cases. All items had a wide range of rank; 80% of items spanned from the absolute minimum of one to the absolute maximum of five for stroke survivors and clinicians.

5.3.2.4*: Reading*

The ranking results for the items in the reading category from both stroke survivors and clinicians are outlined in Table 5.6. The items which were deemed to be the most important by stroke survivors and clinicians and had the highest mean rank were 'normal size print' (2.19, SD 1.10) and 'trouble following lines of print' (2.94, SD 1.73) respectively. The item deemed to be least important by stroke survivors and clinicians and had the lowest mean rank was 'newspaper headlines': (3.68, SD 1.13) and (3.74, SD 1.37) respectively. All items had a wide range of rank; 80% of items spanned from the absolute minimum of one to the absolute maximum of five for stroke survivors and 100% for clinicians.

5.3.2.5*: Driving*

The ranking results for the items in the driving category from both stroke survivors and clinicians are outlined in Table 5.7. The item which was deemed to be the most important by stroke survivors and clinicians and had the highest mean rank was 'ever driven': (2.68, SD 2.77) and (1.31, SD 1.32) respectively. The item deemed to be least important by stroke survivors and clinicians and had the lowest mean rank was 'parking': (7.28, SD 1.43) and (5.95, SD 1.55) respectively. Two items were added by two separate clinicians, being a passenger and using a rear-view mirror, to this category. These were not ranked to be of high importance, but they would be taken into account during future stages. The suggestion of being a passenger item may be more appropriate within the travelling category. All items had a wide range of rank; 75% of items spanned from the absolute minimum of one to the absolute maximum of eight for stroke survivors and 63% for clinicians.

Table 5.3: Mean rank, standard deviation, minimum and maximum position for walking items

	Item	Stroke survivors (n=51)					Clinicians (n=61)				
		Mean rank	SD	Min	Max	Rank	Mean rank	SD	Min	Max	Rank
Walking	Steps or curbs	3.35	1.78	1	9	1	3.73	1.91	1	9	1
	Walking in unfamiliar areas	4.04	2.08	1	9	2	4.61	2.34	1	9	4
	Crossing the road	4.43	2.23	1	9	3	4.41	2.19	1	9	3
	Walking in familiar areas	5.08	2.50	1	9	4	5.49	3.14	1	9	6
	Walking outdoors	5.24	2.21	1	8	5	5.89	2.16	1	9	8
	Walking on uneven ground	5.47	2.41	1	9	6	6.33	2.12	1	9	9
	Trips and falls	5.61	3.16	1	9	7	3.96	2.61	1	9	2
	Bumping into people in crowded areas	5.82	3.06	1	9	8	4.66	2.52	1	9	5
	Walking indoors	5.96	2.49	1	9	9	5.75	2.80	1	9	7

Table 5.4: Mean rank, standard deviation, minimum and maximum position for near vision items

	Item	Stroke survivors (n=48)					Clinicians (n=61)				
		Mean rank	SD	Min	Max	Rank	Mean rank	SD	Min	Max	Rank
Near vision	Writing	2.54	1.62	1	7	1	3.14	1.63	1	7	2
	Recognising faces	3.13	1.77	1	7	2	2.15	1.78	1	7	1
	Leisure activities e.g. sewing, DIY, painting	3.15	1.74	1	7	3	3.57	2.09	1	7	3
	Using a mobile phone	4.04	1.43	1	7	4	5.34	1.55	2	7	7
	Finding an item on a crowded shelf	4.58	1.74	1	7	5	4.46	1.71	1	7	4
	Managing money	5.15	1.90	1	7	6	4.52	1.54	1	7	5
	Telling time on a watch	5.41	1.92	1	7	7	4.93	1.73	1	7	6
	Additional: Reading	-	-	-	-	-	1.00	-	-	-	-

Table 5.5: Mean rank, standard deviation, minimum and maximum position for distance vision items

	Item	Stroke survivors (n=48)					Clinicians (n=61)				
		Mean rank	SD	Min	Max	Rank	Mean rank	SD	Min	Max	Rank
Distance Vision	Recognising people	2.15	1.15	1	5	1	2.18	1.23	1	5	2
	Reading street signs/information boards	2.35	1.06	1	5	2	2.85	1.08	1	5	3
	Orientation	2.42	1.27	1	5	3	2.02	1.09	1	5	1
	Telling time on a clock	3.96	0.87	2	5	4	4.51	0.70	2	5	5
	Identifying the correct bus	4.13	1.28	1	5	5	3.44	1.27	1	5	4

Table 5.6: Mean rank, standard deviation, minimum and maximum position for reading items

	Item	Stroke survivors (n=47)					Clinicians (n=61)				
		Mean rank	SD	Min	Max	Rank	Mean rank	SD	Min	Max	Rank
Reading	Normal size print	2.19	1.10	1	4	1	2.69	1.22	1	5	3
	Reading labels on medication or packets	2.91	1.46	1	5	2	2.61	1.23	1	5	2
	Trouble following lines of print	2.94	1.73	1	5	3	2.30	1.23	1	5	1
	Small print	3.28	1.19	1	5	4	3.67	1.42	1	5	4
	Newspaper headlines	3.68	1.13	2	5	5	3.74	1.37	1	5	5

Table 5.7: Mean rank, standard deviation, minimum and maximum position for driving items

	Item	Stroke survivors (n=47)					Clinicians (n=61)				
		Mean rank	SD	Min	Max	Rank	Mean rank	SD	Min	Max	Rank
Driving	Ever driven	2.68	2.77	1	8	1	1.31	1.32	1	8	1
	Difficult conditions	2.72	1.42	1	7	2	5.03	1.71	2	8	6
	At night	3.11	1.22	1	7	3	4.57	1.90	1	8	3
	During the day in a familiar area	4.28	1.48	1	8	4	5.00	2.42	1	8	5
	Not noticing other cars until the last moment	4.68	1.45	1	8	5	3.29	1.77	1	8	2
	Glare from headlights	4.96	1.82	1	8	6	5.16	2.05	1	8	7
	Changing lanes	6.26	1.55	1	8	7	4.92	1.74	2	8	4
	Parking	7.28	1.43	2	8	8	5.95	1.55	3	8	8
	Additional: Being a passenger	-	-	-	-	-	6.00	-	-	-	
	Additional: Using rear view mirror	-	-	-	-	-	9.00	-	-	-	

5.3.2.6*: Travelling*

The ranking results for the items in the travelling category from both stroke survivors and clinicians are outlined in Table 5.8. The item which was deemed to be the most important by stroke survivors and clinicians and had the highest mean rank was 'travelling alone': (2.00, SD 1.12) and (1.85, SD 1.22) respectively. The item deemed to be least important by stroke survivors and clinicians and had the lowest mean rank was 'orientation': (3.00, SD 0.96) and (2.85, SD 0.93) respectively. One clinician added accessibility of buses, ramps and trains as an item to this category. They did not rank it to be of high importance, but it would be taken into account during future stages. All items had a wide range of rank; 100% of items spanned from the absolute minimum of one to the absolute maximum of four for stroke survivors and clinicians.

5.3.2.7*: Television*

The ranking results for the items in the television category from both stroke survivors and clinicians are outlined in Table 5.9. The item which was deemed to be the most important by stroke survivors and clinicians and had the highest mean rank was 'watching TV': (1.88, SD 1.09) and (1.26, SD 0.51) respectively. The item deemed to be least important by stroke survivors and clinicians and had the lowest mean rank was 'using a computer': (4.56, SD 0.96) and (4.87, SD 0.39) respectively. All items had a wide range of rank; 60% of items spanned from the absolute minimum of one to the absolute maximum of four for stroke survivors, but only 20% for clinicians.

5.3.2.8*: Peripheral vision*

The ranking results for the items in the peripheral vision category from both stroke survivors and clinicians are outlined in Table 5.10. The items which were deemed to be the most important by stroke survivors and clinicians and had the highest mean rank were 'noticing objects off to the side' (2.20, SD 1.00) and 'bumping into things' (1.48, SD 0.79) respectively. The items deemed to be least important by stroke survivors and clinicians and had the lowest mean rank were the same two items, but reversed, 'bumping into things' (2.76, SD 1.05) and 'noticing objects off to the side' (3.21, SD 0.80) respectively. Despite a complete disagreement on the most or least important items, the two groups agreed on the importance of the middle two items. One clinician added negotiating busy places as an item to this category. This may be similar to the 'bumping into people in crowded areas' item in

the walking category. It was not ranked to be of high importance, but it would be taken into account during future stages. All items had a wide range of rank; 100% of items spanned from the absolute minimum of one to the absolute maximum of four for stroke survivors and clinicians.

5.3.2.9*: Self-care*

The ranking results for the items in the self-care category from both stroke survivors and clinicians are outlined in Table 5.11. The items which were deemed to be the most important by stroke survivors and clinicians and had the highest mean rank were 'pouring liquids' (3.61, SD 1.89) and 'toileting' (2.62, SD 2.06) respectively. Clinicians disagreed with regard to 'pouring liquids' with a given rank of fourth (4.10, SD 2.06). Furthermore, stroke survivors disagreed with regard to 'toileting' and ranked this as fifth (4.76, SD 3.06). The items deemed to be least important by stroke survivors and clinicians and had the lowest mean rank were 'grooming' (5.63, SD 2.33) and 'housework' (7.38, SD 1.13) respectively. The clinicians were in close agreement with stroke survivors with regard to 'grooming', which was ranked seventh (5.15, SD 1.94). All items had a wide range of rank; 88% of items spanned from the absolute minimum of one to the absolute maximum of eight for stroke survivors and clinicians.

5.3.2.10*: Lighting*

The ranking results for the items in the lighting category from both stroke survivors and clinicians are outlined in Table 5.12. The items which were deemed to be the most important by stroke survivors and clinicians and had the highest mean rank were adjusting to bright light' (2.61, SD 1.27), 'adjusting to darkness' (2.61, SD 1.41) 'and 'reduced vision in dim light' (2.26, SD 1.22) respectively, with stroke survivors having two items joint first. Clinicians disagreed with regard to 'adjusting to darkness' with a given rank of fifth (3.51, SD 1.27). Moreover, stroke survivors disagreed with regard to 'reduced vision in dim light' and ranked this as fourth (3.04, SD 1.33). The items deemed to be least important by stroke survivors and clinicians and had the lowest mean rank were 'reduced vision in bright light' (4.00, SD 1.38) and 'adjusting to darkness' (3.51, SD 1.27) respectively. Clinicians disagreed with regard to 'reduced vision in bright light' with a given rank of second (3.10, SD 1.51). All items had a wide range of rank; 100% of items spanned from the absolute minimum of one to the absolute maximum of five for stroke survivors and clinicians.

Table 5.8: Mean rank, standard deviation, minimum and maximum position for travelling items

	Item	Stroke survivors (n=25)					Clinicians (n=61)				
		Mean rank	SD	Min	Max	Rank	Mean rank	SD	Min	Max	Rank
Travelling	Travelling alone	2.00	1.12	1	4	1	1.85	1.22	1	4	1
	Using public transport	2.12	0.97	1	4	2	2.34	1.08	1	4	2
	Reading information boards	2.88	1.13	1	4	3	2.95	0.88	1	4	4
	Orientation around station	3.00	0.96	1	4	4	2.85	0.93	1	4	3
	Additional: Accessibility of buses/ramps/trains	-	-	-	-	-	5.00	-	-	-	-

Table 5.9: Mean rank, standard deviation, minimum and maximum position for television items

	Item	Stroke survivors (n=25)					Clinicians (n=61)				
		Mean rank	SD	Min	Max	Rank	Mean rank	SD	Min	Max	Rank
Television	Watching TV	1.88	1.09	1	4	1	1.26	0.51	1	3	1
	Reading text on TV	2.48	1.26	1	5	2	2.38	0.84	1	4	2
	Operating TV	2.56	0.92	1	4	3	2.56	0.81	1	5	3
	Watching a film at the cinema	3.52	1.12	1	5	4	3.93	0.54	2	5	4
	Using a computer	4.56	0.96	2	5	5	4.87	0.39	3	5	5

Table 5.10: Mean rank, standard deviation, minimum and maximum position for peripheral vision items

	Item	Stroke survivors (n=25)					Clinicians (n=61)				
		Mean rank	SD	Min	Max	Rank	Mean rank	SD	Min	Max	Rank
Peripheral Vision	Noticing objects off to the side	2.20	1.00	1	4	1	3.21	0.80	1	4	4
	People suddenly appearing	2.44	1.23	1	4	2	2.25	0.91	1	4	2
	Missing patches of vision	2.60	1.19	1	4	3	3.07	1.01	1	4	3
	Bumping into things	2.76	1.05	1	4	4	1.48	0.79	1	4	1
	Additional: Negotiating busy places e.g. supermarket	-	-	-	-	-	5.00	-	-	-	-

Table 5.11: Mean rank, standard deviation, minimum and maximum position for self-care items

	Item	Stroke survivors (n=46)					Clinicians (n=61)				
		Mean rank	SD	Min	Max	Rank	Mean rank	SD	Min	Max	Rank
Self-Care	Pouring liquids	3.61	1.89	1	8	1	4.10	2.06	1	8	4
	Preparing a meal	3.72	1.93	1	8	2	4.77	1.90	1	8	6
	Dressing	3.91	1.84	1	7	3	3.65	1.81	1	7	2
	Managing medication	4.13	2.32	1	8	4	4.54	2.17	1	8	5
	Toileting	4.76	3.06	1	8	5	2.62	2.06	1	8	1
	Housework	4.93	2.06	1	8	6	7.38	1.13	3	8	8
	Eating	5.30	1.92	1	8	7	3.71	1.85	1	8	3
	Grooming	5.63	2.33	1	8	8	5.15	1.94	1	8	7

Table 5.12: Mean rank, standard deviation, minimum and maximum position for lighting items

	Item	Stroke survivors (n=23)					Clinicians (n=61)				
		Mean rank	SD	Min	Max	Rank	Mean rank	SD	Min	Max	Rank
Lighting	Adjusting to bright light	2.61	1.27	1	5	=1	3.43	1.06	1	5	4
	Adjusting to darkness	2.61	1.41	1	5	=1	3.51	1.27	1	5	5
	Glare	2.74	1.32	1	5	3	2.70	1.60	1	5	3
	Reduced vision in dim light	3.04	1.33	1	5	4	2.26	1.22	1	5	1
	Reduced vision in bright light	4.00	1.38	1	5	5	3.10	1.51	1	5	2

5.3.2.11*: General vision*

The ranking results for the items in the general vision category from both stroke survivors and clinicians are outlined in Table 5.13. The items which were deemed to be the most important by stroke survivors and clinicians and had the highest mean rank were 'rate eyesight' (2.80, SD 1.71), and 'blurred vision' (2.00, SD 1.08) respectively. Clinicians disagreed with regard to 'rate eyesight' with a given rank of fourth (3.94, SD 1.89). Stroke survivors disagreed with regard to 'blurred vision' and ranked this as fifth (3.96, SD 1.54). The items deemed to be least important by stroke survivors and clinicians and had the lowest mean rank were 'deterioration' (4.36, SD 1.93) and 'vision equal in both eyes' (5.08, SD 1.35) respectively. Clinicians disagreed with regard to 'deterioration' with a given rank of second (2.26, SD 1.41). All items had a wide range of rank; 100% of items spanned from the absolute minimum of one to the absolute maximum of six for stroke survivors and 67% for clinicians.

5.3.2.12*: Well-being*

The ranking results for the items in the well-being category from both stroke survivors and clinicians are outlined in Table 5.14. The item which was deemed to be the most important by stroke survivors and clinicians and had the highest mean rank was 'frustrated' (2.91, SD 1.77) and (4.52, SD 2.71) respectively. The item deemed to be least important by stroke survivors and clinicians and had the lowest mean rank was 'avoid eye contact': (8.86, SD 2.20) and (9.84, SD 1.85) respectively. Two items were added by two separate clinicians, depression and awareness of lack of caring, to this category. They did not rank these to be of high importance, but it would be taken into account during future stages. All items had a wide range of rank; 45% of items spanned from the absolute minimum of one to the absolute maximum of 11 for stroke survivors and 73% for clinicians.

5.3.2.13*: Colour*

The ranking results for the items in the colour category from both stroke survivors and clinicians are outlined in Table 5.15. The items which were deemed to be the most important by stroke survivors and clinicians and had the highest mean rank were 'identifying clothes': (1.86, SD 0.71) and (1.57, SD 0.69) respectively, with stroke survivors also having 'matching clothes' as joint highest (1.86, SD 0.83). The item deemed to be least important by stroke survivors and clinicians and had the lowest mean rank was 'variation in colour intensity': (2.27, SD 0.88) and (2.41, SD 0.76) respectively. One clinician added colour controls on

technology as an item to this category. It was not ranked to be of high importance, but it would be taken into account during future stages. All items had a wide range of rank; 100% of items spanned from the absolute minimum of one to the absolute maximum of three for stroke survivors and clinicians.

5.3.2.14*: Ocular pain*

The ranking results for the items in the ocular pain category from both stroke survivors and clinicians are outlined in Table 5.16. The item which was deemed to be the most important by stroke survivors and clinicians and had the highest mean rank was 'pain or discomfort': (1.64, SD 0.66) and (1.57, SD 0.79) respectively. The item deemed to be least important by stroke survivors and clinicians and had the lowest mean rank was 'watering': (2.55, SD 0.74) and (2.28, SD 0.83) respectively. All items had a wide range of rank; 100% of items spanned from the absolute minimum of one to the absolute maximum of three for stroke survivors and clinicians.

5.3.2.15*: Social function*

The ranking results for the items in the social function category from both stroke survivors and clinicians are outlined in Table 5.17. The item which was deemed to be the most important by stroke survivors and clinicians and had the highest mean rank was 'visiting people': (2.45, SD 1.82), and (3.34, SD 1.85) respectively. The item deemed to be least important by stroke survivors and clinicians and had the lowest mean rank was 'making new friends': (7.45, SD 2.00) and (6.80, SD 2.36) respectively. All items had a wide range of rank; 33% of items spanned from the absolute minimum of one to the absolute maximum of nine for stroke survivors and 71% for clinicians.

Table 5.13: Mean rank, standard deviation, minimum and maximum position for general vision items

	Item	Stroke survivors (n=45)					Clinicians (n=61)				
		Mean rank	SD	Min	Max	Rank	Mean rank	SD	Min	Max	Rank
General Vision	Rate eyesight	2.80	1.71	1	6	1	3.94	1.89	1	6	4
	Fluctuation in vision	3.13	1.33	1	6	2	3.33	0.89	1	5	3
	Tired eyes	3.33	1.49	1	6	3	4.16	1.08	1	6	5
	Vision equal in both eyes	3.42	1.80	1	6	4	5.08	1.35	1	6	6
	Blurred vision	3.96	1.54	1	6	5	2.00	1.08	1	5	1
	Deterioration	4.36	1.93	1	6	6	2.26	1.41	1	6	2

Table 5.14: Mean rank, standard deviation, minimum and maximum position for well-being items

	Item	Stroke survivors (n=22)					Clinicians (n=61)				
		Mean rank	SD	Min	Max	Rank	Mean rank	SD	Min	Max	Rank
Well-being	Frustrated	2.91	1.77	1	7	1	4.52	2.71	1	10	1
	Worry	4.27	2.37	1	9	2	5.44	2.84	1	11	5
	Coping	6.23	4.13	1	11	3	5.95	3.54	1	12	8
	Stressed	5.00	2.49	1	9	4	5.92	2.84	1	11	7
	Self-conscious	5.05	2.65	1	11	5	7.21	2.72	1	11	10
	Less control	5.50	2.65	1	11	6	5.73	2.83	1	11	6
	Isolated	5.91	2.78	1	11	7	4.80	2.87	1	10	4
	Vulnerable	7.05	2.32	2	11	8	4.64	2.64	1	10	2
	Anxious	7.09	2.67	1	10	9	4.77	2.31	1	11	3
	Adaptation	8.14	3.34	1	11	10	7.05	3.35	1	11	9
	Avoid eye contact	8.86	2.20	4	11	11	9.84	1.85	3	11	11
	Additional: Depression	-	-	-	-	-	12.00	-	-	-	
	Additional: Awareness of lack of caring	-	-	-	-	-	8.00	-	-	-	

Table 5.15: Mean rank, standard deviation, minimum and maximum position for colour items

	Item	Stroke survivors (n=22)					Clinicians (n=61)				
		Mean rank	SD	Min	Max	Rank	Mean rank	SD	Min	Max	Rank
Colour	Identifying colours	1.86	0.71	1	3	=1	1.57	0.69	1	3	1
	Matching clothes	1.86	0.83	1	3	=1	2.02	0.79	1	3	2
	Variation in colour intensity	2.27	0.88	1	3	3	2.41	0.76	1	3	3
	Additional: Colour controls on technology	-	-	-	-		4.00	-	-	-	

Table 5.16: Mean rank, standard deviation, minimum and maximum position for ocular pain items

	Item	Stroke survivors (n=22)					Clinicians (n=61)				
		Mean rank	SD	Min	Max	Rank	Mean rank	SD	Min	Max	Rank
Ocular Pain	Pain/discomfort	1.64	0.66	1	3	1	1.57	0.79	1	3	1
	Strain	1.82	0.80	1	3	2	2.15	0.66	1	3	2
	Watering	2.55	0.74	1	3	3	2.28	0.83	1	3	3

Table 5.17: Mean rank, standard deviation, minimum and maximum position for social function items

	Item	Stroke survivors (n=22)					Clinicians (n=61)				
		Mean rank	SD	Min	Max	Rank	Mean rank	SD	Min	Max	Rank
Social Function	Visiting people	2.45	1.82	1	8	1	3.34	1.85	1	9	1
	Hobbies	3.64	2.32	1	7	2	3.66	2.49	1	9	2
	Going out socially e.g. cinema, sports events	3.73	2.39	1	9	3	4.72	2.15	2	9	5
	Conversation	4.64	2.38	1.	8	4	3.75	2.65	1	9	3
	Entertaining in your home	4.95	2.10	2	9	5	5.98	2.31	1	9	7
	Sports/outdoor activities	5.27	2.21	1	9	6	6.67	2.02	2	9	8
	Social functions e.g. weddings, parties	6.41	1.68	3	9	=7	5.64	1.84	1	9	6
	Dealing with strangers	6.41	2.44	1	9	=7	4.33	2.54	1	9	4
	Making new friends	7.45	2.00	3	9	9	6.80	2.36	2	9	9

5.3.2.16*: Role limitation*

The ranking results for the items in the role limitation category from both stroke survivors and clinicians are outlined in Table 5.18. The items which were deemed to be the most important by stroke survivors and clinicians and had the highest mean rank were 'accomplishing less than you would like' (2.59, SD 1.59) and 'reduced confidence' (2.26, SD 1.74) respectively. Stroke survivors were in close agreement with the clinicians with regard to 'reduced confidence', which was ranked second (3.64, SD 1.97). The items deemed to be least important by stroke survivors and clinicians and had the lowest mean rank were 'less opportunities' (5.68, SD 2.06) and 'household chores' (6.69, SD 1.74) respectively. Again, stroke survivors were in close agreement with the clinicians with regard to 'household chores', which was ranked seventh (5.64, SD 2.32). 'Household chores' was also ranked least important in the self-care category by clinicians (Section 5.3.2.9). One clinician added change of role as an item to this category. It was not ranked to be of high importance, but it would be taken into account during future stages. All items had a wide range of rank; 63% of items spanned from the absolute minimum of one to the absolute maximum of eight for stroke survivors and 38% for clinicians.

5.3.2.17*: Dependency*

The ranking results for the items in the dependency category from both stroke survivors and clinicians are outlined in Table 5.19. The items which were deemed to be the most important by stroke survivors and clinicians and had the highest mean rank were 'travelling and going outside alone' (2.18, SD 1.24), and 'feel a burden' (1.69, SD 0.92) respectively. Stroke survivors were in close agreement with the clinicians with regard to 'feel a burden', which was ranked second (2.50, SD 1.15). Conversely, clinicians ranked 'travelling and going outside alone' as the fourth and least important item (3.10, SD 1.03). The item deemed to be least important by stroke survivors and had the lowest mean rank was 'stay at home' (2.66, SD 1.12). The clinicians were in close agreement with the stroke survivors with regard to 'stay at home', which was ranked third (2.84, SD 1.13). All items had a wide range of rank; 100% of items spanned from the absolute minimum of one to the absolute maximum of four for stroke survivors and clinicians.

5.3.2.18*: Binocular vision*

The ranking results for the items in the binocular vision category from both stroke survivors and clinicians are outlined in Table 5.20. The items which were deemed to be the most important by stroke survivors and clinicians and had the highest mean rank were ‘problems with depth perception’ (1.81, SD 0.93), and ‘double or multiple images’ (1.38, SD 0.82) respectively. Both groups disagreed with regard to both of these items. The item ranked as first by one group was ranked fourth by the other in both cases. The item deemed to be least important by stroke survivors and clinicians and had the lowest mean rank was ‘eyes are misaligned’ (3.86, SD 0.85) and (4.48, SD 0.83). All items had a wide range of rank; 60% of items spanned from the absolute minimum of one to the absolute maximum of five for stroke survivors and 80% for clinicians.

5.3.2.19*: Symptoms*

The ranking results for the items in the symptom category from both stroke survivors and clinicians are outlined in Table 5.21. The items which were deemed to be the most important by stroke survivors and clinicians and had the highest mean rank were ‘blurred, misty or foggy vision' (3.51, SD 1.96), and ‘double vision’ (1.90, SD 1.19) respectively. The clinicians were in close agreement with the stroke survivors with regard to ‘blurred, misty or foggy vision’, which was ranked second (3.28, SD 2.33). Stroke survivors ranked ‘double vision’ as fifth (5.29, SD 2.19). This was a similar pattern to the item ‘double or multiple images’ in the binocular vision category (Table 5.20). Two clinicians added hallucinations as an item to this category. It has not been included in the overall ranking as it was not available to be ranked by the whole group. However of those that did rank, it would have been placed third. This suggestion would be taken into account during future stages. The item deemed to be least important by stroke survivors and clinicians and had the lowest mean rank was ‘colours dull and faded’: (9.54, SD 3.00) and (9.53, SD 1.80) respectively. All items had a wide range of rank; 45% of items spanned from the absolute minimum of one to the absolute maximum of 11 for stroke survivors and 36% for clinicians.

Table 5.18: Mean rank, standard deviation, minimum and maximum position for role limitation items

	Item	Stroke survivors (n=22)					Clinicians (n=61)				
		Mean rank	SD	Min	Max	Rank	Mean rank	SD	Min	Max	Rank
Role Limitation	Accomplishing less than you would like	2.59	1.59	1	6	1	3.18	1.60	1	7	3
	Reduced confidence	3.64	1.97	1	8	=2	2.26	1.74	1	7	1
	Reduced stamina for activities	3.64	2.28	1	8	=2	3.95	2.04	1	8	4
	Limited type of activities	3.95	1.40	2	7	4	3.15	1.53	1	7	2
	Standard of work	5.36	2.63	1	8	5	6.26	1.54	2	8	7
	Shopping	5.50	1.90	2	8	6	5.02	2.09	1	8	5
	Household chores	5.64	2.32	1	8	7	6.69	1.74	1	8	8
	Less opportunities	5.68	2.06	1	8	8	5.49	1.60	2	8	6
	Additional: Change of roles e.g. husband not able to mow lawn etc.	-	-	-	-	-	9.00	-	-	-	-

Table 5.19: Mean rank, standard deviation, minimum and maximum position for dependency items

	Item	Stroke survivors (n=44)					Clinicians (n=61)				
		Mean rank	SD	Min	Max	Rank	Mean rank	SD	Min	Max	Rank
Dependency	Travelling/going outside alone	2.18	1.24	1	4	1	3.10	1.03	1	4	4
	Feel burden on others	2.50	1.15	1	4	2	1.69	0.92	1	4	1
	Need help from others	2.66	0.91	1	4	=3	2.38	0.86	1	4	2
	Stays at home	2.66	1.12	1	4	=3	2.84	1.13	1	4	3

Table 5.20: Mean rank, standard deviation, minimum and maximum position for binocular vision items

	Item	Stroke survivors (n=21)					Clinicians (n=61)				
		Mean rank	SD	Min	Max	Rank	Mean rank	SD	Min	Max	Rank
Binocular Vision	Problems with depth perception	1.81	0.93	1	4	1	3.30	1.05	1	5	4
	Closing one eye helps	2.38	1.56	1	5	2	3.28	1.20	1	5	3
	Difficulty picking up objects - under/overshoot	3.29	1.42	1	5	3	2.59	1.02	1	5	2
	Double/multiple images	3.67	1.11	1	5	4	1.38	0.82	1	5	1
	Eyes are misaligned	3.86	0.85	2	5	5	4.48	0.83	2	5	5

Table 5.21: Mean rank, standard deviation, minimum and maximum position for symptoms items

	Item	Stroke survivors (n=41)					Clinicians (n=61)				
		Mean rank	SD	Min	Max	Rank	Mean rank	SD	Min	Max	Rank
Symptoms	Blurred/Misty/Foggy vision	3.51	1.96	1	8	1	3.28	2.33	1	10	2
	Dryness	4.17	2.44	1	11	2	7.70	2.74	1	11	8
	Headaches	4.41	2.67	1	10	3	5.85	2.87	1	11	6
	Watering	4.85	2.65	1	11	4	7.33	2.46	1	11	7
	Double vision	5.29	2.19	1	10	5	1.90	1.19	1	7	1
	Patches missing	5.63	4.01	1	10	6	4.57	2.46	1	10	4
	Distortion	6.34	2.77	1	11	7	4.44	1.70	1	9	3
	Jumping objects	6.93	2.31	1	11	8	5.00	2.21	1	10	5
	Haloes	7.44	2.31	2	11	9	8.00	1.79	3	11	9
	Starbursts	7.88	2.57	2	11	10	8.57	2.19	2	12	10
	Colours dull and faded	9.54	3.00	1	11	11	9.53	1.80	5	12	11
	Additional: Hallucinations	-	-	-	-	-	3.5	2.12	2	5	<3

5.3.3: Item reduction

Both the category and individual item rankings displayed a wide range of ranks. Stroke survivors gave the full range of rank for all items within a category for nine out of twenty item blocks. Clinicians used the full range of rank for all items within a category for eight out of twenty item blocks. Only in four of the twenty item blocks did both stroke survivors and clinicians use the full range of rank for less than half the items. In view of this, the decision was made to include all 20 categories and a maximum of nine items per category. The limit in the number of items per category was to reduce the larger categories. This was not based on a standardised cut-off point across all categories. The variability in the number of items in each category prevented direct comparisons and, therefore, a standardised cut-off point. This resulted in the loss of one item from two categories; well-being and symptoms. 'Adaptation' was removed from the well-being category and 'starbursts' from the symptoms category. Stroke survivors and clinicians were in agreement with the low ranking of these items.

5.3.4: Limitations

Demographic information was not provided by all clinicians and stroke survivors who completed the ranking exercise. It is therefore not possible to outline in detail, who completed the exercise.

Due to limited online resources at the time of this study it was necessary to split the ranking exercise into two parts. Although the two parts were sent together, this split may have contributed to the limited response to the second half of the survey. However, if it had been created as one single survey, the long length may, quite likely, have also resulted in partial completions. The organisation of the split, including category ranking and the top ranked categories by clinicians in the first part of the survey, allowed for a larger sample size for those items.

5.4: Scoping of existing instruments

The majority of items were carried forward from the ranking exercise. These were mapped against the existing PROMs, to cross check whether a pre-existing instrument would be appropriate for use with a stroke population. Firstly, duplicate items which had been linked to two or more categories were removed, in order for that item to only appear once. This resulted in the following duplicates being removed: 'watering', 'missing patches of vision', 'colours dull and faded' and 'double vision' from the symptom category, 'orientation' and 'reading information boards' from the travelling category, 'leisure activities' from the near vision category, 'travelling alone' from the dependency category, 'blurred vision' from the general vision category, 'household chores' from the role limitations category, 'avoid eye contact' from the well-being category and 'bumping into people' from the walking category.

The item coverage within the existing instruments can be seen in Table 5.22. This table was used to establish which instrument or instruments would cover the items remaining following the ranking exercise. The VQoL (Vision related Quality of Life questionnaire) alone includes 66 of the 107 items (61.7%). An additional 20 items would be covered if the NEI VFQ-25 (Neuro 10) (National Eye Institute Visual Functioning Questionnaire with Neuro 10 supplement) was used, increasing the coverage to 80.4%. To increase the coverage further to 86.9% the NHV-VFQ (Nursing Home Vision Targeted Health-related Quality of Life questionnaire) includes an additional seven items. The VAQ (Visual Activity Questionnaire) includes another additional five items, increasing the coverage to 91.6%. This would leave nine items outstanding: 'trouble following lines', 'operating TV', 'cinema', 'medication', 'fluctuation', 'strain', 'conversation', 'reduced confidence' and 'standard of work'.

Due to the lack of consensus on which items would be important to include in a new PROM, four instruments would be required, in combination, to achieve 91.6% item coverage. This combination of instruments would total 282 items. In order to achieve 100% coverage an additional seven instruments (AS-20, QoL-VFQ, QoV, SRA-FVP, VA LV VFQ, VisQoL and VF Severity) would be required, increasing the total number of items across the instruments to 422. If the four instruments which achieve 91.6% item coverage were used in combination there would be a high degree of duplication. An overview of the duplication is outlined in Table 5.23. Of the items covered 54.1% (n=53) are duplicated in two or more of the instruments, 20.4% (n=20) in three or more instruments and 2.0% (n=2) are duplicated in all four instruments.

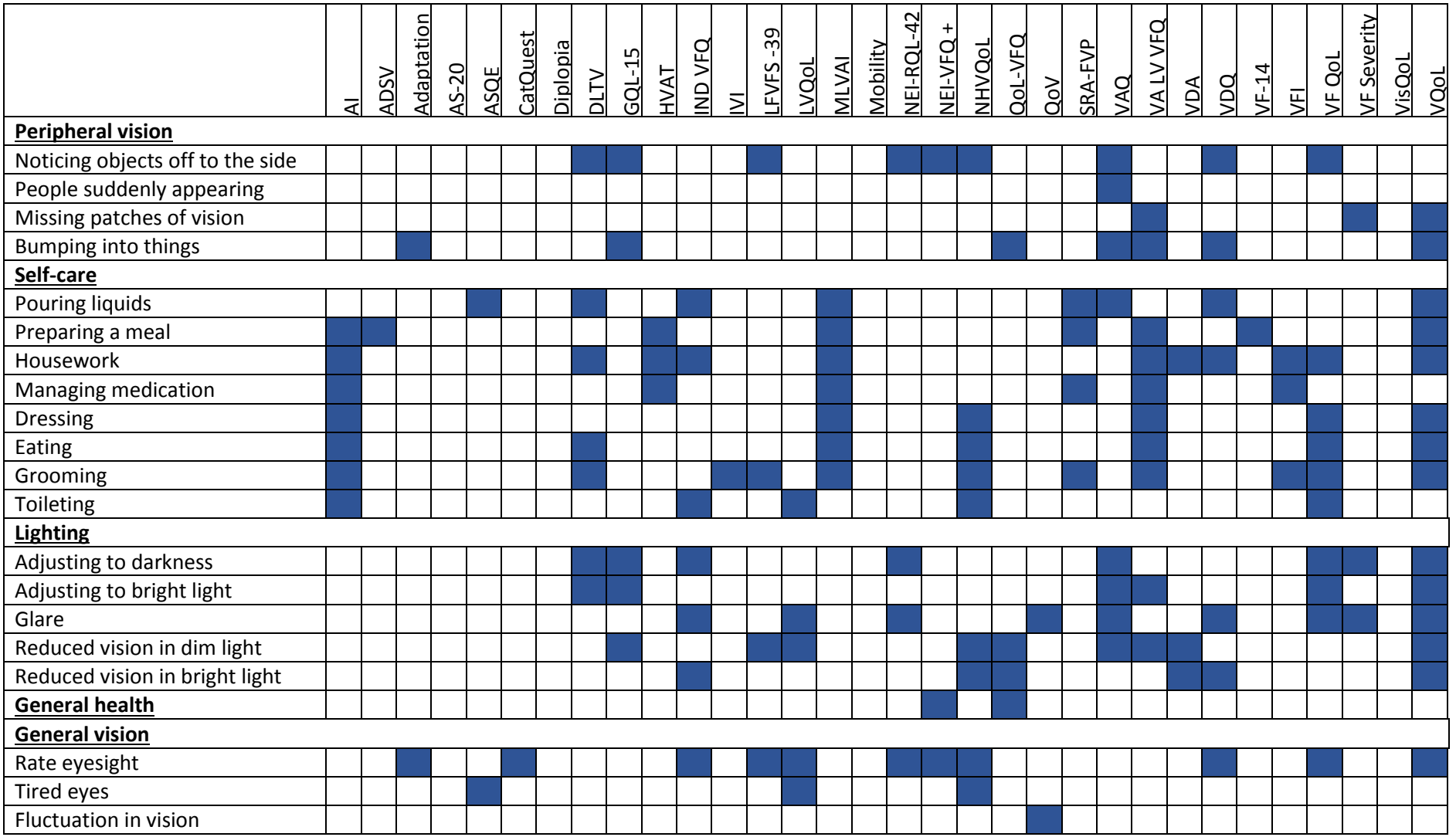
In the pre-testing study of the VQoL, Frost *et al.* found 200 items to be the burden limit for an elderly population (164). If the VQoL, NEI VFQ-25, NHV-VFQ and VAQ were used in combination as an assessment of quality of life in a stroke population, the task burden and the degree of item repetition are too high for this to be deemed a feasible or acceptable assessment. It also has to be considered that, of these instruments, all but one have not yet been validated with a stroke population. The NEI VFQ-25 (Neuro 10) has been validated with a sub-population (144, 176). In view of these factors the decision was taken to develop a new instrument targeted at stroke survivors with visual impairment and which would involve stroke survivors in its development.

Table 5.22: Overview of item coverage by existing patient reported outcome measures

■ Item present in instrument

	AI	ADSV	Adaptation	AS-20	ASQE	CatQuest	Diplopia	DLTV	GQL-15	HVAT	IND VFQ	IVI	LFVFS -39	LVQoL	MLVAI	Mobility	NEI-RQL-42	NEI-VFQ +	NHVQoL	QoL-VFQ	QoV	SRA-FVP	VAQ	VA LV VFQ	VDA	VDQ	VF-14	VFI	VF QoL	VF Severity	VisQoL	VQoL
Walking																																
Steps/curbs		■			■			■	■		■	■	■	■		■	■	■	■	■		■		■	■		■		■	■		■
Familiar areas								■								■			■					■					■			■
Unfamiliar areas								■								■								■	■							■
Crossing road									■		■			■			■			■				■	■				■			■
Indoors																■			■					■	■			■				■
Outdoors												■		■	■	■								■	■			■	■			■
Uneven ground						■																■										■
Trips/falls									■			■										■				■				■	■	■
Near vision																																
Writing	■	■						■						■	■				■					■			■					■
Recognising faces						■		■										■						■			■					■
Using a mobile phone												■		■	■				■													■
Finding item											■		■					■	■				■	■					■			■
Managing money	■							■			■				■							■		■								■
Telling time on a watch														■	■									■								■
Distance vision																																
Recognising people		■			■				■		■	■	■		■			■	■	■				■	■	■			■			■
Reading street sign/info boards		■										■	■	■				■	■				■	■	■		■					■
Orientation					■						■													■								■
Telling time on a clock															■				■			■										■
Identifying correct bus																																■

	AI	ADSV	Adaptation	AS-20	ASQE	CatQuest	Diplopia	DLTV	GQL-15	HVAT	IND VFQ	IVI	LFVFS -39	LVQoL	MLVAI	Mobility	NEI-RQL-42	NEI-VFQ +	NHVQoL	QoL-VFQ	QoV	SRA-FVP	VAQ	VA LV VFQ	VDA	VDQ	VF-14	VFI	VF QoL	VF Severity	VisQoL	VQoL
Reading																																
Normal size print		■		■		■		■	■			■	■	■	■		■	■	■	■		■		■	■		■					■
Newspaper headlines								■						■					■					■			■					■
Small print		■											■		■		■	■				■	■	■			■					■
Reading labels		■										■		■	■							■		■								■
Trouble following lines																													■			
Driving																																
Ever driven		■																■		■						■		■				■
Difficult conditions																	■	■					■									
At night		■								■							■	■					■		■		■					
During the day/familiar		■								■								■							■		■					
Not noticing cars																							■									
Glare from headlights										■										■			■									
Changing lanes																							■									
Parking					■												■	■														
Travelling																																
Using public transport		■										■				■								■	■							■
Travelling alone																																■
Television																																
Watching TV	■	■						■		■		■	■	■					■					■	■	■	■					■
Operating TV																						■										
Reading text on TV		■					■																	■								■
Watching film at the cinema																								■								
Computer																		■						■								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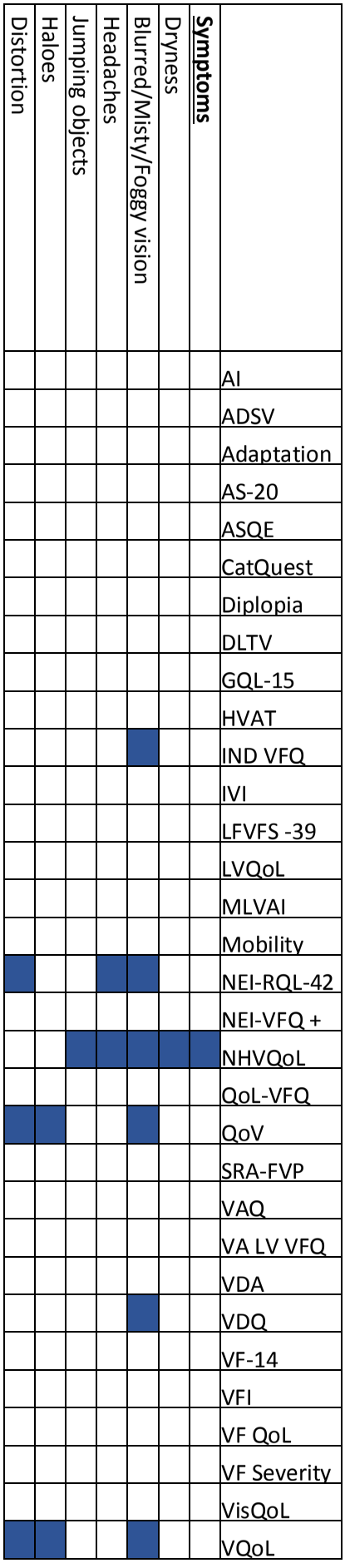
AS-20
ASQE
CatQuest
Diplopia
DLTV
GQL-15
HVAT
IND VFQ
IVI
LFVFS -39
LVQoL
MLVAI
Mobility
NEI-RQL-42
NEI-VFQ +
NHVQoL
QoL-VFQ
QoV
SRA-FVP
VAQ
VA LV VFQ
VDA
VDQ
VF-14
VFI
VF QoL
VF Severity
VisQoL
VQoL
Peripheral vision
Noticing objects off to the side
People suddenly appearing
Missing patches of vision
Bumping into things
Self-care
Pouring liquids
Preparing a meal
Housework
Managing medication
Dressing
Eating
Grooming
Toileting
Lighting
Adjusting to darkness
Adjusting to bright light
Glare
Reduced vision in dim light
Reduced vision in bright light
General health
General vision
Rate eyesight
Tired eyes
Fluctuation in vision

	AI	ADSV	Adaptation	AS-20	ASQE	CatQuest	Diplopia	DLTV	GQL-15	HVAT	IND VFQ	IVI	LFVFS -39	LVQoL	MLVAI	Mobility	NEI-RQL-42	NEI-VFQ +	NHVQoL	QoL-VFQ	QoV	SRA-FVP	VAQ	VA LV VFQ	VDA	VDQ	VF-14	VFI	VF QoL	VF Severity	VisQoL	VQoL
General vision *continued*																																
Vision equal in both eyes					■													■								■						
Deterioration					■																									■		■
Well-being																																
Worry				■							■		■				■	■	■	■						■						■
Frustrated													■	■				■	■	■												
Self-conscious				■	■						■		■					■	■													■
Less control			■															■	■													■
Stressed				■										■				■														
Isolated													■						■													■
Vulnerable			■								■								■													■
Anxious				■																												■
Coping			■										■						■												■	■
Colour																																
Matching clothes													■					■	■			■		■								■
Identifying clothes													■					■	■			■										
Variation in colour intensity											■				■					■			■		■	■			■	■		■
Ocular pain																																
Pain/discomfort																	■	■	■													
Watering																	■		■							■						
Strain				■																												
Social function																																
Visiting people	■											■		■				■	■	■									■		■	■
Going out socially	■											■	■					■	■			■		■								■
Entertaining at home	■																	■	■													

	AI	ADSV	Adaptation	AS-20	ASQE	CatQuest	Diplopia	DLTV	GQL-15	HVAT	IND VFQ	IVI	LFVFS -39	LVQoL	MLVAI	Mobility	NEI-RQL-42	NEI-VFQ +	NHVQoL	QoL-VFQ	QoV	SRA-FVP	VAQ	VA LV VFQ	VDA	VDQ	VF-14	VFI	VF QoL	VF Severity	VisQoL	VQoL
Social function *continued*																																
Sports/outdoor activities	■			■						■		■	■				■	■					■			■						
Hobbies	■			■						■		■							■			■		■	■							■
Conversation				■																												
Social functions	■										■							■											■			
Dealing with strangers				■																												■
Making new friends			■																											■	■	■
Role limitations																																
Accomplishing less					■						■	■		■				■	■				■			■		■			■	
Reduced stamina			■	■	■													■	■				■					■				
Limited type of activities																	■	■	■						■			■				■
Reduced confidence					■																								■		■	
Shopping	■											■			■							■										■
Less opportunities				■																						■						■
Standard of work											■									■												
Dependency																																
Stays at home																		■	■													
Need help from others			■									■						■	■									■			■	■
Feel burden on others											■	■								■									■			■
Binocular vision																																
Closing one eye helps				■														■														
Problems with depth perception				■	■				■					■			■				■		■									■
Eyes are misaligned					■													■														
Double/multiple images					■		■												■		■					■						
Difficulty picking up objects																							■						■			


Distortion
Haloes
Jumping objects
Headaches
Blurred/Misty/Foggy vision
Dryness
Symptoms
AI
ADSV
Adaptation
AS-20
ASQE
CatQuest
Diplopia
DLTV
GQL-15
HVAT
IND VFQ
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LFVFS -39
LVQoL
MLVAI
Mobility
NEI-RQL-42
NEI-VFQ +
NHVQoL
QoL-VFQ
QoV
SRA-FVP
VAQ
VA LV VFQ
VDA
VDQ
VF-14
VFI
VF QoL
VF Severity
VisQoL
VQoL

Table 5.23: Overview of item duplication by four instruments required to achieve 91.6% item coverage

■ Item present in instrument

	NEI-VFQ +	NHVQoL	VAQ	VQoL	
Steps/curbs	■	■		■	3
Familiar areas		■		■	2
Unfamiliar areas				■	1
Crossing road				■	1
Indoors		■		■	2
Outdoors				■	1
Uneven ground				■	1
Trips/falls				■	1
Writing		■		■	2
Recognising faces	■			■	2
Using a mobile phone		■		■	2
Finding item	■	■	■	■	4
Managing money				■	1
Telling time on a watch				■	1
Recognising people	■	■		■	3
Reading street sign/info boards	■	■	■	■	4
Orientation				■	1
Telling time on a clock		■		■	2
Identifying correct bus				■	1
Normal size print	■	■		■	3
Newspaper headlines		■		■	2
Small print	■		■	■	3

	NEI-VFQ +	NHVQoL	VAQ	VQoL	
Parking	■				1
Using public transport				■	1
Travelling alone				■	1
Watching TV		■		■	2
Operating TV					0
Reading text on TV				■	1
Watching film at the cinema					0
Computer	■				1
Noticing objects off to the side	■	■	■		3
People suddenly appearing			■		1
Missing patches of vision				■	1
Bumping into things			■	■	2
Pouring liquids			■	■	2
Preparing a meal				■	1
Housework				■	1
Managing medication					0
Dressing		■		■	2
Eating		■		■	2
Grooming		■		■	2
Toileting		■			1
Adjusting to darkness			■	■	2
Adjusting to bright light			■	■	2

	NEI-VFQ +	NHVQoL	VAQ	VQoL	
Reading labels				■	1
Trouble following lines					0
Ever driven	■			■	2
Difficult conditions	■		■		2
At night	■		■		2
During the day/familiar	■				1
Not noticing cars			■		1
Glare from headlights			■		1
Changing lanes			■		1
Worry	■	■		■	3
Frustrated	■	■			2
Self-conscious	■	■		■	3
Less control	■	■		■	3
Stressed	■				1
Isolated		■		■	2
Vulnerable		■		■	2
Anxious				■	1
Coping		■		■	2
Matching clothes	■	■		■	3
Identifying clothes	■	■			2
Variation in colour intensity			■	■	2
Pain/discomfort	■	■			2
Watering		■			1
Strain					0
Visiting people	■	■		■	3

	NEI-VFQ +	NHVQoL	VAQ	VQoL	
Glare			■	■	2
Reduced vision in dim light		■	■	■	3
Reduced vision in bright light		■		■	2
General health	■				1
Rate eyesight	■	■		■	3
Tired eyes		■			1
Fluctuation in vision					0
Vision equal in both eyes	■				1
Deterioration				■	1
Making new friends				■	
Accomplishing less				■	1
Reduced stamina	■	■	■		3
Limited type of activities	■	■	■		3
Reduced confidence	■	■		■	3
Shopping					0
Less opportunities				■	1
Standard of work				■	1
Stays at home					0
Need help from others	■	■		■	3
Feel burden on others	■	■			2
Closing one eye helps			■	■	2
Problems with depth perception	■				1
Eyes are misaligned			■	■	2
Double/multiple images	■				1
Difficulty picking up objects		■			1

	NEI-VFQ +	NHVQoL	VAQ	VQoL	
Going out socially	■	■		■	3
Entertaining at home	■	■			2
Sports/outdoor activities	■				1
Hobbies		■		■	2
Conversation					0
Social functions	■				1
Dealing with strangers				■	1

	NEI-VFQ +	NHVQoL	VAQ	VQoL	
Dryness			■		1
Blurred/Misty/Foggy vision		■			1
Headaches		■		■	2
Jumping objects		■			1
Haloes		■			1
Distortion				■	1

5.5: Pilot instrument construction (version one)

The database was used as the basis for the pilot instrument construction following a decision that a new instrument was required as outlined in Section 5.4. It was also supported by a formal consultation with stroke survivors and clinicians who agreed a new instrument was warranted.

A decision regarding the wording of items in the new instrument was taken based on recommendations from the analysis of existing instruments (Chapter 4, Section 4.4). All items would ask about "difficulty due to eyes or eyesight" to support the purpose of the instrument (176). A standardised wording for the majority of items, of "how much difficulty have you found, due to your eyes or eyesight with…?", was used throughout the instrument to reduce cognitive burden. The scale was also standardised, using a five-point rating scale measuring the level of problem (181). The scale ranged from 1 'none at all' to 5 'it limits my activity', with an additional 'not applicable' option (Figure 5.3). A box was also provided to allow explanation of why the item was not applicable. The exception to this was for the two overall items, 'general health' and 'rate eyesight' - both items used the same wording and a visual analogue scale ranging from zero (worst possible) to 100 (best possible) (Figure 5.4).

The individual items (n=1,270) within the database were grouped under the categories and items for use in the ranking exercise (Figure 5.1 and Figure 5.2). The differing wording and/or scales of the grouped items were assessed for use in the new instrument. Items were shortlisted if found to be appropriate, in terms of language (e.g. "driving...during rush hour on the freeway" whereas motorway would be the English terminology), not being too detailed on the specifics of an activity (e.g. "meal preparation - chop, slice, cut, peel, use knives safely") or not being too specific on the location of an activity (e.g. "moving about in classrooms"). The number of items grouped and shortlisted is outlined in Table 5.24. The shortlisted items (n=186) were then assessed for the new instrument. One hundred and two items were selected from the shortlisted items and reworded into the agreed standardised format. Three items were created by combining two or more shortlisted items to create one item. These items included combining 'small print' and 'reading labels on packets' under the reading category, 'not noticing other cars until the last moment' and 'changing lanes' under the driving category and 'going out socially' and 'social function' under the social function category. These items were combined to reduce repetition. One new item, 'travelling in a car as a passenger', was added as a result of a suggestion made in the ranking exercise, in response to the driving category (Section 5.3.2.5).

The 102 selected and reworded items which made up the pilot instrument (version one) were largely kept within the previously devised categories. The exceptions were; 'shopping' was moved from the role limitation category to the self-care category, 'dryness' and 'headaches' were moved from the symptoms category to the pain category and 'blurred vision', 'jumping objects' and 'distortion' were moved from the symptoms category to the general vision category. These changes were made as the new categorisation was deemed more appropriate and resulted in the removal of the symptom category heading. Another amendment was made to the pain category which was renamed as the discomfort category due to the inclusion of 'watering' and 'dryness' items. These decisions were made in consultation with the wider research team.

The pilot questionnaire (version one) was constructed of 102 items under 18 categories. The 18 categories were organised in two overarching sections – vision/eyes and functioning, with the two general items separate. All text in the instrument was presented in a san serif typeface (Arial) at 16-point size; which meets the recommendations for producing printed material by Action for Blind People (182). The order and layout of the pilot questionnaire (version one) can be seen in Appendix 2. An analysis page was added at the end of the instrument. The two general items were kept separate but reverse scoring was required to keep the scoring in line with the remainder of the items (higher score = increased impact). A total score would not offer much information at this stage, therefore each category was totalled individually and marked on the graph. This allowed the clinician to quickly identify the areas in which the individual completing the instrument was having difficulty (Figure 5.5).

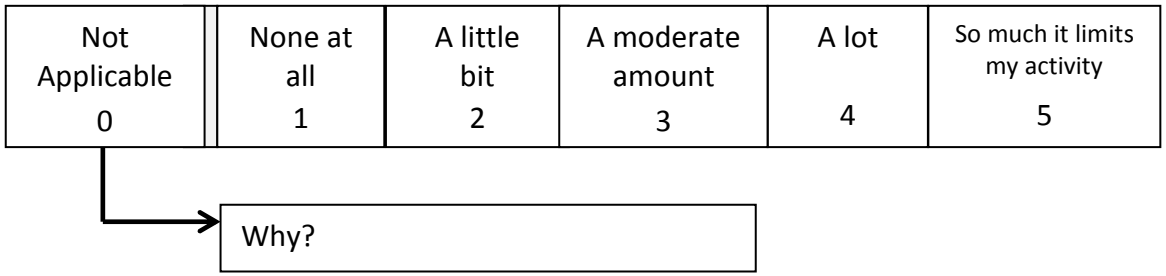


Figure 5.3: Example 5-point rating scale used in the pilot instrument (version one)

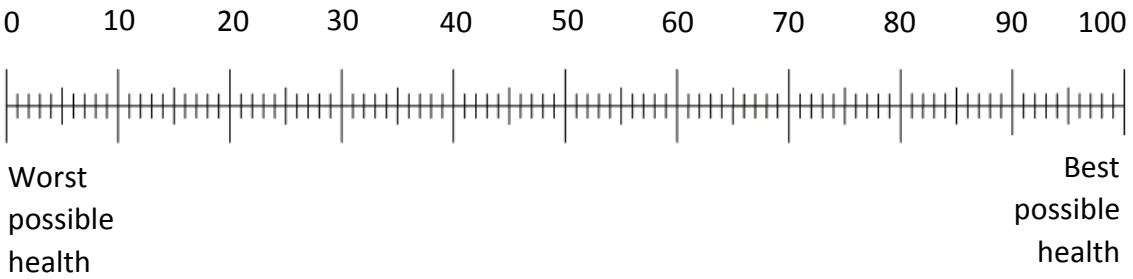


Figure 5.4: Example visual analogue scale used in the pilot instrument (version one).

Table 5.24: Overview of the number items grouped from the database and shortlisted for the new instrument.

		Data base	Short listed
Walking	Steps/curbs	25	3
	Familiar areas	8	1
	Unfamiliar areas	7	1
	Crossing road	14	3
	Indoors	7	2
	Outdoors	13	2
	Uneven ground	3	1
	Trips/falls	6	1
Near vision	Writing	25	3
	Recognising faces	10	3
	Using a mobile phone	11	3
	Finding item	6	1
	Managing money	7	1
	Telling time on a watch	7	2
	Recognising people	30	6
Distance vision	Reading street sign/info boards	30	4
	Orientation	5	1
	Telling time on a clock	4	2
	Identifying correct bus	4	1
Reading	Normal size print	41	3
	Newspaper headlines	8	1
	Small print	25	4
	Reading labels	4	1
	Trouble following lines	2	2

		Data base	Short listed
Travel -ling	Distortion	2	1
	Using public transport	13	4
	Travelling alone	1	1
Television	Watching TV	18	5
	Operating TV	1	0
	Reading text on TV	8	2
	Watching film at the cinema	5	1
	Computer	1	1
Peripheral vision	Noticing objects off to the side	7	6
	People suddenly appearing	2	2
	Missing patches of vision	3	2
	Bumping into things	15	1
Self-care	Pouring liquids	9	1
	Preparing a meal	24	2
	Housework	4	1
	Managing medication	7	1
	Dressing	8	1
	Eating	10	2
	Grooming	22	5
	Toileting	2	1
Lighting	Adjusting to darkness	9	1
	Adjusting to bright light	7	1
	Glare	13	0
	Reduced vision in dim light	11	2
	Reduced vision in bright light	10	2

Driving	Ever driven	7	5
	Difficult conditions	2	1
	At night	5	3
	During the day/familiar	5	3
	Not noticing cars	1	1
	Glare from headlights	4	1
	Changing lanes	1	1
	Parking	2	1
	Deterioration	3	1
Well-being	Worry	8	4
	Frustrated	5	2
	Self-conscious	10	3
	Less control	2	1
	Stressed	2	1
	Isolated	2	1
	Vulnerable	4	1
	Anxious	1	1
	Coping	3	2
	Matching clothes	9	2
Colour	Identifying clothes	10	1
	Variation in colour intensity	2	2
	Pain/discomfort	4	1
Symptoms	Watering	1	1
	Strain	1	1
	Dryness	1	1
	Blurred/Misty/Foggy vision	15	2
	Headaches	1	1
	Jumping objects	2	1
	Haloes	4	1

	General health	4	1
General vision	Rate eyesight	10	1
	Tired eyes	3	1
	Fluctuation in vision	3	2
	Vision equal in both eyes	4	1
	Visiting people	7	2
Social function	Going out socially	14	2
	Entertaining at home	2	1
	Sports/outdoor activities	9	1
	Hobbies	36	2
	Conversation	3	2
	Social functions	3	2
	Dealing with strangers	2	1
	Making new friends	2	1
	Accomplishing less	4	1
Role limitation	Reduced stamina	4	1
	Limited type of activities	7	3
	Reduced confidence	2	1
	Shopping	3	1
	Less opportunities	1	1
	Standard of work	12	1
	Stays at home	1	1
Depen -dency	Need help from others	17	1
	Feel burden on others	6	1
	Closing one eye helps	2	1
Binocular vision	Problems with depth perception	10	1
	Eyes are misaligned	2	2
	Double/multiple images	15	2
	Difficulty picking up objects	2	1

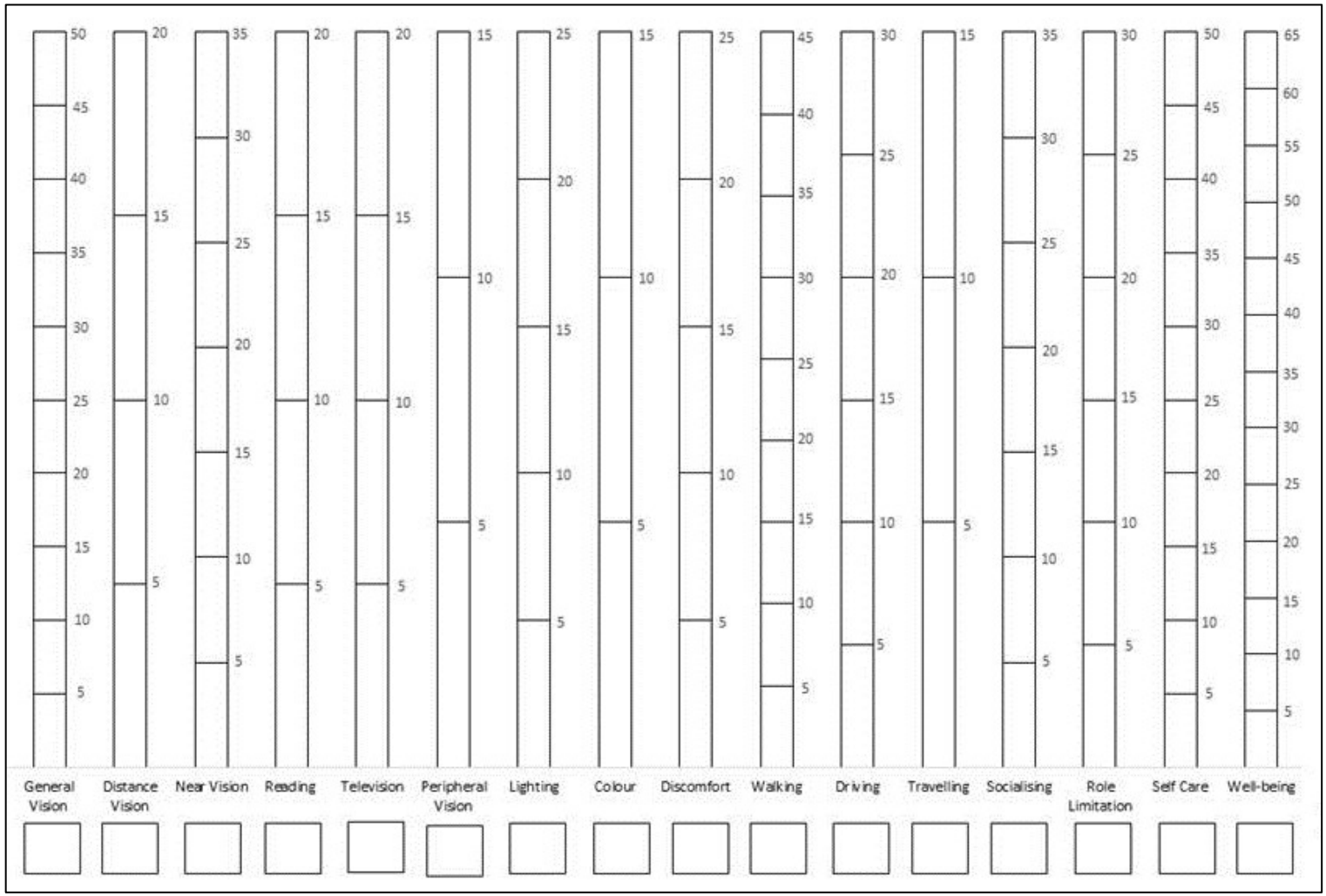


Figure 5.5: The quick analysis page used in the pilot instrument (version one).

Chapter 6

New instrument pilot – version one

6.1: Introduction

The pilot instrument (version one) was developed from a database of items following a ranking exercise completed by stroke survivors and clinicians (Chapter 5).

Pilot work is a crucial element of instrument development. The data collected from pilot testing can be analysed to assess for items which are not appropriate for the population, and highlights items which are unclear to participants (177). Pilot testing is also the best method for providing data to inform item reduction (45, 183).

The aim of this phase of the study was to reduce the number of items within the instrument, to improve its usability and reduce its burden.

6.2: Methods

This study prospectively piloted the new instrument (version one). Participants were recruited in two different ways, (a) acute stroke survivors with stroke related visual impairment were recruited through NHS hospitals (Section 6.2.1) and (b) long-term stroke survivors with stroke related visual impairment were recruited through voluntary sector channels (Section 6.2.2). Both participant groups were asked to complete version one of the new instrument along with a feedback form. The feedback form (Figure 6.1) aimed to collect the views of the participants on completing the questionnaire.

Are the instructions on how to complete the questionnaire clear? Yes ☐ No ☐
Do you think any of the questions are repetitive? Yes ☐ No ☐ If yes, which ones?
Could any questions be removed or combined? Yes ☐ No ☐ If yes, which ones?
How long did it take you to complete the questionnaire? …….minutes
Would you change the response scale? Yes ☐ No ☐ If yes, how?
Were any questions upsetting or inappropriate? Yes ☐ No ☐ If yes, which ones?
Other comments?

Figure 6.1: Feedback form for version one of the new instrument

6.2.1: Acute stroke survivors

Ethical approval was granted by the West of Scotland Research Ethics Service (REC reference: 14/WS/0090).

Patients were offered a routine clinical screen for visual problems following a stroke on three acute stroke units (Aintree University Hospital, Salford Royal Hospital and Warrington General Hospital).

The following inclusion and exclusion criteria were used to identify suitable participants to complete the questionnaire.

6.2.1.1*: Inclusion criteria*

- 18 years of age or older
- Clinically or radiologically confirmed stroke (ischaemic or haemorrhagic)
- Stroke related visual impairment
- Ability to agree to completion of the questionnaire using verbal or non-verbal indications of agreement

6.2.1.2*: Exclusion criteria*

- Younger than 18 years of age
- Severe cognitive impairment preventing use of questionnaire
- Unable to provide consent

6.2.1.3*: Recruitment*

All individuals admitted following an acute stroke episode were identified using the stroke unit admission book. All stroke survivors were offered routine visual assessment as soon as clinically appropriate (Section 6.2.1.4). This assessment was carried out by an orthoptist, as per national guidelines, to determine whether stroke-related visual impairment was present (184). Stroke survivors identified as having visual impairment were followed-up and managed as per national guidelines and local protocols (185). As the study was being conducted within existing services, local protocols may have been used to provide more specific guidance on treatment options and appointment intervals available for use in the local department.

Stroke survivors identified as having a visual problem were provided with a participant information sheet; available in standard and aphasia friendly formats. Once finally satisfied with all information, they were approached to complete and sign the consent form, also available in standard and aphasia friendly formats.

Following receipt of informed consent, the participant was given the questionnaire to complete. The questionnaire could be administered by either self-completion or interview.

6.2.1.4*: Clinical assessment*

A routine visual assessment was completed prior to receiving consent.

The visual assessment consisted of several elements:

- Case history: visual symptoms and observations
- Visual acuity test at near and distance: LogMAR or Cardiff grating cards
- Reading ability: Radner reading chart
- Cover test
- Ocular movements: smooth pursuit, saccades and convergence
- Binocular vision: simultaneous perception, fusion and stereoacuity
- Visual fields: confrontation, kinetic or static perimetry
- Visual inattention: line bisection, clock drawing and cancellation test
- Visual perception

This data was recorded on the case report forms from the hospital notes after consent was received.

6.2.2: Longstanding stroke survivors

Ethical approval was granted by the University of Liverpool Institute of Psychology, Health and Society Research Ethics Committee (Reference: IPHS-14145-040).

6.2.2.1*: Recruitment*

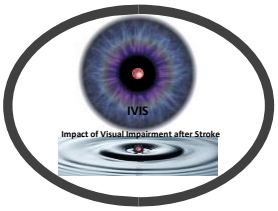
The recruitment announcement was circulated via patient and public forums, including Connect, Speakability, Stroke Association, North West Stroke Research Network consumer

reference panel, Royal National Institute of Blind People (RNIB), North West People in Research forum and local patient involvement groups. The advert provided outline information about the study and contact details (Figure 6.2). Interested individuals could contact the research team via telephone, email or post.

The inclusion and exclusion criteria were the same as the acute recruitment criteria outlined in Sections 6.2.1.1 and 6.2.1.2.

Interested individuals were sent a participant information sheet and the questionnaire. Informed written consent was not sought. If the participant chose to complete the questionnaire, the completion was deemed indicative of the individual's informed consent.

HAVE YOU SUFFERED A STROKE?



HAVE YOU GOT VISUAL PROBLEMS AS A RESULT?

WOULD YOU LIKE TO HELP?

Volunteers are required to help with a study to assess the impact of visual problems after stroke.

You are invited to take part in this study which aims to ask how visual problems after stroke affect the daily life of stroke survivors.

If you kindly agree to take part we would like you to complete a questionnaire. The questionnaire is being developed so we can use this in the future to find out how visual problems after stroke affect quality of life. The questionnaire takes about 15 minutes to complete.

If you would like to help us with this research study please email me at the following address and I will be in contact with more information.

Figure 6.2: Advert for recruitment of longstanding stroke survivors

6.2.2.2*: Clinical information*

In the absence of a clinical examination, participants were asked to complete key background detail questions including date of birth, approximate date of stroke, visual symptoms and visual diagnosis if known.

6.2.3: Sample size

As items were selected from a wider pool, rather than using a theoretical underpinning, a larger sample size was required to enable the detection of problematic items. Sample size for Rasch analysis is based upon item calibration stability. To achieve item calibration stability within ±0.5 logit based on a 99% confidence interval, for a potentially poor targeted instrument, a sample size of 243 subjects is reported as the sample requirement (186).

6.3: Results

Following 12 months of recruitment (July 2014 to June 2015) there was a 71.2% (n=37/52) return rate. This is broken down to 26 acute and 11 long-term stroke survivors, who completed and returned the questionnaire from 41 acute (63.4% response rate) and 11 long-term (100% response rate) participants recruited. The wider research team took the decision that the lack of recruitment was partially due to the large number of items within the instrument and the burden this created. Due to the lack of numbers, Rasch analysis was not possible at this stage. In view of this, a first round item reduction was required to increase subsequent recruitment to the pilot study.

Simple item analysis was conducted, focusing on the spread of responses to identify items with large floor and ceiling effects, not applicable responses and inter-item correlation to identify any potential redundancy. An inter-item correlation matrix was constructed using SPSS, to allow comparison between each item within the instrument (187). Only a high inter-item correlation (>0.8) would be considered at this stage. Items with such high inter-item correlation is suggestive that the items are in effect duplications of the same question (177). The scores created by the instrument are ordinal, although it is common for such scores to be treated as interval data (188). It cannot be guaranteed that each adjacent score is equally spaced from each other as in an interval scale, potentially creating misleading results (188, 189). The decision was therefore taken not to conduct any statistical analysis on the raw score data of the two general items, other than the percentage of missing data.

Transformation to interval data is possible once fit to the Rasch model has been achieved, allowing meaningful parametric statistics to be undertaken (190).

The aim of this analysis was to identify items which could be removed from the instrument reducing the burden to participants. It must be considered that the participants who completed version one may be of slightly higher functioning ability. Although ceiling effects and not applicable responses were considered, these items may be important in future versions for lower functioning participants. It is important to maintain a range of item difficulty to increase the likelihood that the instrument will be able to distinguish between different levels of quality of life (45).

6.3.1: Participants

6.3.1.1*: Returned questionnaire*

Of the acute stroke survivors who returned a completed questionnaire 69.2% (n=18) were male and the mean age at the time of recruitment was 67.5 years (SD 10.5). The mean number of days since stroke onset at the time of recruitment was 24.2 days (SD 25.8). The mean number of days since stroke onset at the time of completion was 34.2 days (SD 33.6). It took a mean number of 10.2 days (SD 16.3) for participants to complete the questionnaire.

The mean Barthel Index score at stroke onset as an indication of stroke severity was 16.4 (SD 4.9), indicating a moderate dependency on average: the poorest score being 0 (total dependence) and the best score being 20 (independent) (191, 192). Of the stroke survivors recruited in the acute phase, 61.5% (n=16) were inpatients when recruited and 38.5% (n=10) were outpatients.

Seventy-seven percent (n=20) of the acute survivors who returned a questionnaire had two or more visual impairments. The most common number of co-existing visual impairments in this group was three (34.6%). The numbers and types of visual impairment are outlined in Table 6.1. Thirty-four percent did not complain of any specific visual symptoms related to their visual impairment. The most commonly reported symptom was visual field loss (38.5%, n=10) followed by diplopia (26.9%, n=7).

Table 6.1: Types of visual impairment in acute stroke survivors returning a questionnaire

Visual impairment	n (%)
Ocular motility defect	22 (84.6)
Visual field loss	11 (42.3)
Ocular alignment defect	10 (38.5)
Central vision loss	10 (38.5)
Visual perception problems	3 (11.5)
Visual inattention	2 (7.7)

6.3.1.2*: Did not return questionnaire*

Of the acute stroke survivors who did not return a questionnaire 66.7% (n=10) were male and the mean age at time of recruitment was 65.3 years (SD 14.9). The mean number of days since stroke onset at time of recruitment was 19.7 days (SD 18.9).

The mean Barthel Index score at stroke onset as an indication of stroke severity was 11.9 (SD 6.5), indicating a severe dependency on average (191). Of the stroke survivors recruited in the acute phase, 80.0% (n=12) were inpatients when recruited and 20.0% (n=3) were outpatients.

Eighty-seven percent (n= 13) of the acute survivors who did not return a questionnaire had two or more visual impairments. The most common number of co-existing visual impairments in this group was three (46.7%). The numbers and types of visual impairment are outlined in Table 6.2. Forty-seven percent did not complain of any specific visual symptoms related to their visual impairment. The most commonly reported symptoms were blurred, altered or reduced vision (40%, n=6) and diplopia (40%, n=6) followed by visual field loss (20%, n=3).

Table 6.2: Types of visual impairment in acute stroke survivors not returning a questionnaire

Visual impairment	n (%)
Ocular motility defect	12 (80.0)
Central vision loss	10 (66.7)
Visual field loss	6 (40.0)
Ocular alignment defect	5 (33.3)
Visual inattention	2 (13.3)
Visual perception problems	1 (6.7)

6.3.1.3*: Comparing groups*

The two groups of participants (those who returned and those who did not) are similar in terms of age at the time of stroke (67.5 years versus 65.3 years) and have similar gender splits (69.2% versus 66.7% male).

Four areas of difference were identified between the two groups; timing of recruitment post-stroke, location at time of recruitment, stroke severity and symptoms reported. The non-returning group were recruited a mean of 4.5 days earlier after stroke than the returning group. A higher proportion of the non-returning group were inpatients when recruited than the returning group (18.5% difference). The non-returning group had a lower mean score on the Barthel Index indicating a higher level of dependency (4.5 points difference) than the returning group. More of the non-returning participants reported no symptoms associated with their visual impairment than the returning participants (13% difference).

The differences found between the returning and non-returning participants could have potentially contributed to the non-return of questionnaires. These factors would be investigated in more detail with a larger sample size following the version two pilot.

6.3.2: Response frequency

The response frequencies are portrayed visually in Figure 6.3. Items 56 to 63 were not present in this analysis as, due to the logic navigation from item 55 to item 61, if the participant responded ‘never driven’ or ‘given up driving’, these items were not answered by any participant.

6.3.2.1*: Missing data*

A small amount of missing data was present across 32 of the 102 items within the instrument. Of those items which had missing data, the maximum proportion was 8.1% (n=3) in one item ‘travelling alone’. Missing data for all items was under the acceptable level of <10% (193). Regardless, the cause of any missing data should be investigated to assess the potential for introduction of bias, whether the data is missing at random or not missing at random (194). This is discussed further in the not applicable analysis (Section 6.3.3.8), which may indicate that this data was not missing at random, but instead the participants did not understand the question and therefore left it blank. For the item which had the largest amount of missing

data it is unclear whether this was random or not. Missing data was present for the last ten items of the instrument which may be due to a fatigue effect.

6.3.2.2*: Floor and ceiling effects*

Floor and ceiling effects are a result of a significant proportion of participants scoring items as either the minimum or maximum respectively. The figures used to describe the presence of a floor or ceiling effect varied widely, ranging from ≥15% to ≥80% using the minimum or maximum score (195, 196). Floor and ceiling effects result in the instrument being unable to accurately measure a participant's level of trait (e.g. quality of life) when at the extreme ends of the scale (196).

There appeared to be floor effects within the colour category (items 38 to 40) with the percentage response as option 1 'none at all' ranging from 62.2% to 75.7% across the three items. Also within the self-care category, eight of the ten items (excluding 'household chores' and 'shopping') had floor effects ranging from 62.2% to 78.4%. The largest ceiling effect was found in item 55 'ever driven'; 54.1% responded choosing the maximum score equivalent to 'so much I can't do this activity', the only other option chosen for this item was equivalent to not applicable. The remaining items used the full range of responses.

6.3.2.3*: Not applicable option*

Within this version, the option of 'not applicable' was given. This option was used across 91 of the 100 items with 5-point rating scales. The percentage use of the not applicable option for each item can be visualised in Figure 6.3. The scoring systems of some instruments would treat this as missing data, for example the NEI VFQ-25 (155). Twenty-four of the items had not applicable response rates which would breach the acceptable level of missing data of <10% (193). Six of these items were slightly over the acceptable level at 10.8%; four items had a 13.5% not applicable response rate. A further six items had a 16.2% not applicable response rate. These include; items 17 'doing work and hobbies', 20 'telling time on a wristwatch', 37 'noticing haloes', 53 'walking outdoors', 76 'limiting opportunities' and 77 'working to usual standards'. All items within the travelling categories had high not applicable ratings ranging from 24.3% to 29.7%. A further five items had higher not applicable response rates; the highest being item 55 'ever driven' with 43.2%, followed by item 28 'watching a film at the cinema' with 37.8%, item 29 'using a computer' with 27.0%, item 70 'outdoor

activities' with 24.3% and item 13 'reading bus numbers' with 18.9%. The reasons for the use of the not applicable option will be discussed further in Section 6.3.3.

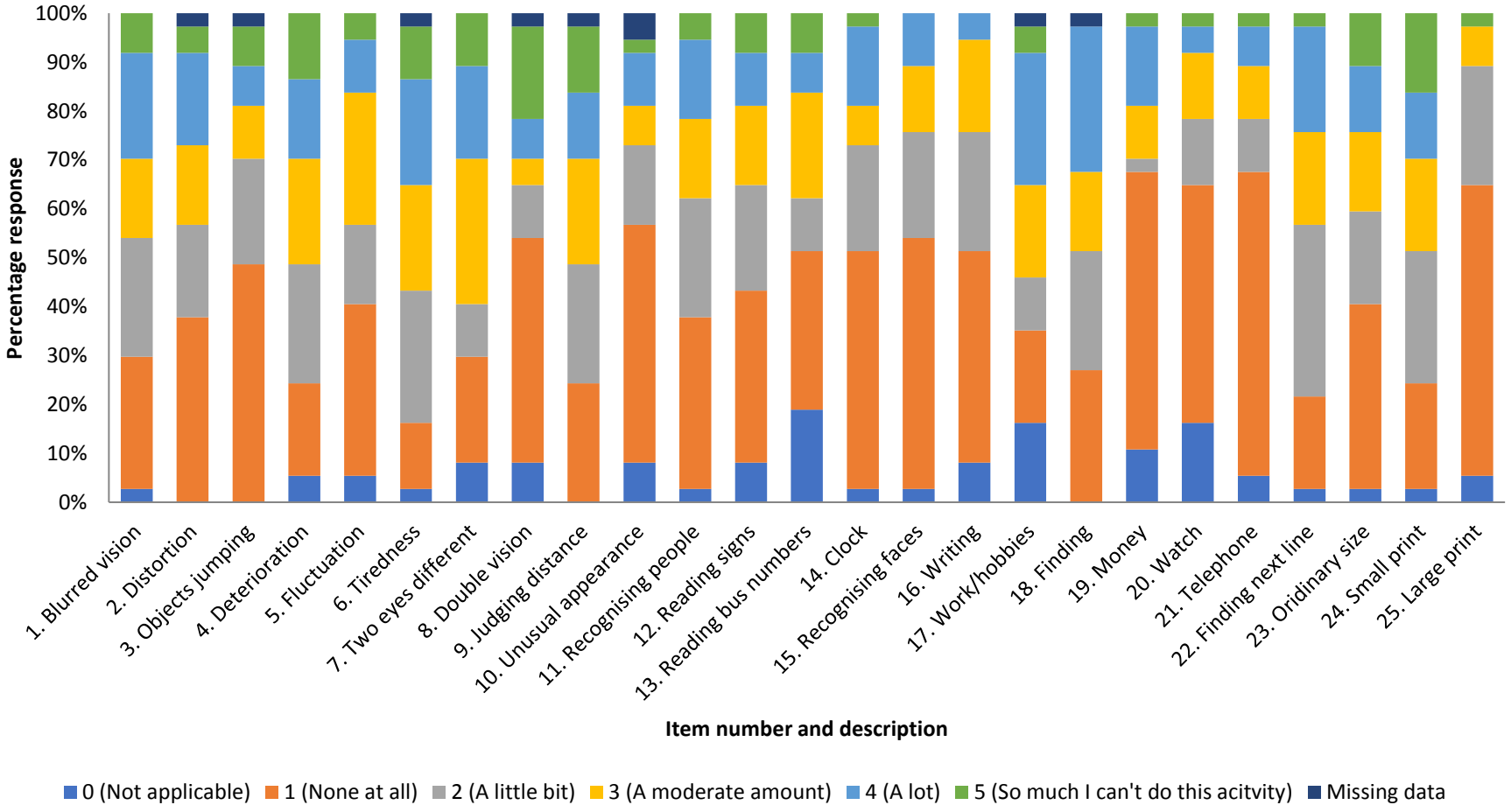
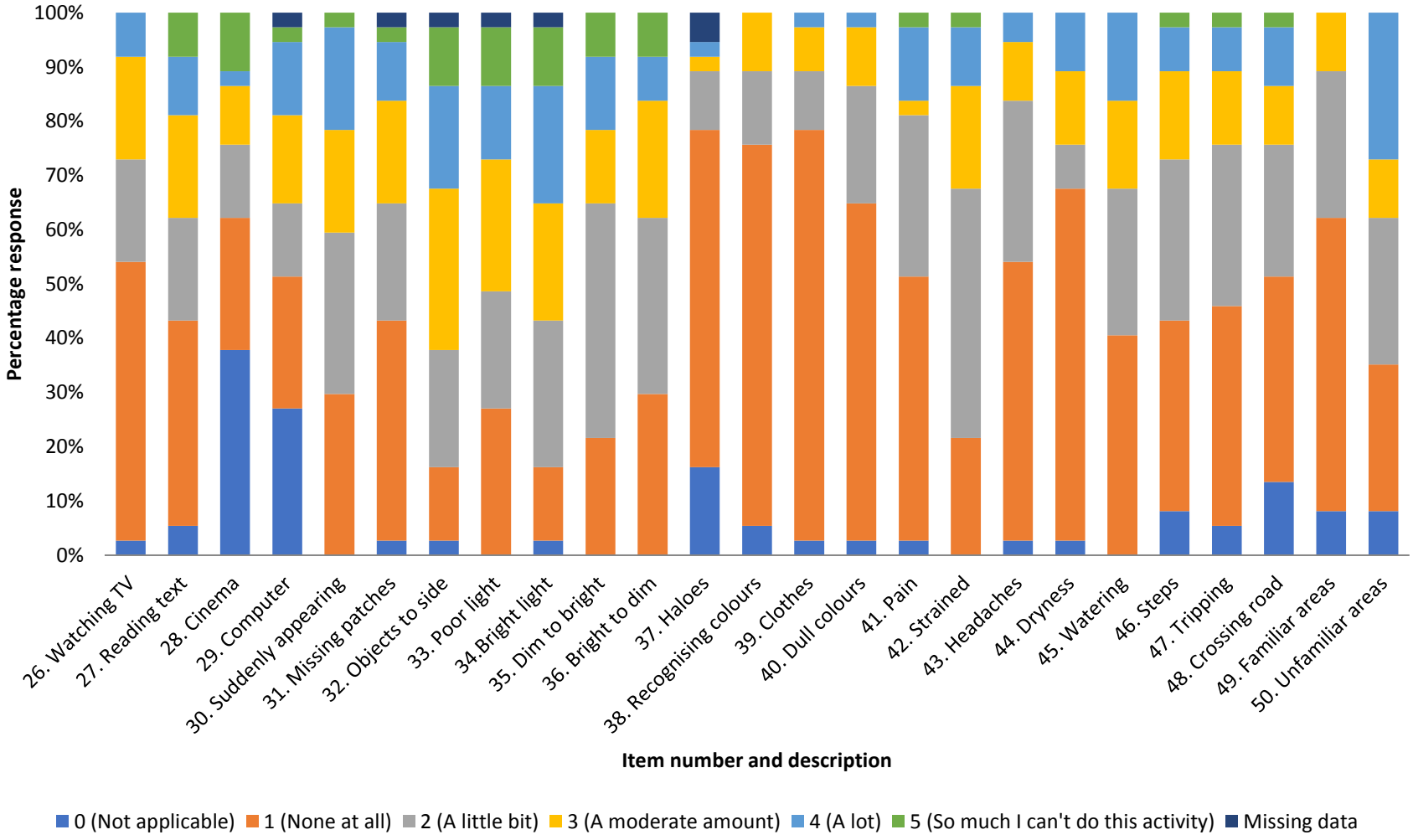
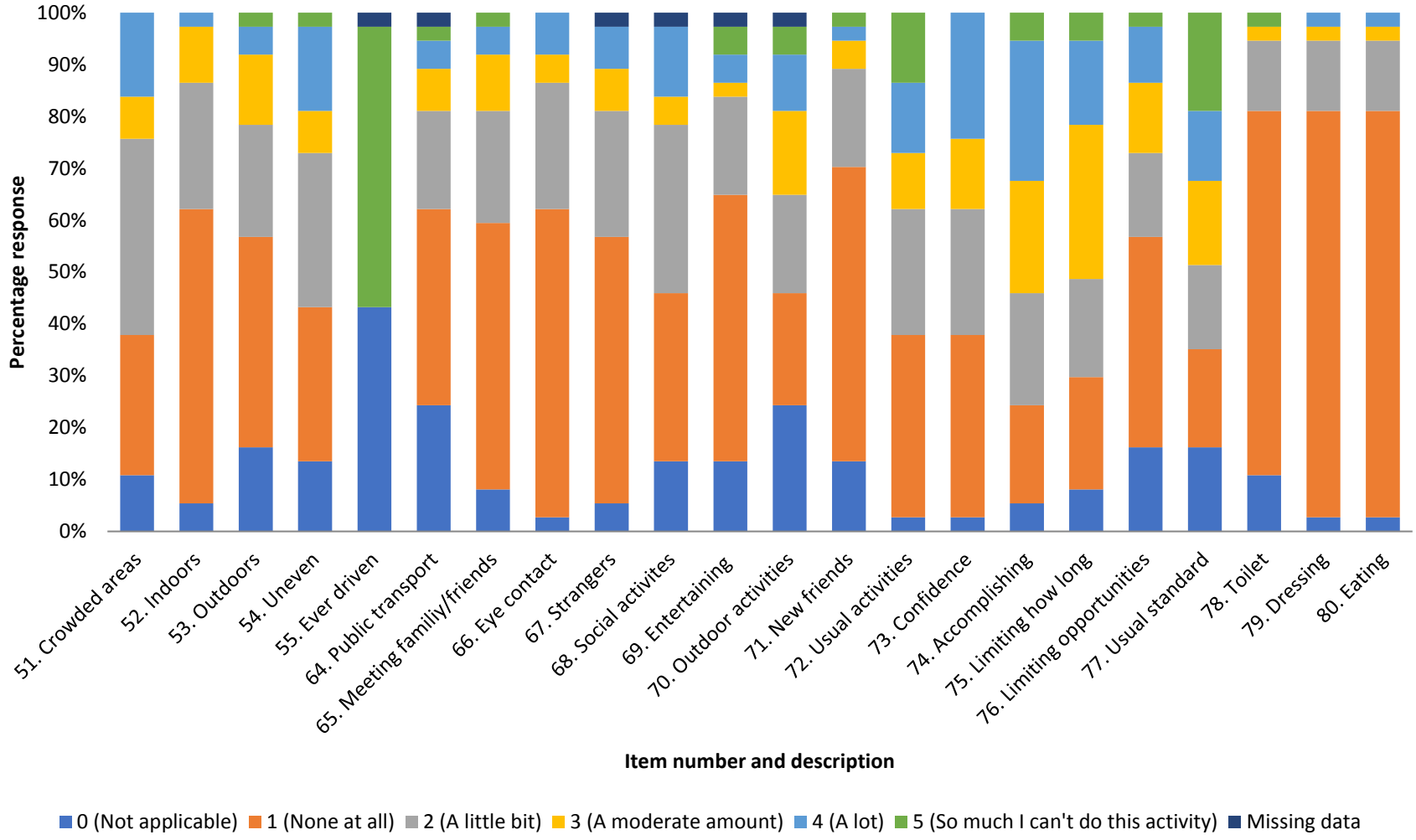
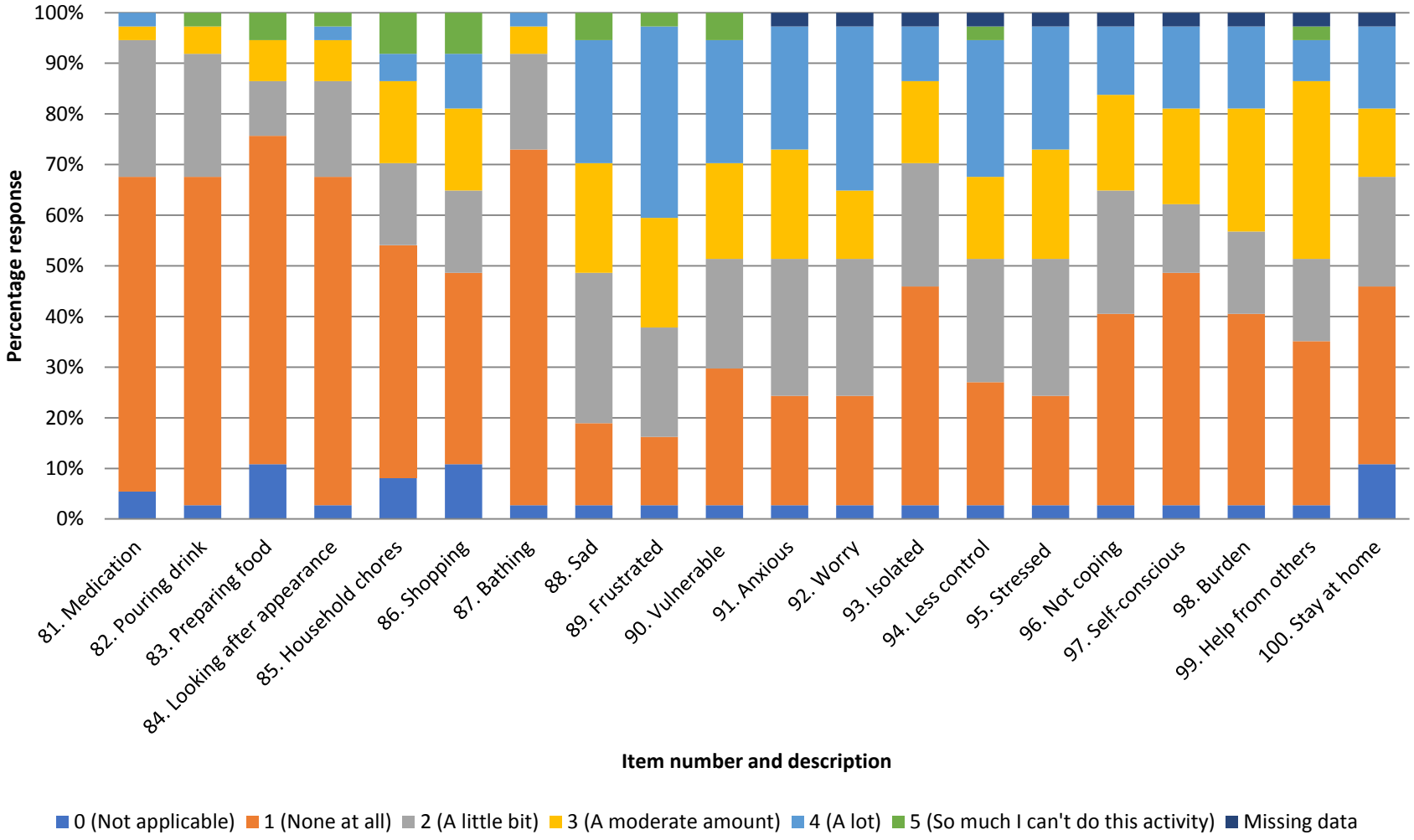


Figure 6.3: Percentage of response rating use across each item


100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
Percentage response
26. Watching TV
27. Reading text
28. Cinema
29. Computer
30. Suddenly appearing
31. Missing patches
32. Objects to side
33. Poor light
34.Bright light
35. Dim to bright
36. Bright to dim
37. Haloes
38. Recognising colours
39. Clothes
40. Dull colours
41. Pain
42. Strained
43. Headaches
44. Dryness
45. Watering
46. Steps
47. Tripping
48. Crossing road
49. Familiar areas
50. Unfamiliar areas
Item number and description
0 (Not applicable)
1 (None at all)
2 (A little bit)
3 (A moderate amount)
4 (A lot)
5 (So much I can't do this activity)
Missing data


100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
Percentage response
51. Crowded areas
52. Indoors
53. Outdoors
54. Uneven
55. Ever driven
64. Public transport
65. Meeting family/friends
66. Eye contact
67. Strangers
68. Social activites
69. Entertaining
70. Outdoor activities
71. New friends
72. Usual activities
73. Confidence
74. Accomplishing
75. Limiting how long
76. Limiting opportunities
77. Usual standard
78. Toilet
79. Dressing
80. Eating
Item number and description
0 (Not applicable)
1 (None at all)
2 (A little bit)
3 (A moderate amount)
4 (A lot)
5 (So much I can't do this activity)
Missing data


100%
90%
80%
70%
60%
50%
40%
30%
20%
10%
0%
Percentage response
81. Medication
82. Pouring drink
83. Preparing food
84. Looking after appearance
85. Household chores
86. Shopping
87. Bathing
88. Sad
89. Frustrated
90. Vulnerable
91. Anxious
92. Worry
93. Isolated
94. Less control
95. Stressed
96. Not coping
97. Self-conscious
98. Burden
99. Help from others
100. Stay at home
Item number and description
0 (Not applicable)
1 (None at all)
2 (A little bit)
3 (A moderate amount)
4 (A lot)
5 (So much I can't do this activity)
Missing data

6.3.3: Reasons for using the not applicable option

In cases where the item was not applicable to the participant, they were asked to state the reason the item was not applicable. The comments provided were coded using NVivo qualitative analysis Software, Version 10 for Windows (197). From both the acute and long-term stroke survivors a total of nine codes emerged; do not do this activity, not tried this activity yet, still an inpatient, can do with help, do not experience this problem, problem caused by other difficulty, not working, adaptation and did not understand the question. The number of times each code was used across the whole instrument and the usage of acute versus long-term stroke survivors are outlined in Table 6.3.

Table 6.3: Codes which emerged from the reason items were not applicable and the number of times used across the whole instrument by number of participants

Code	Times used	Participants	
		Acute	Long-term
Don't do this activity	73	18	2
Not tried this activity yet	41	9	1
Still an inpatient in hospital	31	5	-
Can do with help	26	4	2
Do not experience this problem	23	7	4
Problem caused by other difficulty	18	3	2
Not working or retired	11	7	-
Adaptation	8	2	1
Didn't understand the question	8	6	1

6.3.3.1*: Do not do this activity*

Not all activities in the instrument are applicable to everyone at all stages of stroke. The most commonly used (n=73) reason for an item not being applicable to the participant was that they did not do the activity in question. This code was used for 23 separate items within the instrument; 11 items had single uses and a further five items had two uses of this code. The two items most commonly not done by participants were 'watching a film at the cinema' (n=14) and 'using a computer' (n=15). Other items which received multiple uses of this code were; 'telling time on a wristwatch' (n=6), 'travelling somewhere alone' (n=6), 'using public transport' (n=4), 'taking part in outdoor activities' (n=4) and 'preparing something to eat' (n=3). Acute stroke survivors were the predominant users of this code; it was used four times by long-term stroke survivors across four different items.

6.3.3.2 *Not tried this activity yet*

Due to the process of rehabilitation following stroke some activities may not yet have been attempted especially during the acute phase. This code was used for 22 separate items within the instrument; 13 items had single uses and a further four items had two uses of this code. The item most commonly not yet tried by participants was 'watching a film at the cinema' (n=5). Other items which received multiple uses of this code were; 'walking on uneven ground' (n=3), 'travelling somewhere alone' (n=3), 'using public transport' (n=3) and 'taking part in outdoor activities' (n=3). The items which commonly used this code are similar to those which used the do not do this activity code. This code was used only once by a long-term stroke survivor, highlighting the possibility this code was used due to the rehabilitation process within the acute phase. It may be that some participants reported doing the activity but this does not reveal if they wish to return to doing it or they were not interested in the activity prior to their stroke.

6.3.3.3*: Still an inpatient*

As participants were recruited within the acute phase it was possible they had not yet experienced their visual impairment outside of the ward setting and therefore were unable to comment on some activities. This code was used for 20 separate items within the instrument; 13 items had single uses and a further five items had two uses of this code. The items most commonly prevented by being an inpatient were 'stay at home' (n=3) and 'reading bus numbers' (n=3). This code was not used by any long-term stroke survivors.

6.3.3.4*: Can do the activity with help*

Due to the process of rehabilitation following stroke some participants may still need to be aided in doing some activities during the acute and long-term phases. However, it has to be considered that some individuals may be happy to accept help without it impacting on quality of life whereas that loss of independence may have a significant impact on others. This code was used for 18 separate items within the instrument; 11 items had single uses and a further six items had two uses of this code. The item most commonly completed with help was 'crossing the road' (n=3). Acute stroke survivors were the predominant users of this code; it was used twice by long-term stroke survivors across two different items.

6.3.3.5*: Do not experience the problem*

Due to the varied nature of visual impairment following stroke not all items would be applicable to every participant. This code was used for 18 separate items within the instrument; 15 items had single uses and a further three items had two uses of this code. In these cases it was expected for the participant to choose the 'none at all' option. It is clear from the number of participants (n=11) who reported this not applicable reason that the instruction was not clear or the appropriate options were not available.

6.3.3.6*: Problem caused by other difficulties*

Stroke commonly causes additional impairment and/or participants may have pre-existent co-morbidities. This code was used for eight separate items within the instrument primarily across two categories 'reading' and 'walking'. Five items were single uses and a further three items had two uses of this code. The other disabilities reported were wheelchair use, dyslexia and colour-blindness.

6.3.3.7*: Not working or retired*

This code was used for four separate items within the instrument. One item had a single use and a further two items had two uses of this code. The item most commonly not applicable was because the participant was not working 'doing your usual work to your usual standard' (n=6). It is apparent from the number of participants (n=7) who reported this not applicable reason that the instructions were not clear that these items do not necessarily relate to formal employment but instead an individual's usual activities.

6.3.3.8*: Did not understand the question*

This code was used for four separate items within the instrument. Three items had single uses of this code. The item most commonly not understood was 'noticing haloes' (n=4). This provides evidence where clarification on some items was required.

6.3.3.9*: Adaptation*

Through the rehabilitation process individuals adopt mechanisms which allow them to adapt to a deficit over time and allowing normal functioning. This code was used for six separate

items within the instrument; the items most commonly adapted to were 'crossing the road' and 'telling time on a watch', both of which had two uses and a further four items had a single use of this code.

6.3.4: Participant feedback

Of those who completed the pilot instrument (version one), 15 participants (40.5%) also returned the feedback form. Five of the returned forms were incomplete, however, all responses were analysed.

The majority (73.3%, n=11) reported that the instructions were clear. One comment regarding the clarity of the instructions highlighted the importance of making it explicit that the items ask about changes in eyesight after stroke rather than old age or pre-existing problems.

There was an equal spilt view on whether the instrument had repetitive items. One participant was irritated by the repetition of the instructions "due to your eyes and eyesight" and also felt the items 'toileting' and 'personal hygiene' were asking the same thing. Two participants reported the items within the well-being section to be repetitive. One participant reported that the 'missing patches' item had potentially already been covered. Another participant suggested three of the reading items, 'ordinary sized print', 'small print' and 'large print' could be combined.

The majority (66.7%, n=8) reported that no change was required to the scale. Of those that reported the scale should be changed the comments included, "a little bit and moderate are hard to define" and the suggestion of the addition of a new option "can do this activity aided" between options 4 (a lot) and 5 (so much I can't do this activity).

All, with the exception of one individual (92.3%, n=12) reported no upsetting items within the instrument. This participant did not specify which item(s) they found upsetting.

Three comments were made in the general comments section; one related to the wording of a specific item ('limiting opportunities') and one related to the timing of completing the instrument during the acute phase and having not tried many of the activities asked about. The final comment highlighted the first item in the driving section needed further sign-posting depending on the answer given.

6.3.5: Nominal group technique session

The data from the item analysis was provided to participants in a nominal group technique session to make decisions on which items could be removed and the future formatting of version two. The nominal group technique was first developed in the 1960s to improve the process of group decision making (198). A key element of nominal group technique is that participants meet in person. This allows for time efficient decision making (199).

Traditionally in nominal group technique participants would have time during the face-to-face meeting to generate ideas in silence. It was decided that, due to the lengthy nature of the information being provided, the information would be sent prior to the meeting to allow participants to consider this at a time to suit them. The process of the meeting, following an introduction, would use the following steps for each item within the instrument:

1. Idea sharing
2. Group discussion and clarification
3. Decision agreement

Three stroke survivors, two statisticians and one orthoptist were invited to the meeting. All were sent the frequency tables (displayed graphically in Figure 6.3) and the collated feedback form responses prior to the meeting to allow them to write down their views on the data prior to the meeting. On the day of the meeting two stroke survivors sent apologies that they could not attend. There were a total of five participants who sat in a semi-circular arrangement around a meeting table and refreshments were provided to encourage a relaxed atmosphere (199). The author took the role of facilitator for the meeting.

Each section and item was discussed individually in terms of response frequencies, inter-item correlations, item wording and participant feedback. Written notes were taken during the meeting of issues discussed and decisions made, which are described fully in the following sections. A summary of the changes made are outlined in Table 6.4.

Table 6.4: Summary of changes made to version one to create version two of the new instrument

Version one		Changes Made	Version two	
Section heading	**No of items**		**Section heading**	**No of Items**
General vision	10	• 'Blurred vision' and 'distortion' merged	General vision	9
Distance vision	4	• All items replaced by general distance vision items 'difficulty seeing far side of a room' and 'difficulty seeing far away'	Distance vision	2
Near vision	7	• Wording change in 'recognising faces and seeing facial expressions' to 'seeing faces and facial expressions' • 'Doing work or hobbies', 'identifying coins and bank notes', 'telling time on a watch' and 'using a telephone' replaced by new item 'difficulty with close up vision'. • Addition of 'difficulty using a computer' item from television section	Near vision	5
Reading	4	• 'ordinary print' 'small print' and 'large print' items replaced by 'reading same size print as before'	Reading	2
Television	4	• 'Watching television' and 'reading text on television' removed used as example for 'difficulty seeing far side of a room' item in distance vision section • 'Watching a film at the cinema' removed • 'Difficulty using a computer' item reworded and moved to near vision section	-	Section removed
Peripheral vision	3	No changes made	Peripheral vision	3
Lighting	5	• 'Adjusting to brightness from dim light' and 'adjusting to darkness from bright light' combined to create 'adjusting to differing lighting' • 'Haloes' item removed • Addition of 'change in colour' from colour section	Light	4
Colour	3	• All items replaced by 'change in colour' item • 'Change in colour' item moved to light section	-	Section removed

Version one		Changes Made	Version two	
Section heading	**No of items**		**Section heading**	**No of Items**
Discomfort	5	• 'Pain and discomfort', 'headaches and 'eyes feeling strained' items removed	Discomfort	2
Walking	9	• 'Steps, curbs and stairs' item combined with 'uneven ground' item • 'Tripping and falling' and 'bumping into' items reworded • Walking replaced by moving around in all items • Addition of 'travelling as a passenger' item from travelling section	Moving around	9
Driving	7	• All items removed	-	Section removed
Travelling	3	• 'Travelling alone' and 'using public transport' items removed • 'Travelling in a car as a passenger' reworded and moved to moving around section	-	Section removed
Socialising	7	• 'Visiting family and friends', 'entertaining in your home' and 'making new friends' items removed • Wording of the 'social activities' and the 'outdoor activities' items combined to create two items, 'indoor social activities' and 'outdoor social activities'.	Socialising	4
Role limitations	6	• 'Performing usual activities' and 'people limiting your opportunities' items removed • 'Doing usual work to usual standard' and 'limit of how long you can work' reworded	Role limitations	4
Self-care	10	No changes made	Independent living	10
Well-being	13	• 'Feeling sad and low', 'frustrated', 'anxious', 'worry', 'feeling isolated', 'feeling less control' and 'stressed' combined into one item 'negative emotions' • 'Feeling a burden' and 'needing help from others' combined into one item, 'feeling a burden'	Well-being	6

6.3.5.1*: General vision*

Two high inter-item correlations were found within this section:

‘blurred vision’ ——— ‘distortion’ (0.801)

‘objects jumping around’ ——— ‘double vision’ (0.813)

In the discussion regarding ‘blurred vision’ and ‘distortion’, it was agreed to remove the item on ‘distortion’ as the former would cover a broader range of changes in vision. Regarding the second correlation, no changes were made as both user and clinical judgements deemed these to be unrelated.

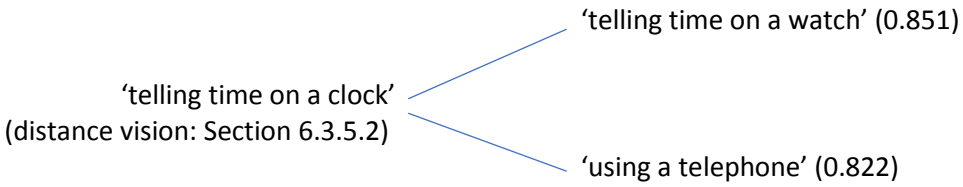
Whilst discussing this section comments were made relating to the ‘eyes tired’ item. It was debated that it may be difficult to differentiate between ocular and neurological fatigue. No actions were taken based on this comment, however it was noted and will be considered in future stages.

6.3.5.2*: Distance vision*

No high inter-item correlations were found. The discussion in this section related to two items which referred to very specific tasks: ‘bus numbers’ and ‘telling time on a clock’. In addition to this, ‘bus numbers’ featured with a high ‘not applicable’ response in relation to still being an inpatient in hospital. User and clinical delegates judged these two items to be too specific with general questions being more appropriate. This resulted in all four items being replaced by two general distance vision items; one relating to seeing the distance across a room and the other to seeing much further away. Examples were included within the two new items which related to the previous items of ‘recognising people’ and ‘reading street signs’.

6.3.5.3*: Near vision*

Two high inter-item correlations were found between two items in this section and an item from the distance vision section:



No action was taken for these correlations as clinically they are assessing different activities.

Discussion initially focused on the wording of the 'recognising faces and seeing facial expressions'. This item has two focus points which render it difficult to answer. The wording of this question also currently relates to the perceptual problem of prosopagnosia (inability to recognise faces) rather than vision. In view of this the wording of this item was changed to 'seeing faces or facial expressions'.

A similar decision was taken to that made in the distance vision section - the specific task items should be combined into a general near vision item with examples. Two items within this section featured in the analysis as having a high not applicable response rate. Therefore 'doing work or hobbies', 'identifying coins and bank notes', 'telling time on a watch' and 'using a telephone' were replaced by 'difficulty with close up vision'.

The user and clinical delegates also deemed it was important especially in this section to specify that items should be answered based on experience when wearing appropriate glasses correction if required by the participant.

6.3.5.4*: Reading*

No high inter-item correlations were found. The discussion in this section focused on the items relating to ability to see different sizes of print 'ordinary' 'small' and 'large'. On the basis that it is possible for the target population of stroke survivors to have pre-existing ocular conditions these items do not isolate the impact of stroke related visual impairment on reading. A suggestion was made on the participant feedback form to combine these three items. The decision was made to replace these three items with one item asking about ability to read the size of print they were previously able to read prior to the stroke.

6.3.5.5*: Television*

No high inter-item correlations were found. Through discussion it was decided that items 'watching television' and 'reading text on television' were linked to the new item in the distance section (Section 6.3.5.2) 'seeing something on the far side of a room'. It was therefore decided to discard these two items and use watching TV as an example for the 'seeing something on the far side of a room' item.

The 'watching a film at the cinema' was removed due to the high number of participants who reported this as not applicable (26.9%). The 'using a computer' item also had a high not applicable response rate (19.2%). However, it was considered important to leave this item within the instrument as it will likely become more relevant in the future. Furthermore, the item 'using a computer' was judged to sit well within the near vision section (Section 6.3.5.3) with the addition of laptop or tablet to bring the item up to date with use of modern technology. This resulted in the television section becoming redundant.

6.3.5.6*: Peripheral vision*

No high inter-item correlations were found. All delegates agreed with the items within this section so no changes were required.

6.3.5.7*: Lighting*

One high inter-item correlation was found:

'adjusting to brightness from dim light' ——— 'adjusting to darkness from bright light' (0.810)

It was decided to combine these two items into one item 'adjusting to differing lighting', with examples based on the original items.

The 'haloes' item had a significant floor effect with 44.2% of participants reporting no problem at all and a further 11.5% reporting this as not applicable. It is clear from the reasons written for choosing the not applicable option that the term halo was not understood by all participants. The whole group decided to remove this item.

6.3.5.8*: Colour*

One high inter-item correlation was found:

'recognising colours' ——— 'picking and matching clothes' (0.842)

All items within this section were discussed as having large floor effects. As in the reading section (Section 6.3.5.4), it is the impact of any change in colour perception since a stroke which should be captured rather than pre-existing colour vision defects. A pre-existing colour vision defect was reported in the not applicable reasons. It was therefore decided to replace the three existing items with a 'change in colour' item leaving this section with one item. As this item could fit within the light section (Section 6.3.5.7), the colour section was disbanded.

6.3.5.9*: Discomfort*

No high inter-item correlations were found. Discussion focused on the relevance of all five items to the target population. The 'pain and discomfort' and 'headaches related to vision' were discussed as not being related directly or easy to differentiate to vision or ocular causes, therefore both these items were discarded. The 'eyes feeling strained' item, although related to vision, could be accompanied by other symptoms which were already covered in the general vision section (Section 6.3.5.1) with the 'blurred vision' item, therefore this item was also discarded. Both the 'dry eyes' and 'watery eyes' remained due to problems linked with facial palsies following stroke.

6.3.5.10*: Walking*

One high inter-item correlation was found:

'walking around outdoors' ——— 'walking on uneven ground' (0.796)

Limited mobility due to other reasons was reported in the not applicable reasons. The wording of this section was therefore questioned, as all items refer specifically to walking. Following a stroke, individuals may not mobilise by walking. This may be done by other means such as wheelchair or mobility scooter. A wording change was discussed; mobilising was thought to be too complicated a word. Thus 'moving around' was chosen to replace 'walking' in all items in this section including the section title. Other wording changes were

made; ‘over objects’ was removed from the ‘tripping and falling’ item and ‘objects and people’ were added to the ‘bumping into’ item for better context.

Two items were combined as user and clinical judgements deemed that ‘using steps, curbs or stairs’ covered a very similar activity as ‘walking on uneven ground’. The new item of ‘moving around on uneven ground’ item had the addition of steps, curbs or stairs as examples.

6.3.5.11*: Driving*

This section had large floor and ceiling effects; all respondents had either never driven, given up driving prior to having their stroke or had given up following their stroke. The latter response group are those that may appreciate an impact on their quality of life, resulting from no longer being able to drive. However, none of the respondents qualified to answer any of the further six items on driving. Thus, these were discarded.

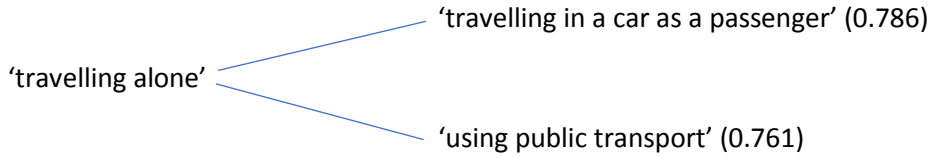
The driving data was pulled from an incomplete research database (n=239) of a co-running study at the time of the meeting. This data was presented to the delegates (Table 6.5). The number of non-drivers (55.6%) at the time point of stroke was larger than those who were driving (44.4%). The decision was taken to remove this section entirely as driving items are potentially not relevant to a large proportion of the target population.

Table 6.5: Driving status of stroke survivors from IVIS incidence study database in July 2015

Driving status	**n**
Driving	101
Restricted driving	5
Gave up prior to stroke	46
Gave up due to stroke	0
Never driven	85
Other reason for not driving	2

6.3.5.12*: Travelling*

Two high inter-item correlations were found between the three items in this section:

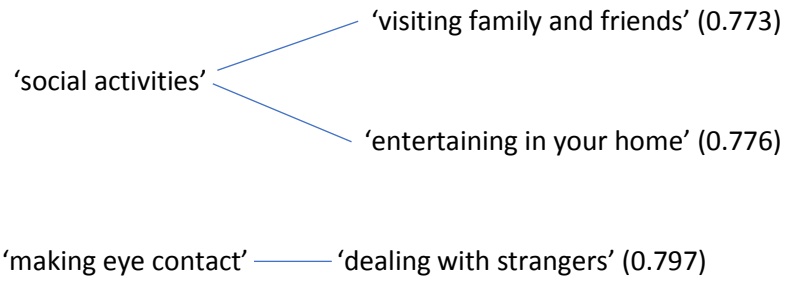


Due to the inter-correlation and the high not applicable responses seen it was decided to remove the 'travelling alone' and 'using public transport' items.

The remaining 'travelling in a car as a passenger' was reworded to incorporate 'travelling on public transport' and the word 'car' was replaced with 'vehicle', in an attempt to maintain the range of item difficulty. This one remaining item was deemed to fit appropriately within the moving around section (previously walking) (Section 6.3.5.10). Thus, the travelling section was made redundant.

6.3.5.13*: Socialising*

Three high inter-item correlations were found between five items in this section:



In view of the first set of inter-item correlations, it was decided to remove the 'visiting family and friends' and 'entertaining in your home' items as both these activities are covered by the more general 'social activities' item.

Although there was a high not applicable response rate for 'taking part in outdoor activities' (17.3%), the reasons for this included having not tried this yet. Therefore, it was decided not to remove this item to maintain items relevant to participants later in their rehabilitation journey. However, it was decided that a differentiation between indoor and outdoor activities was required. The wording of the 'social activities' and the 'taking part in outdoor

activities' items were combined to create two items; 'indoor social activities' and 'outdoor social activities'.

The stroke survivor delegate proffered that the 'making new friends' item was not applicable. This was supported by the floor effect seen; 40.4% of participants reported 'none at all' and 9.6% reported not applicable, so this item was removed.

6.3.5.14*: Role limitations*

Two high inter-item correlations were found between within this section:

'performing usual activities' ——— 'doing usual work to usual standard' (0.816)

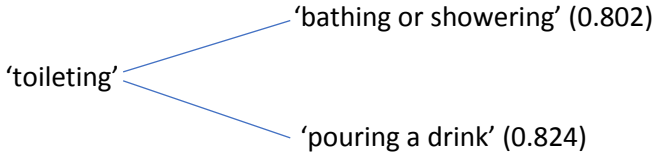
'loss of confidence' ——— 'accomplishing as much as you would like' (0.847)

Due to the inter-item correlation it was decided to remove the 'performing usual activities' item. In view of the unacceptable level of not applicable responses (11.5%) and the reasons for this response of 'not working or retired', it was decided to reword the 'doing usual work to usual standard' and 'limit of how long you can work' items. To encompass individuals who do not work, the word 'work' was replaced by the phrase 'role or activities'.

The item 'people limiting your opportunities' was discussed which also had an unacceptable level of not applicable responses (11.5%). It was decided by both user and clinical delegates that this impact may not be detected until many years after a stroke and it is a very difficult concept to grasp. Taking these issues into account the item was removed.

6.3.5.15*: Self-care*

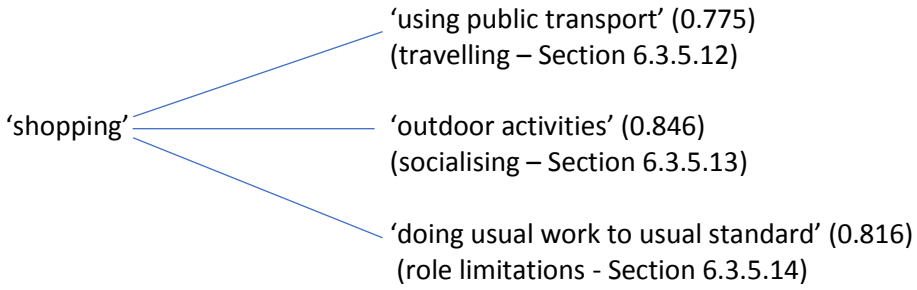
Two high inter-item correlations were found between the three items in this section:



These items do not clinically measure the same concept; therefore, no changes could be recommended. Eight items within this section had floor effects. It was discussed that the

participants completing such a lengthy instrument are likely to be higher functioning stroke survivors both physically and cognitively. In order to maintain the range of item difficulty to detect lower functioning, all items remained unchanged.

Three high inter-item correlations were found between the 'shopping' item from this section and three items in three different sections:

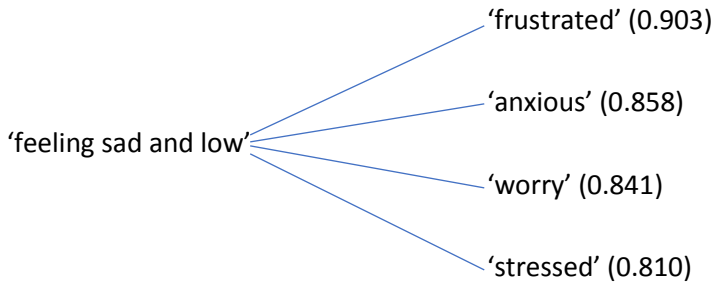


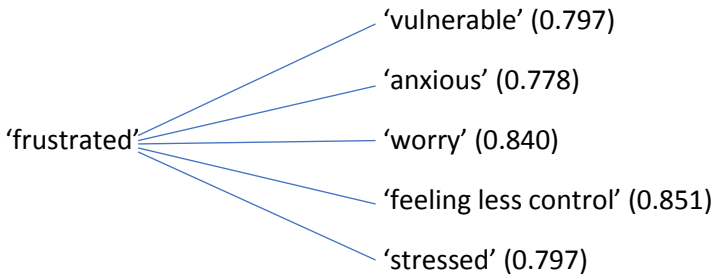
Changes were made to all three of the items from other sections and no change was required for the 'shopping' item.

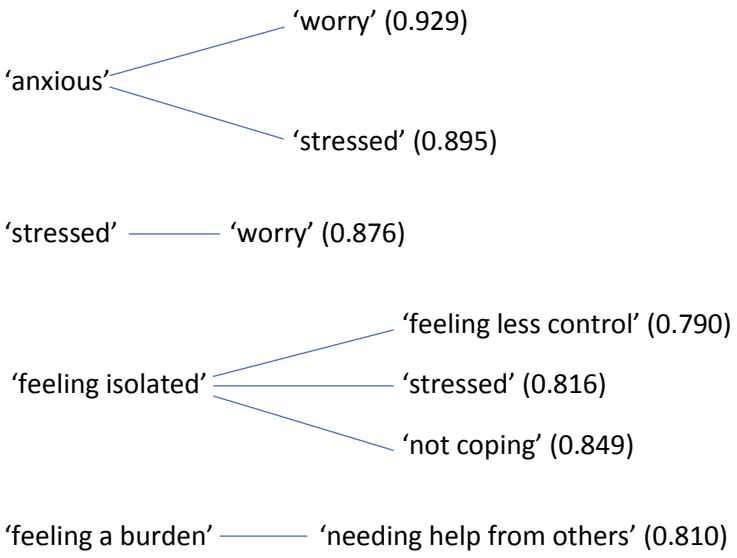
The title heading was discussed and revised to 'independent living' as the focus of many of the items is the ability to carry out activities of daily living.

6.3.5.16*: Well-being*

Sixteen high inter-item correlations were found between the ten items in this section:







A comment had been made on the participant feedback about the repetition in this section. In view of this and the large amount of inter-item correlation the decision was taken to combine the following items: 'feeling sad and low', 'frustrated', 'anxious', 'worry', 'feeling isolated' 'feeling less control' and 'stressed' into one item of 'negative emotions' whilst adding the previous separate items as examples. The two items 'feeling a burden' and 'needing help from others' were also combined into one item. It was decided to keep the wording of 'feeling a burden'.

A further inter-item correlation was found between:

'staying at home' ——— 'performing usual activities' (0.760)
(role limitation - Section 6.3.5.14)

The 'performing usual activities' had already been removed from the instrument; therefore, no further action was required.

6.3.5.17*: Formatting*

The formatting of the instrument was mentioned in the participant feedback form. One participant had found the repetition of the instructions "due to your eyes and eyesight" within the majority of items irritating. The stroke survivor delegate commented within the meeting that the current layout created a very busy page and may be difficult for participants with severe visual impairment to navigate. It is important to have a clear layout as this can impact on the amount of missing data in self-administered instruments (200).

Ideas for new formatting were suggested within the meeting. All ideas were sketched out to enable delegates to visualise how the suggestions may appear on paper. The main idea put forward was based on the aim of reducing the number of times the instruction “due to your eyes and eyesight” was given, to once per category. The method for achieving this was developed during discussion and took the form of altering the way the question is posed by separating it into two parts. The first part would consist of asking ‘do you have’ followed by a list underneath of the focus of the items. The participant would be offered the options of answering ‘no’ or ‘yes’, proffered in that order on the page. The second part would only be completed by participants who had indicated that they do have difficulty with the item in question. There would be an indication that those who have answered ‘yes’ are required to complete the second part. This would consist of ‘if yes, how much difficulty do you have on this scale’. It was decided by all delegates that each category should be given a page of its own regardless of the number of items within the category. The addition of a line of explanation of what the category was asking about, and in what conditions e.g. using normal glasses correction for activities, was suggested. The two general items would remain unchanged in wording and format. In order to create a good flow to the new two-part question format, more space was required horizontally, the decision was therefore taken to present the whole instrument in landscape orientation.

As a result of the new suggested layout of instructions and question, the formatting of the scale was examined. The nomenclature of the 5-point rating scale would not change. However, the numbering was changed to fit with the Rasch analysis convention of starting at zero. It was also debated at length the score that a response of ‘no’ is given. It was seen by the delegates that if an item was not applicable to a participant that they would be not be having any difficulty and therefore would answer ‘no’. These decisions also allowed for the not applicable option to be removed. It was finally agreed that instead of this being seen as missing data as often is the case with a ‘not applicable’ option it would score as zero.

The changes decided in the nominal group meeting were applied to the whole instrument after the meeting. An example page is outlined in Figure 6.4. The proposed version two pilot instrument was circulated to all delegates, including the two stroke survivors who were unable to attend on the day of the meeting, for comment. The delegates who were in attendance, confirmed that the new version reflected the decisions made. The absent delegates agreed the new formatting improved the clarity of the instrument.

The pilot questionnaire (version two) was constructed of 62 items under 14 categories. The 14 categories remained organised in two overarching sections – vision/eyes and functioning, with the two general items separate. All text in the instrument was presented using the same font and size as version one; san serif typeface (Arial) at 16-point size (182). The order and layout of the pilot questionnaire (version two) can be seen in Appendix 3. The analysis page at the end of the instrument was amended to reflect the changes in categories and scale. Again, a total score would not offer much information at this stage, therefore each category was totalled individually and marked on the graph. This allowed the clinician to quickly identify the areas in which the individual completing the instrument was having difficulty.

C. Distance vision: In this section we are asking if you are having any difficulty with your distance vision when you are wearing the correct glasses if needed, and if it is having an impact on your life.

	Do you have? (please tick)			If yes, how much difficulty do you have on this scale from 0 to 4?				
		No	Yes	None at all 0	A little bit 1	A moderate amount 2	A lot 3	It limits my activity 4
10.	Difficulty seeing something on the far side side of a room e.g. TV, people							
11.	Difficulty seeing something far away e.g. street signs, looking out of a window							

Figure 6.4: Example page of items in the pilot instrument (version two)

Chapter 7

Further development pilot - version two

7.1: Introduction

The instrument in its current form has been through various stages of development. The development of version one of the pilot instrument (Chapter 5) was achieved by bringing together a literature review of existing instruments and a ranking exercise with stroke survivors and clinicians. Version one was completed by a small number of stroke survivors. Difficulty with recruitment with this pilot was in part due to task burden of 102 items. In view of the small return of completed version one questionnaires, item reduction was instigated and the formatting altered to create version two (Chapter 6). It was necessary to continue the instrument pilot work on a larger sample, to assess if the remaining items were all appropriate for the population (177). The aim of this stage of development was to collect the number of questionnaires (n=243) required to perform Rasch analysis to achieve further item reduction.

7.2: Methods

Participants were recruited from inpatient and outpatient settings within NHS hospital trusts as well as through the voluntary sector (e.g. Stroke Association). The recruitment and assessment methods remained the same as for the pilot of version one (Chapter 6: Section 6.2), comprising inclusion of both acute and long-standing stroke survivors. Ethical approval was granted by the West of Scotland Research Ethics Service (REC reference: 14/WS/0090) and the University of Liverpool Institute of Psychology, Health and Society Research Ethics Committee (Reference: IPHS-14145-040).

Some demographic data regarding the stroke survivors who were recruited from the voluntary sector and completed version one was not collected (e.g. gender), therefore the key background detail questions were amended to include these for version two.

Stamped addressed envelopes were introduced in an attempt to improve questionnaire return rate. Rather than relying on the participant to return the questionnaire at their next appointment if they could not complete it on the day of recruitment, they were now able to complete the questionnaire at home and return the questionnaire by post.

Additional NHS hospital recruiting sites were added to maximise recruitment and questionnaire returns. The new sites are listed in Table 7.1, along with the dates on which approval was granted by the local research and development departments. The new recruiting sites had established orthoptic stroke services, therefore the clinics included

stroke survivors at various stages post-stroke. There were no exclusion criteria relating to the age of the stroke, therefore no limit was placed.

During the process of adding new recruiting sites the overarching ethical approval process changed on 31st March 2016. The addition of further new sites beyond this date required a conversion of the pre-HRA approval to HRA approval (201).

Table 7.1: New recruiting sites added for pilot of version two

Site name	Date approval granted
Blackpool – Blackpool Victoria Hospital	22/12/2015
Bournemouth – Royal Bournemouth Hospital	14/01/2016
Sheffield – Royal Hallamshire Hospital	22/01/2016
Torbay – Torbay District General Hospital	22/03/2016
Birmingham – City Hospital	14/04/2016
Wirral – Arrowe Park Hospital	22/06/2016
Oxford – John Radcliffe Hospital	18/07/2016
Chester – Countess of Chester Hospital	06/09/2016

7.3: Results

7.3.1: Recruitment rate

Within 17 months of recruitment, 236 participants from NHS hospitals and 39 participants through the voluntary sector were recruited. The breakdown of the recruitment rate and increasing number of recruiting sites is outlined in Figure 7.1. Recruitment continued until the target of 243 returned questionnaires was achieved on 1st December 2016. A few questionnaires arrived following the cessation of recruitment. The total number returned was 247, equating to an 89.8% return rate. This included 211 (89.4% response rate) from stroke survivors recruited in NHS hospitals and 36 (92.3% response rate) from stroke survivors recruited through the voluntary sector.

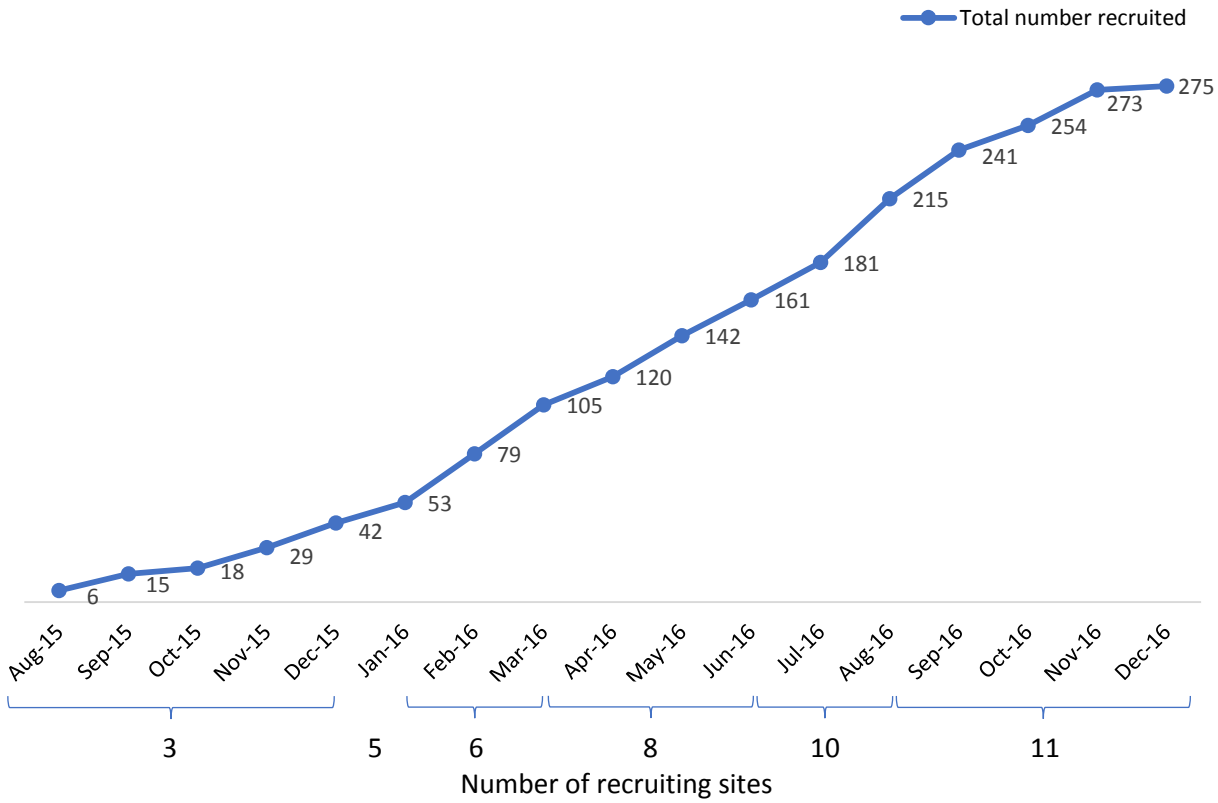


Figure 7.1: Recruitment rate for the version two pilot instrument

7.3.2: Participants

7.3.2.1*: Returned questionnaire*

Of the stroke survivors recruited in NHS hospitals who returned a completed questionnaire 59.2% (n=125) were male and the mean age at time of recruitment was 68.9 years (SD 13.0). The mean number of days since stroke onset at time of recruitment was 101.7 days (SD 202.1), due to a number of individuals recruited from outpatient clinics several months post-stroke. However, the median was 32 (IQR 7-96), clarifying that participants were also recruited in the acute phase. The mean number of days since stroke onset at time of completion was 110.7 days (SD 204.2); the median was 39 (IQR 9-113). A mean number of 9.1 days (SD 28.2) was required for participants to complete the questionnaire.

The mean Barthel Index score as an indication of stroke severity was 14.4 (SD 5.9), indicating a moderate dependency on average: the poorest score being 0 (total dependence) and the best score being 20 (independent) (191, 192). Of the stroke survivors recruited in NHS hospitals, 47.9% (n=101) were inpatients when recruited and 52.1% (n=110) were outpatients.

Sixty-eight percent (n=143) of the stroke survivors recruited in NHS hospitals who returned a questionnaire had two or more visual impairments. The most common number of co-existing visual impairments for this group was two (30.8%). The numbers and types of visual impairment are outlined in Table 7.2. Three percent (n=7) did not complain of any specific visual symptoms related to their visual impairment. The most commonly reported symptom was visual field loss (52.6%, n=111), followed by reading difficulties (31.8%, n=67).

Table 7.2: Types of visual impairment in acute stroke survivors returning a questionnaire

Visual impairment	**n (%)**
Visual field loss	182 (86.3)
Ocular motility defect	104 (49.3)
Central vision loss	77 (36.5)
Ocular alignment defect	44 (20.9)
Visual inattention	26 (12.3)
Visual perception problems	5 (2.4)

Of the stroke survivors recruited through the voluntary sector who returned a completed questionnaire 66.7% (n=24) were male and the mean age at time of recruitment was 59.9

years (SD 9.7). The mean number of months since stroke onset at time of recruitment was 91.1 (SD 95.6). A mean number of 3.2 days (SD 7.2) was required for participants in this group to complete the questionnaire.

Ninety-two percent (n=33) of the stroke survivors recruited through the voluntary sector who returned a questionnaire reported visual field loss as their visual impairment. The most commonly reported symptom was visual field loss (72.2%, n=26), followed by reading difficulties (13.9%, n=5) and blurred, altered or reduced vision (13.9%, n=5).

7.3.2.2*: Did not return questionnaire*

Of the 28 stroke survivors recruited in NHS hospitals who did not return a questionnaire 57.1% (n=16) were male and the mean age at time of recruitment was 66.4 years (SD 10.0). The mean number of days since stroke onset at time of recruitment was 80.2 days (SD 102.0); the median number of days was 39 (IQR 10-94).

The mean Barthel Index score at stroke onset as an indication of stroke severity was 12.0 (SD 7.6), indicating a moderate dependency on average (191). Of the stroke survivors recruited in NHS hospitals, 46.4% (n=13) were inpatients when recruited and 53.6% (n=15) were outpatients.

Seventy-one percent (n=20) of the stroke survivors recruited in NHS hospitals who did not return a questionnaire had two or more visual impairments. The most common number of co-existing visual impairments for this group was two (32.1%). The numbers and types of visual impairment are outlined in Table 7.3. Four percent (n=1) did not complain of any specific visual symptoms related to their visual impairment. The most commonly reported symptoms were visual field loss (50%, n=14) followed by blurred, altered or reduced vision (25%, n=7) and diplopia (25%, n=7).

No demographic information was available for the stroke survivors recruited from the voluntary sector (n=3) who did not return the questionnaire.

Table 7.3: Types of visual impairment in acute stroke survivors not returning a questionnaire

Visual impairment	n (%)
Visual field loss	21 (75.0)
Ocular motility defect	12 (42.9)
Visual perception problems	9 (32.1)
Ocular alignment defect	8 (28.6)
Central vision loss	7 (25.0)
Visual inattention	4 (14.3)

7.3.2.3: *Comparing groups*

The two groups of participants recruited through NHS hospitals, those who returned and those who did not, had no statistical difference in terms of age at the time of stroke (t=0.96, df=237, p=0.339), gender (χ^2=0.05, df=1, p=0.832) and inpatient or outpatient status at the time of recruitment (χ^2=0.02, df=1, p=0.886). It would appear the non-returning group were recruited earlier post-stroke than the returning group when considering the mean (21.5 days). However, the median for the two groups was identical (U=2879.5, p=0.828). The non-returning group had a slightly lower mean score on the Barthel Index indicating a slightly higher level of dependency (2.4 points difference) than the returning group, however this was not statistically significant (U=2540.5, p=0.309). Very few participants did not report any symptoms associated with their visual impairment in either group (χ^2=0.005, df=1, p=0.944).

Differences were found in four areas between the returning and non-returning participants in the version one pilot (Chapter 6, Section 6.3.1.3). The non-returning group were on average recruited earlier post-stroke, a higher proportion were inpatients at the time of recruitment, they had a higher level of dependency as measured by the Barthel Index and a higher proportion reported no visual symptoms associated with the visual impairment found on assessment. It was hypothesised these differences could have contributed to the non-return of questionnaires. These differences were not found in this larger sample size and the groups were found to not have any statistically significant differences.

7.3.3: Data analysis

The psychometric analysis performed on the version two pilot data using the Rasch measurement model is detailed in Chapter 9.

7.3.3.1*: Missing questionnaire data*

Four participants (1.6%) did not fully complete the questionnaire, resulting in missing data. The missing data involved 14 of the 62 items within the instrument; one occurrence per item with the exception of one, item 56 'self-conscious', which had two. The number of items missed per person varied from one to eight.

The cause of any missing data should be investigated to assess the potential for introduction of bias; whether the data is missing at random or not missing at random (194). Although with such a small amount of missing data (1.6%) there is very little scope for it to introduce bias. Two participants missed a complete section of items. One of these included the last section with a note from the interviewer regarding fatigue. The other missed section could have been due to missing a page. The participant who missed the last section due to fatigue also missed the two general items 'overall health' and 'overall vision' with a note from the interviewer that these two items were not understood by the participant. The other three remaining missed items were mid-section.

7.4: Discussion

The stroke population recruited to this study followed similar trends to the general stroke population. The study recruited a higher proportion of men, which matches the national statistics reports that men are more likely to have a stroke (111). In terms of age, national stroke data reports stroke to most commonly occur at 75 years or older. The mean age of stroke in this study population was slightly younger than the nationwide average (111). A possible explanation is the fact that the majority of the study population was recruited from the North West of England, known to be a socially deprived area which, in turn, increases the likelihood of strokes occurring at a younger age (202, 203).

The return rate seen in the pilot of version two (89.8%) surpassed that of the national NHS PROMs programme which saw a return of 75.6% for the pre-operative questionnaires in 2014-2015 (204).

No data is available for the number of stroke survivors who were approached and chose not to partake in the study. The recruitment rate was slower than expected, even with the increase in number of recruiting sites. This may be an indication that the pilot instrument (version two) requires further item reduction. This chapter has given an overview of the participants who were involved in the piloting of version two. The analysis and processes

(involving the Delphi technique and Rasch analysis) for the further development of the new instrument will be discussed in the upcoming chapters.

Chapter 8
Delphi Process

8.1: Introduction

The Delphi technique is a recognised method of achieving a consensus view amongst experts within health research (205). Uses have included forecasting clinical problems, identifying research priorities and core competencies (206), development of outcome sets (207) and patient centred outcome measures (208). It was a process initially developed by Dalkey and colleagues at the RAND Corporation in the 1950's (209). It is a method which can be used for goal setting as it investigates "what could/should be" rather than routine surveys which investigate "what is" (210). Since the conception of the 'Classic Delphi', variations in the technique have emerged. These include the Modified Delphi, the Policy Delphi and the Decision Delphi (211).

A 'Classic Delphi' commences with a first round which is qualitative in nature, with open-ended questions; the summary of which forms the basis of a questionnaire for the second round (212). Modified Delphi methods of capturing these initial views have been described, including one-to-one interview, focus groups and literature reviews (213). This has paved the way for the Reactive Delphi which requires participants to rate items that have been prepared in advance rather than the participant group generating items (214).

The Delphi technique has a number of key components. It uses a series of surveys incorporating a feedback loop, with an aim of consensus building (215). Participants are experts within the required field. The feedback loop following each round of surveys, allows participants to reflect on their initial response in relation to that of the whole group (216). The process is anonymous, preventing potential dominant characters from leading or biasing the group of participants (217). This is especially important when involving a mixture of stroke survivors, clinicians and researchers.

There has been debate in the literature about the strengths and weaknesses of the Delphi approach and whether it has methodological rigour. Concerns focus around unaccountable sampling methods, the concept of 'expert' and lack of consideration around reliability of measurement (218). The need for 'goodness criteria' has now been recognised in order to improve credibility of the method (219). It should also be acknowledged that evidence based practice has been described as 'integrating clinical expertise with the best available external clinical evidence from systematic research' (220).

8.1.1: Aims and objectives

The aim of this Delphi survey was to ascertain what items stroke survivors and stroke care professionals think are important when assessing quality of life in stroke survivors with visual impairment.

The objectives were:

1) to identify which items are important in the assessment of vision-related quality of life with visual impairment following stroke to aid development of the new patient reported outcome measure (PROM)
2) to identify items which could underpin a core item set for all visual impairments following stroke
3) to identify items for a hub and spoke model, which could underpin spoke items in addition to a 'hub' core item set, for specific visual impairment following stroke e.g. visual field loss, ocular motility defects, visual perception problems.

8.2: Method

Ethical approval was granted by the University of Liverpool Institute of Psychology, Health and Society Research Ethics Committee (Reference: IPHS-14145-040).

8.2.1: Design

The Delphi process in this study was planned to involve three rounds of an electronic-based questionnaire using SurveyMonkey (221). This platform has previously been used to conduct Delphi surveys (222). The survey involved two parts. The first asked participants to judge the importance of 62 items on a 9-point scale, from 1 'not important' to 9 'critical'. The second asked participants to decide if the same 62 items apply to all types of visual impairment following stroke or to specific taxonomies (reduced central vision, visual field loss, ocular motility defects or perceptual problems) or were considered not relevant to visual impairment following stroke. The 62 items were derived from version two of the new instrument. The original source of these items was a systematic review (176) which created the basis for version one (Chapter 5). An item reduction stage was conducted resulting in version two (Chapter 6) prior to starting the Delphi process. From the stages of instrument

development already conducted, the items for the Delphi survey were in place. Therefore, the Reactive Delphi approach was taken (214).

8.2.2: Consensus definition

The literature provides very little clear guidance on the level at which consensus is defined (211, 223, 224). Consensus definitions in the literature vary from 50% to 100% agreement between participants (225-227). In addition to assessing for consensus, studies recommend exploring how that consensus has been reached by measuring level of agreement between rounds (stability) (223, 228).

The end point which was used for this study was the number of rounds, set at three, to limit attrition of participants (229). Despite this, consensus was defined 'a priori' in order for this to be reported (207). Items were prioritised if more than 70% of participants scored the item as 'critical' (options 7 to 9) and fewer than 15% of participants scored the item as 'not important' (options 1 to 3). Items were considered for removal if more than 70% of participants scored the item as 'not important' (options 1 to 3) and fewer than 15% of participants scored the item as 'critical' (options 7 to 9). All other scoring patterns were taken to indicate non-consensus (230). This conclusion was also reached by Williamson *et al.* where the rationale of agreement has been made by the majority on the critical elements and a minority of opposition judging the same item to be not important (231).

In the case of part two, consensus could be achieved if 70% of participants allocated an item to either 'relevant to all visual impairment following stroke' or 'not relevant to visual impairment following stroke'. In cases where an item may be relevant to more than one taxonomy (reduced central vision, visual field loss, ocular motility defect and visual perception), if the total across three or less of the categories reached 70%, consensus was deemed to have been achieved. Fewer than 15% must have chosen the opposing stand point 'not relevant to all visual impairment following stroke' or 'relevant to all visual impairment following stroke'.

8.2.3: Participants

A Delphi survey calls for a panel of 'experts'. Stroke survivors and clinicians who would have knowledge of visual impairment following stroke were targeted. One group of stakeholders

comprised stroke survivors with visual impairment resulting from stroke; judged to be experts of living with the condition and offering a different perspective to clinicians (207, 219). The other groups were made up of orthoptists and occupational therapists involved in stroke care. These are the two allied health professions who most frequently assess and manage visual impairment soonest following stroke.

Anonymity of participants is a key element of a Delphi survey. Participants were not aware of the identity of other participants but the facilitator of the survey was aware of the individual responses of each participant (214, 232). The participants create a heterogeneous group; members of the panel may judge other groups of participants or individuals to have more authority on the subject matter. Anonymity allows all participants to voice their own point of view without feeling the need to bow to perceived higher authority or peer pressure (217, 225, 233, 234).

8.2.4: Recruitment process

Participants were sent an email advertisement outlining the project. Stroke survivors were identified from a register of those who had expressed interest in participating in research studies. Orthoptists and occupational therapists were contacted via their respective national bodies. Individuals replied to this email advert expressing interest in participating.

There is no empirical evidence available for guidance on the number of participants required (230). Murphy *et al.* suggested a larger sample size is better (235). However, Duffield demonstrated that large samples were not required (236). The panel is not required to be representative in terms of statistical analysis (219). For the purposes of this Delphi survey it was decided not to exclude anyone who expressed interest in participating.

8.2.5: Delphi round one

All volunteers were emailed a personalised link to the survey to allow them to return to the survey if it could not be completed in one sitting. The first page of the survey acted as a participant information sheet and consent form prior to the start of the survey, with the opportunity to decline participation. Contact details of the researcher were available if participants wished to ask questions about the study.

Demographic data regarding the participant's status as a stroke survivor or clinician, gender and age were collected. The type of visual impairment diagnosis (i.e. central vision loss, visual field loss, ocular motility defect or visual perception problems) or professional background was also collected.

For both parts of the survey the 62 items from version two of the new instrument were presented in two blocks of 11 and four blocks of 10. Examples of part one can be seen in Figure 8.1 and part two in Figure 8.2. The order the blocks were presented to each participant was randomised as were the items within each block. Part one only allowed one response per item, whereas part two allowed more than one selection to be made.

Non-responders or partial completers were sent up to two reminder emails, which included an option to withdraw from the study.

8.2.6: First round analysis

The group feedback was prepared using histograms to show the distribution of responses as one group. Individual response sheets were also prepared for each participant.

Part one of the Delphi survey was analysed using the Holey *et al.* method of assessing consensus and stability (223). This requires four steps for round one:

1) Percentage response rate
2) Level of agreement in percentage terms for each item to allow for differing response rates
3) Median and range
4) Mean and standard deviation, along with rank of importance for each item

The above analysis used SPSS Statistics software (187).

As part two is categorical data this was analysed using percentage response rates, against the consensus definition discussed in Section 8.2.2.

All items were carried forward to round two.

*** Please view the items listed and score their importance with 1 being not important and 9 being critical.**

	1	Not important 2	3	4	Important but not critical 5	6	7	Critical 8	9
Overall vision	○	○	○	○	○	○	○	○	○
Objects jumping around	○	○	○	○	○	○	○	○	○
Deterioration of vision	○	○	○	○	○	○	○	○	○
Eyes getting tired	○	○	○	○	○	○	○	○	○
Difficulty seeing something far away e.g. street signs, looking out of a window	○	○	○	○	○	○	○	○	○
Objects suddenly appearing	○	○	○	○	○	○	○	○	○
Difficulty with adjusting to differing light e.g. bright to dim or dim to bright light	○	○	○	○	○	○	○	○	○
Difficulty moving around in unfamiliar areas	○	○	○	○	○	○	○	○	○
Taking medication	○	○	○	○	○	○	○	○	○
Pouring a drink	○	○	○	○	○	○	○	○	○
Not coping with everyday life	○	○	○	○	○	○	○	○	○

Figure 8.1: One bank of items from part one of round one of the Delphi survey

*** Please view the items listed and decide whether you think they are relevant to all visual impairment or one or more specific types of visual impairment following stroke or not relevant to visual impairment following stroke.**

	All visual impairment following stroke	Reduced central vision	Visual field loss	Eye movement problems and/or double vision	Visual perception problems	Not relevant to visual impairment following stroke
Difficulty with adjusting to differing light e.g. bright to dim or dim to bright light	☐	☐	☐	☐	☐	☐
Dry eyes	☐	☐	☐	☐	☐	☐
Completing household chores	☐	☐	☐	☐	☐	☐
Eyes having an unusual appearance	☐	☐	☐	☐	☐	☐
Overall vision	☐	☐	☐	☐	☐	☐
Difficulty using a desktop computer, laptop or tablet	☐	☐	☐	☐	☐	☐
Difficulty accomplishing as much as would like	☐	☐	☐	☐	☐	☐
Fluctuation of vision	☐	☐	☐	☐	☐	☐
Judging how close or far away things are	☐	☐	☐	☐	☐	☐
Bumps into or against objects or people in crowded areas	☐	☐	☐	☐	☐	☐

Figure 8.2: One bank of items from part two of round one of the Delphi survey

8.2.7: Delphi round two

All participants who completed the first round were invited to participate in round two. An email was sent to each participant with a record of their individual responses and advising them that the link to round two would be sent shortly. Personalised links to the survey were then sent out. As with round one, the first page of the survey acted as a participant information sheet and consent form prior to the start of the survey, with the opportunity to decline participation.

The 62 items for both parts of the survey were presented individually, with the distribution of response feedback above the corresponding item requiring a response. Examples of part one can be seen in Figure 8.3 and part two in Figure 8.4. The order items were presented to each participant was not randomised in round two. This was to allow the individual response sheets to be presented in the same order as the items in the survey. The response options remained the same as round one.

Non-responders or partial completers were sent up to two reminder emails, which included an option to withdraw from the study.

8.2.8: Second round analysis

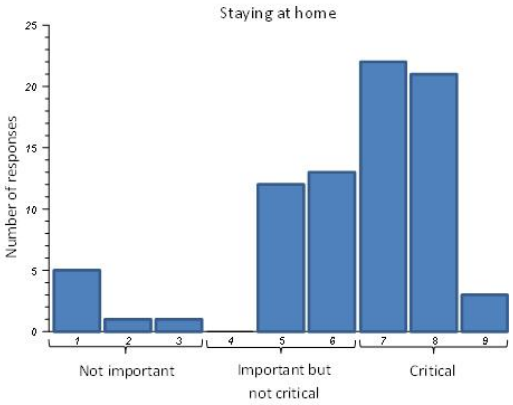
Following round two participant feedback was prepared using histograms to show the distribution of responses as one group. Individual response sheets were also prepared.

Following the Holey *et al.* method of assessing for consensus and stability for part one of the survey an additional step to measure agreement was required following round two to those listed earlier (Section 8.2.6) (223):

5) Weighted Kappa (K) values – assessing chance-eliminated agreement between rounds one and two. The interpretation used is outlined in Table 8.1.

This analysis used StatsDirect Statistical Software (237).

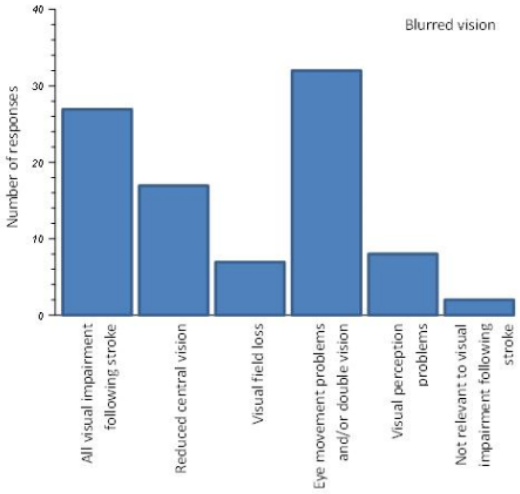
The weighted Kappa is required for data with ordered categories, allowing for less disagreement between two neighbouring categories than categories which are further apart (238).



*** Please score their importance with 1 being not important and 9 being critical.**

	1	Not important 2	3	4	Important but not critical 5	6	7	Critical 8	9
Staying at home	○	○	○	○	○	○	○	○	○

Figure 8.3: One item from part one of round two of the Delphi survey



*** Please decide whether you think this item is relevant to all visual impairment following stroke or one or more specific types of visual impairment following stroke or not relevant to visual impairment following stroke.**

	All visual impairment following stroke	Reduced central vision	Visual field loss	Eye movement problems and/or double vision	Visual perception problems	Not relevant to visual impairment following stroke
Blurred vision	☐	☐	☐	☐	☐	☐

Figure 8.4: One item from part two of round two of the Delphi survey

Table 8.1: Interpretation guide of level of agreement represented by K-values (223)

K-value	Agreement level
0.0-0.2	Poor
0.21-0.4	Fair
0.41-0.6	Moderate
0.61-0.8	Substantial
0.81-1.0	Almost perfect

Part two was analysed, as previous, using percentage response rates, against the consensus definition.

All items were carried forward to round three.

8.2.9: Delphi round three

All participants who completed the second round were invited to participate in round three. The participants who had completed round one but had not responded to round two were sent an email informing them round two was complete but inviting them to make contact if they wished to continue in the process. The same process as round two was followed. An email was sent to each participant with a record of their individual responses and the link to the round three survey. The first page of the survey again acted as a participant information sheet and consent form prior to the start of the survey, with the opportunity to decline participation.

The 62 items for both parts of the survey were presented individually, with the distribution of response feedback above the item requiring a response, as in round two (Figure 8.3 and Figure 8.4). The order items were presented to each participant was not randomised in round three. Additional demographic information was requested in this final round. For clinicians, this included the hospital trust they work for, number of years' experience in stroke care and the types of setting they work in. For stroke survivors, this included their closest hospital and number of years since stroke onset.

8.2.10: Third round analysis

All five steps the of Holey *et al.* method of assessing for consensus and stability were followed for part one of the survey (223). The Kappa values were calculated for between both rounds two and three, and rounds one and three. Part two was analysed as previously, using percentage response rates against the consensus definition.

8.3: Results

8.3.1: Response rate

In total, there were 113 emails of interest registered for participating in the Delphi survey. Response rates to the three rounds were 78 of 113 (69.0%), 61 of 76 (81.3%) and 49 of 64 (76.6%) respectively (Figure 8.5).

From the original emails of interest, 47 (41.6%) participants participated in all three rounds and 30 (26.5%) did not participate in any of the rounds. Over the course of the three rounds, a total of ten (8.8%) participants opted out; these were all due to lack of time. A further 28 participants (24.8%) failed to respond to the second or third round invitations after completing at least one round.

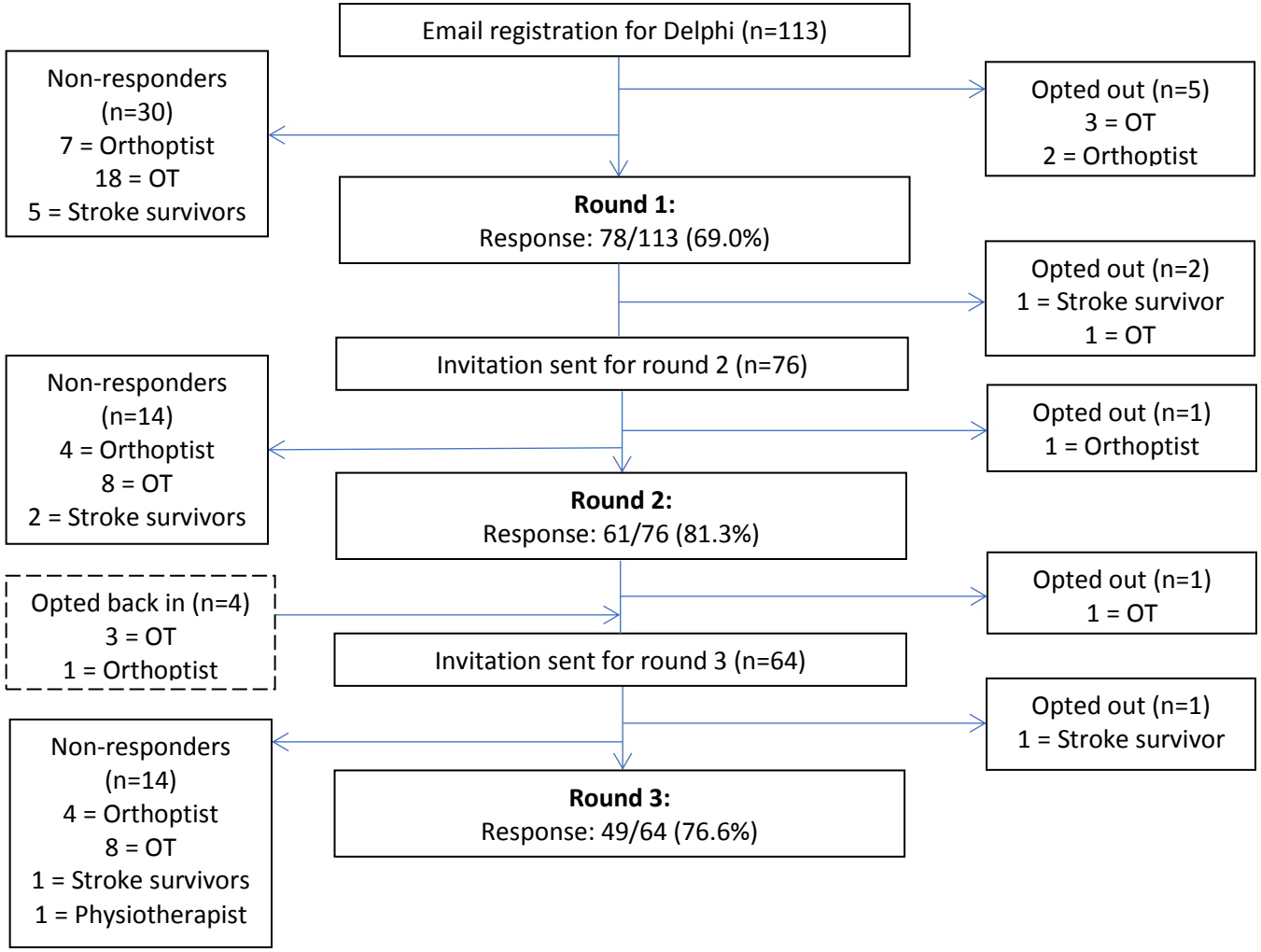


Figure 8.5: Flow chart showing responses to Delphi survey, rounds one to three.

8.3.2: Demographics

All demographics collected from the first round and tracked through the process are outlined in Table 8.2. Participants were predominantly clinicians (87.2% to 89.8%). The clinical professions were almost equally divided between occupational therapists (OTs) (51.5% to 45.5%) and orthoptists (47.0% to 54.5%). A small group of stroke survivors (12.8% to 10.2%) participated in the survey. The majority of the stroke survivors had visual field loss. There was representation from the other two major visual impairment categories (ocular motility defects and visual perception problems).

The participants were predominantly female (88.5% to 91.8%). This may be primarily due to occupational therapy and orthoptics being female dominant professions (239).

Additional demographics were collected in the third round. The clinicians completing the third round were highly experienced in both years and types of setting. Fifty percent had more than ten years' experience working with stroke survivors and only one participant had less than one years' experience (Figure 8.6). The cohort also worked across the whole care pathway from the acute stroke unit to outpatient appointments and community home visits (Figure 8.7). Forty-one percent of clinicians worked in two or more of these settings, with nine percent covering four of the settings. The stroke survivors completing the third round were also highly experienced. Two had experienced stroke related visual impairment for over ten years and three for between three and seven years. The geographical spread of responses was wide and included England, Ireland, Scotland, Wales and Jersey; as detailed in Figure 8.8.

Table 8.2: Demographics of participants to Delphi survey, rounds one to three

	Round 1, n (%)	**Round 2**, n (%)	**Round 3**, n (%)
All participants	78	61	49
Male	9 (11.5)	5 (8.2)	4 (8.2)
Female	69 (88.5)	56 (91.8)	45 (91.8)
18 – 24 years	1 (1.3)	1 (1.6)	0 (0.0)
25 – 34 years	16 (20.5)	13 (21.3)	11 (22.4)
35 – 44 years	26 (33.3)	18 (29.5)	14 (28.6)
45 – 54 years	26 (33.3)	21 (34.4)	19 (38.8)
55 – 64 years	8 (10.3)	7 (11.5)	4 (8.2)
65 – 74 years	0 (0.0)	0 (0.0)	0 (0.0)
75 – 84 years	1 (1.3)	1 (1.6)	1 (2.0)
85 years and older	0 (0.0)	0 (0.0)	0 (0.0)
Stroke survivors	10 (12.8)	7 (11.5)	5 (10.2)
Visual field loss	7 (70.0)	4 (57.1)	3 (60.0)
Visual perception	1 (10.0)	1 (14.3)	1 (20.0)
Ocular motility defect	2 (20.0)	2 (28.6)	1 (20.0)
Clinicians	68 (87.2)	54 (88.5)	44 (89.8)
Occupational therapists	35 (51.5)	26 (48.1)	20 (45.5)
Orthoptists	32 (47.0)	27 (50.0)	24 (54.5)
Physiotherapists	1 (1.5)	1 (1.9)	0 (0.0)

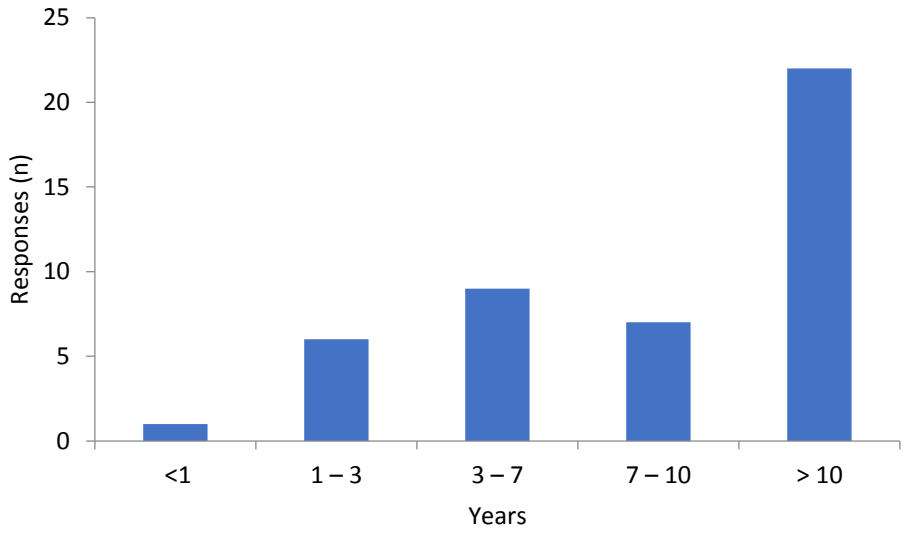


Figure 8.6: Number of years' experience clinicians completing round three have working in stroke care

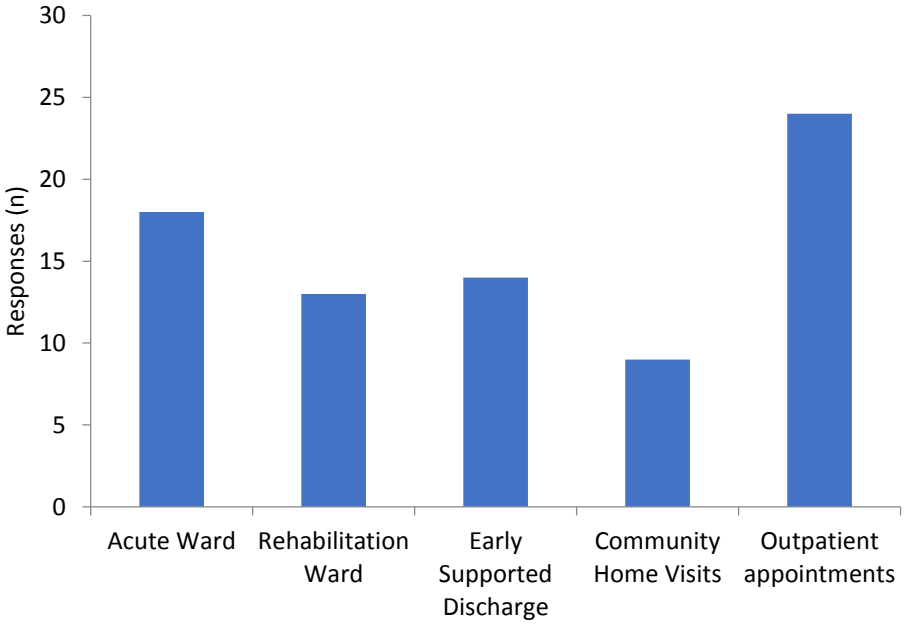


Figure 8.7: The types of settings the clinicians from the third round work in with stroke survivors

Figure 8.8: Geographical distribution of participants in the third round (240)

8.3.3: Consensus and stability evolution

Consensus was reached on 55% (n=34) of items across the three round process for part one; all of which decided to include the item. Of these, 15 were reached in the first round, a further 11 in the second round and a further nine in the third round.

Consensus was reached for 84% (n=52) of items across the three round process for part two. Of these, 21 were reached in the first round, a further 22 in the second round and a further nine in the third round. However, of the items which reached consensus in the second round, five subsequently lost this in the third round, resulting in a total of 47 items (67% with consensus after the final round. The majority (83%, n=43) of the consensuses were relevant to 'all visual impairment following stroke'. Of the remainder two were for a single category, four were across two categories, one was across three categories and two were deemed 'not relevant to visual impairment following stroke'.

The level of disagreement between the stakeholder groups of stroke survivors and clinicians was low, therefore the two groups were combined and treated as one. This results section will summarise if and how consensus and stability evolved through the Delphi rounds one to three for each item, in terms of agreement percentages and importance rankings. A higher importance is demonstrated by a larger mean value. The indicators for increasing consensus are a narrowing of the options used shown by a reduction in the range and standard deviation (SD).

8.3.3.1*: 'Overall health'*

Consensus (80.0%) to include the item was reached in the second round and strengthened into the third (87.7%) (Table 8.3). Agreement increased over the three rounds, with range interval and standard deviation decreasing (by 2 and 0.7, respectively) indicating convergence. The mean bounced across the three rounds initially increasing in the second round and subsequently decreasing. The ranking of importance decreased from 17th in the first round to 27th in the final round.

A high proportion of participants believed 'overall health' was relevant to 'all visual impairment following stroke' in rounds one and two (73.2% and 84.7% respectively) (Figure 8.9). Although this meets one criterion for achieving consensus, a significant proportion responded that it was not relevant (21.1% and 15.3%, respectively). It was only within round

three the proportion responding not relevant dropped below the required level to 12.2% to achieve consensus with 87.8%.

8.3.3.2*: 'Overall vision'*

Consensus (78.2%) to include the item was reached in the first round and strengthened in subsequent rounds to 96.0% in the third (Table 8.4). The range interval and standard deviation increased (by 2 and 0.2, respectively) in the second round, indicating divergence. Subsequently in the third round they decreased (by 3 and 0.6, respectively), indicating convergence. The mean was stable until an increase in the third round, whereas the rank dropped in the second round but recovered in the third round to 4th.

A consensus (91.4%) that 'overall vision' was relevant to 'all visual impairment following stroke' was achieved in the first round (Figure 8.10). This continued to strengthen throughout the process, to achieve a complete consensus (100%) in the final round.

8.3.3.3*: 'Blurred vision'*

Consensus (71.4%) to include the item was reached in the third round (Table 8.5). The range interval and standard deviation increased (by 2 and 0.1, respectively) in the second round, indicating divergence. Subsequently, in the third round they decreased (by 2 and 0.2, respectively), indicating convergence. Rank increased from 36th initially to 30th in the final round, despite the mean decreasing.

No consensus was reached on which category of visual impairment 'blurred vision' was most relevant to (Figure 8.11). The number of responses to 'all visual impairment following stroke' did decrease through the three rounds. The most popular other categories were 'reduced central vision' and 'eye movement problems/double vision'.

Table 8.3: Agreement and importance values for the 'overall health' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	0.0%	3.9%	0.0%	0.0%	0.0%	0.0%
		2	0.0%		0.0%		0.0%	
		3	3.9%		0.0%		0.0%	
	Important but not critical	4	5.1%	26.9%	0.0%	20.0%	0.0%	12.3%
		5	5.1%		6.7%		8.2%	
		6	16.7%		13.3%		4.1%	
	Critical	7	30.8%	69.2%	51.6%	80.0%	65.3%	87.7%
		8	26.9%		21.7%		20.4%	
		9	11.5%		6.7%		2.0%	
Importance	Median		7.0		7.0		7.0	
	Range		3-9		5-9		5-9	
	Mean		6.9		7.1		7.0	
	SD		1.5		0.9		0.8	
	Mean Rank		=17		=19		27	

= Consensus

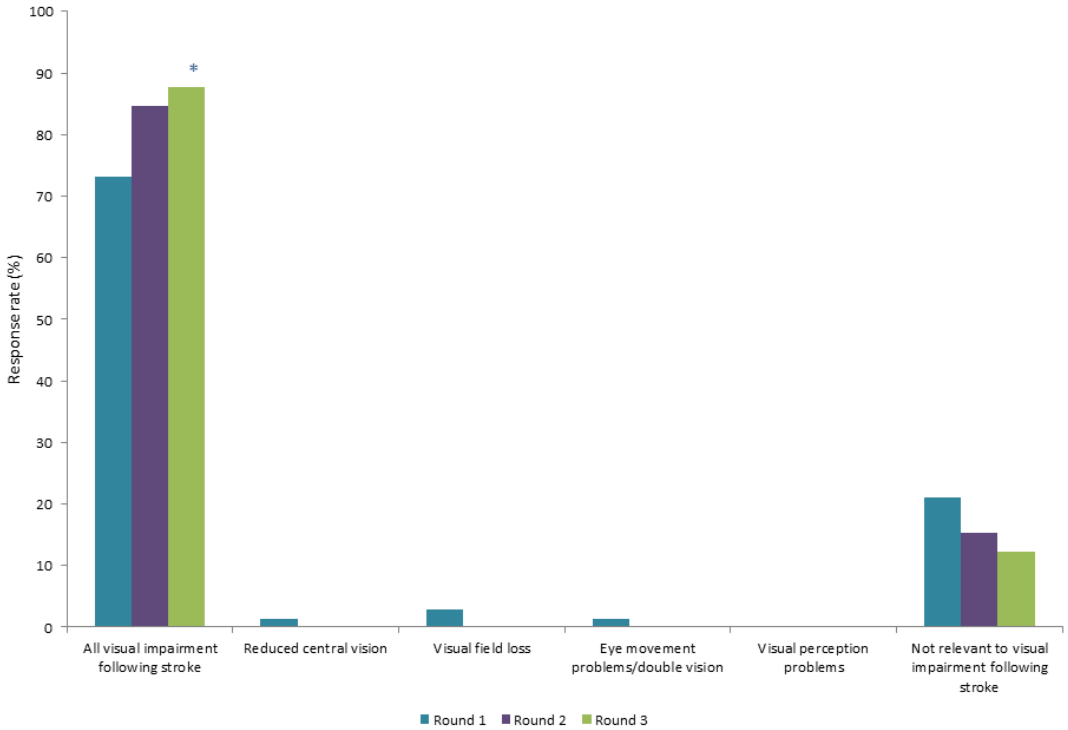


Figure 8.9: Agreement of application of 'overall health' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.4: Agreement and importance values for the 'overall vision' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	0.0%	0.0%	0.0%	3.2%	0.0%	0.0%
		2	0.0%		1.6%		0.0%	
		3	0.0%		1.6%		0.0%	
	Important but not critical	4	1.3%	21.8%	1.6%	14.8%	0.0%	4.0%
		5	9.0%		3.4%		2.0%	
		6	11.5%		9.8%		2.0%	
	Critical	7	21.8%	78.2%	23.0%	82.0%	16.3%	96.0%
		8	38.5%		39.3%		59.3%	
		9	17.9%		19.7%		20.4%	
Importance	Median		8.0		8.0		8.0	
	Range		4-9		2-9		5-9	
	Mean		7.4		7.4		7.9	
	SD		1.2		1.4		0.8	
	Mean Rank		4		8		4	

= Consensus

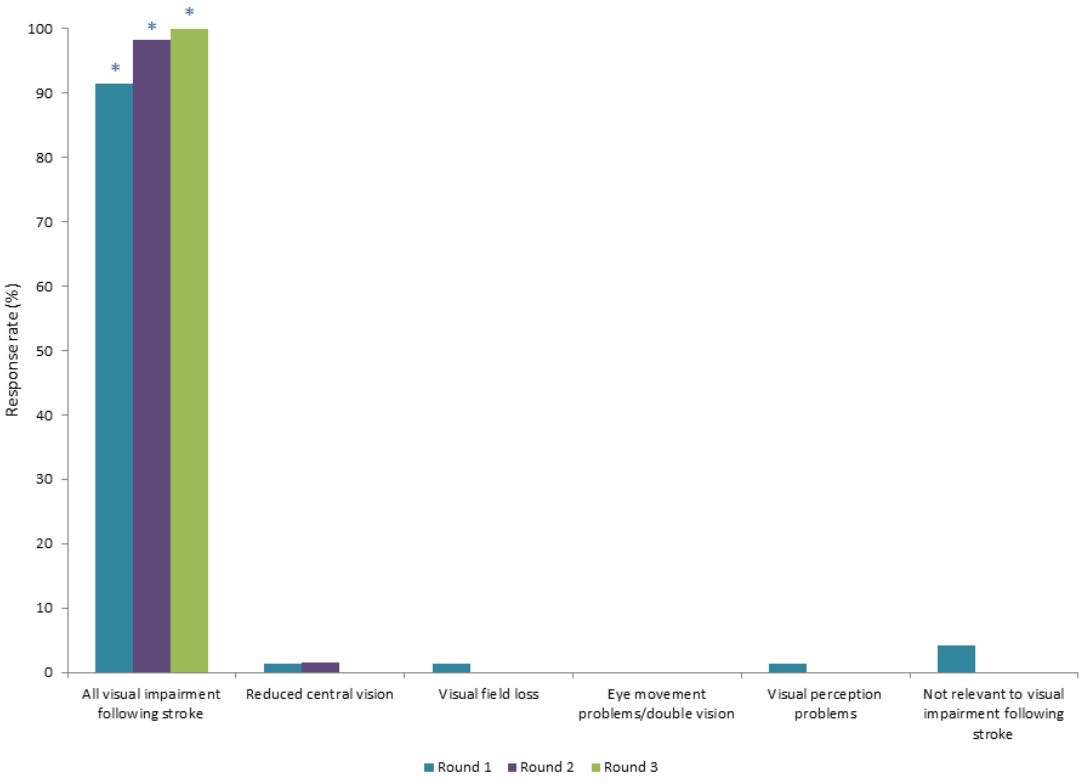


Figure 8.10: Agreement of application of 'overall vision' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.5: Agreement and importance values for the 'blurred vision' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	2.6%	9.0%	0.0%	1.7%	0.0%	0.0%
		2	2.6%		1.7%		0.0%	
		3	3.8%		0.0%		0.0%	
	Important but not critical	4	6.4%	28.2%	3.4%	28.8%	4.1%	28.6%
		5	6.4%		8.5%		4.1%	
		6	15.4%		16.9%		20.4%	
	Critical	7	37.2%	62.8%	45.8%	69.5%	40.8%	71.4%
		8	16.6%		18.6%		26.5%	
		9	9.0%		5.1%		4.1%	
Importance	Median		8.0		7.0		7.0	
	Range		4-9		2-9		4-9	
	Mean		7.4		6.8		6.9	
	SD		1.2		1.3		1.1	
	Mean Rank		=36		29		=30	

= Consensus

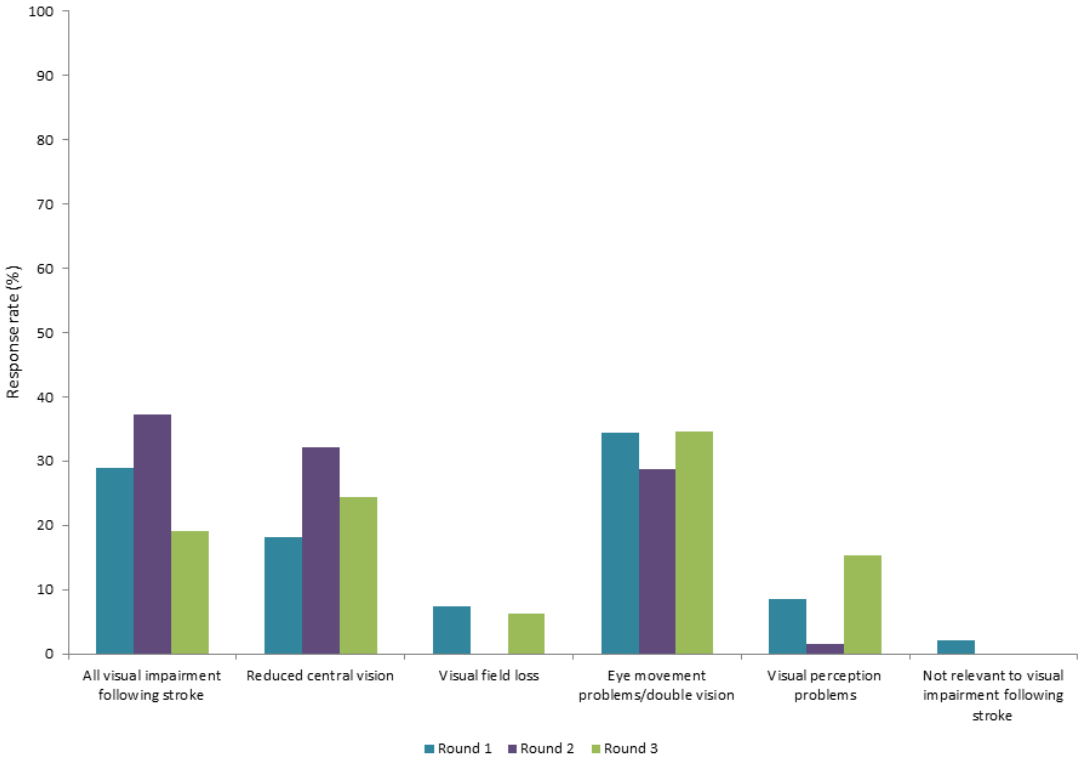


Figure 8.11: Agreement of application of 'blurred vision' item to a category of visual impairment. When and where consensus is reached shown by *

8.3.3.4*: 'Objects jumping around'*

Consensus (73.5%) to include the item was reached in the third round (Table 8.6). Range interval and standard deviation decreased (by 3 and 0.6, respectively) indicating convergence. The mean increased over the three rounds, as did the rank slightly from 34th to 32nd.

Most participants responded that 'objects jumping around' was most relevant to both 'eye movement problems/double vision' and 'visual perception problems' (Figure 8.12). The figures between these two categories varied across the three rounds. A two-category consensus (76.9%) was reached in round three, as the proportion responding as relevant to 'all visual impairment following stroke' dropped to 14.1%.

8.3.3.5*: 'Deterioration of vision'*

Consensus (74.3%) to include the item was reached in the first round and strengthened in subsequent rounds to 81.7% in the third (Table 8.7). Agreement increased over the three rounds, with range interval and standard deviation decreasing (by 2 and 0.4, respectively) indicating convergence. Inversely the mean ranking of importance decreased. The mean increased over the three rounds, whereas the rank dropped from 10th initially to 15th in the final round.

A consensus (93.2%) that 'deterioration of vision' was relevant to 'all visual impairment following stroke' was achieved in the second round (Figure 8.13). The strength of the consensus decreased slightly in the third round to 90.4%.

8.3.3.6*: 'Fluctuation'*

No consensus was reached to either include or exclude this item (Table 8.8). Most participants selected an 'important but not critical' option; 67.3% in the final round. Both the range interval and standard deviation remained high throughout the three rounds, decreasing slightly (by 1 and 0.4, respectively). The item rank remained low, initially 49th and decreased throughout the rounds along with the mean, finishing 52nd in the final round.

A consensus (81.4%) that 'fluctuation' was relevant to 'all visual impairment following stroke' was achieved in the second round (Figure 8.14). The strength of the consensus decreased slightly in the third round to 73.2%.

Table 8.6: Agreement and importance values for the 'objects jumping around' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	2.6%	6.5%	0.0%	0.0%	0.0%	0.0%
		2	1.3%		0.0%		0.0%	
		3	2.6%		0.0%		0.0%	
	Important but not critical	4	3.8%	29.5%	1.6%	36.1%	4.1%	26.5%
		5	16.7%		11.5%		6.1%	
		6	9.0%		23.0%		16.3%	
	Critical	7	38.4%	64.0%	47.5%	63.9%	49.0%	73.5%
		8	17.9%		13.1%		20.4%	
		9	7.7%		3.3%		4.1%	
Importance	Median		7.0		7.0		7.0	
	Range		1-9		4-9		4-9	
	Mean		6.5		6.7		6.9	
	SD		1.7		1.0		1.1	
	Mean Rank		34		32		=32	

= Consensus

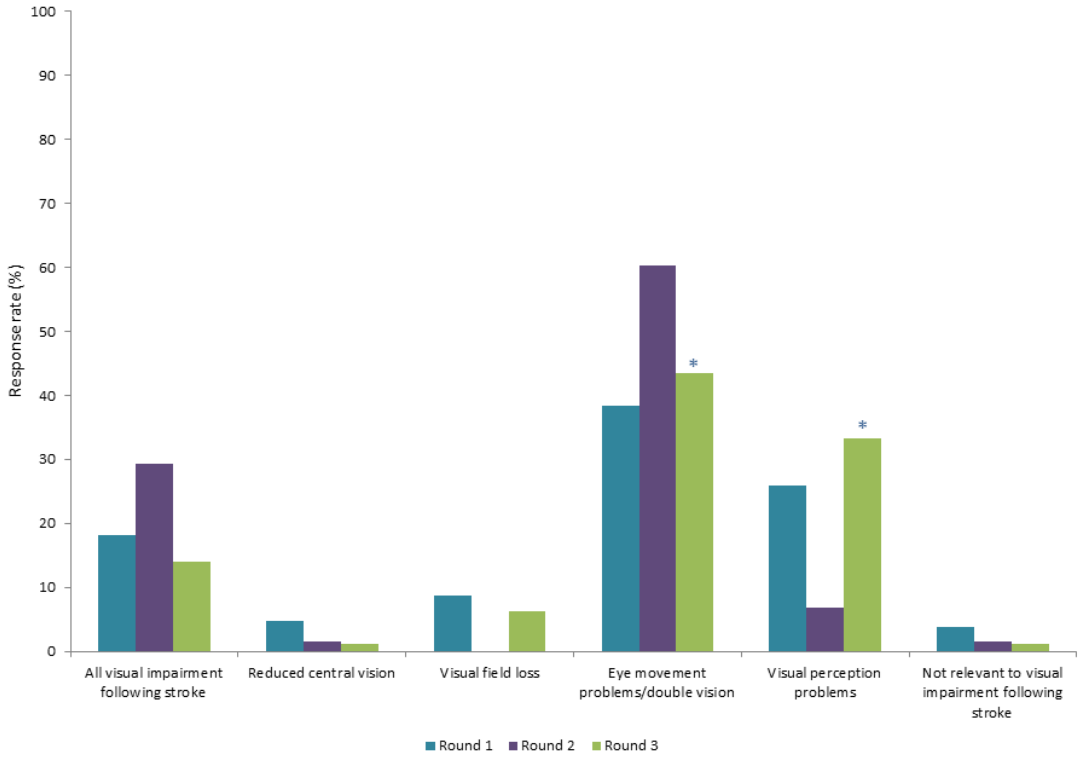


Figure 8.12: Agreement of application of 'objects jumping around' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.7: Agreement and importance values for the 'deterioration of vision' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	0.0%	2.6%	0.0%	1.6%	0.0%	0.0%
		2	2.6%		1.6%		0.0%	
		3	0.0%		0.0%		0.0%	
	Important but not critical	4	3.9%	23.1%	1.6%	18.0%	2.0%	18.3%
		5	5.1%		3.3%		4.1%	
		6	14.1%		13.1%		12.2%	
	Critical	7	26.9%	74.3%	32.8%	80.4%	28.6%	81.7%
		8	33.3%		37.7%		42.9%	
		9	14.1%		9.9%		10.2%	
Importance	Median		7.0		7.0		8.0	
	Range		2-9		2-9		4-9	
	Mean		7.1		7.3		7.4	
	SD		1.5		1.2		1.1	
	Mean Rank		10		=14		15	

= Consensus

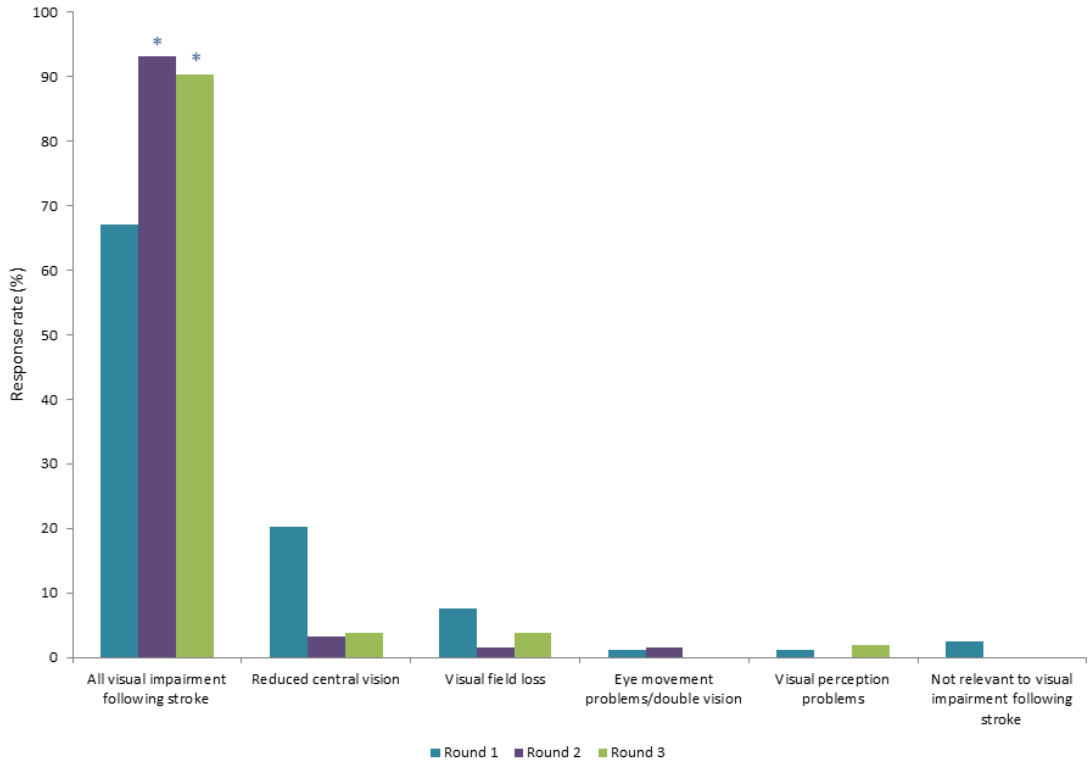


Figure 8.13: Agreement of application of 'deterioration of vision' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.8: Agreement and importance values for the 'fluctuation' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	2.6%	5.2%	0.0%	4.9%	0.0%	6.1%
		2	1.3%		3.3%		2.0%	
		3	1.3%		1.6%		4.1%	
	Important but not critical	4	6.4%	52.5%	4.9%	59.0%	0.0%	67.3%
		5	25.6%		27.9%		30.6%	
		6	20.5%		26.2%		36.7%	
	Critical	7	24.4%	42.3%	24.6%	36.1%	18.4%	26.6%
		8	17.9%		11.5%		8.2%	
		9	0.0%		0.0%		0.0%	
Importance	Median		6.0		6.0		6.0	
	Range		1-8		2-8		2-8	
	Mean		6.0		5.9		5.8	
	SD		1.6		1.4		1.2	
	Mean Rank		=49		49		=52	

= Consensus

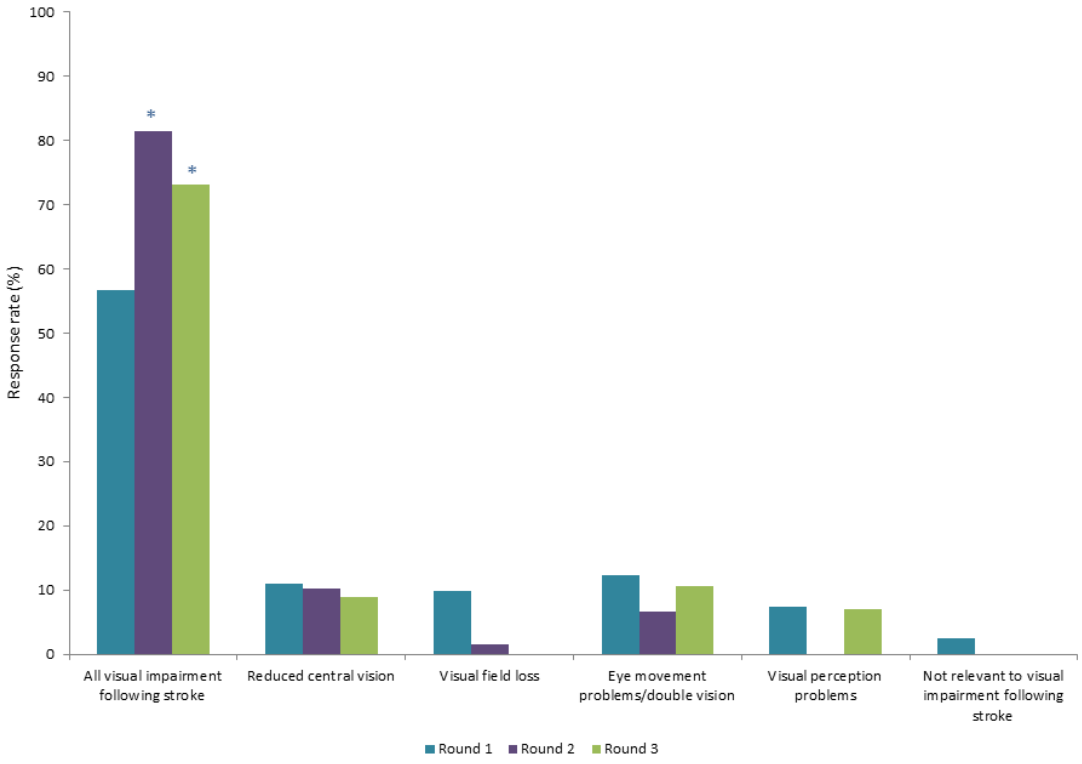


Figure 8.14: Agreement of application of 'fluctuation' item to a category of visual impairment. When and where consensus is reached shown by *

8.3.3.7*: 'Tired eyes'*

No consensus was reached to either include or exclude this item (Table 8.9). The majority responded that the item was 'important but not critical'; 87.8% in the final round. The range interval and standard deviation decreased throughout the three rounds (by 2 and 0.6, respectively), indicating convergence. The item has a low rank, initially 56th and decreased along with the mean throughout the rounds to 58th in the final round.

A consensus (71.2%) that 'tired eyes' was relevant to 'all visual impairment following stroke' was reached in the second round (Figure 8.15). The strength of the consensus decreased slightly in the third round to 70.9%, in favour of the 'reduced central vision' and 'visual perception problems' categories.

8.3.3.8*: 'Eyes seeing differently'*

No consensus was reached to either include or exclude this item (Table 8.10). This was due to the proportion of participants who selected an 'important but not critical' option; 38.8% in the final round. The range interval and standard deviation decreased throughout the three rounds (by 3 and 0.6 respectively) indicating convergence. The item had a low rank throughout the rounds, 46th initially increasing slightly along with the mean to 45th in the final round.

A consensus (83.1%) that 'eyes seeing differently' was relevant to 'all visual impairment following stroke' was reached in the second round (Figure 8.16). The strength of the consensus decreased slightly in the third round to 75.0%, in favour of the 'reduced central vision' and 'visual perception problems' categories.

8.3.3.9*: 'Double vision'*

Consensus (76.6%) that the item should be included was reached in the second round and strengthened into the third (91.8%) (Table 8.11). The range interval and standard deviation decreased across the three rounds (by 4 and 1.1, respectively) indicating convergence. The rank and mean increased across the rounds, rank 12th initially to 7th in the final round.

A single category consensus (71.6%) that 'double vision' was most relevant to 'eye movement problems/double vision' was reached in the first round (Figure 8.17). The figure varied across the three rounds, with a slightly higher response in the 'visual perception problems' category in the first and third rounds.

8.3.3.10*: 'Judging distances'*

Consensus (73.3%) was reached to include the item in the second round and remained stable into the third (73.5%) (Table 8.12). The range interval and standard deviation decreased throughout the three rounds (by 4 and 0.4 respectively) indicating convergence. The mean increased slightly as did the rank across the three rounds from 25th initially to 24th in the final round.

No consensus was reached on which category of visual impairment 'judging distances' was most relevant to (Figure 8.18). The only category which did not receive any responses was the 'not relevant' category, indicating agreement that it is a relevant item for stroke survivors with visual impairment. The most popular categories were 'all visual impairment following stroke', 'eye movement problems/double vision' and 'visual perception problems'.

8.3.3.11*: 'Unusual appearance'*

No consensus either to include or exclude this item was reached across the three rounds (Table 8.13). The majority responded using an 'important but not critical' option (77.5%) in the final round. The range interval and standard deviation did slightly decrease across the three rounds (by 1 and 0.3 respectively), indicating convergence. The mean and rank remained stable in the second round and then increased in the final round although remaining low from 61st initially to 59th in the final round.

A high proportion of participants related 'unusual appearance' to 'eye movement problems/double vision' category (Figure 8.19). Consensus (86.0%) on this was not reached until the third round as a proportion of participants responded that this item was 'not relevant to visual impairment following stroke' in both the first (28.4%) and second rounds (15.3%).

Table 8.9: Agreement and importance values for the 'tired eyes' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	0.0%	9.0%	0.0%	9.8%	0.0%	4.1%
		2	2.6%		1.6%		0.0%	
		3	6.4%		8.2%		4.1%	
	Important but not critical	4	7.7%	62.8%	11.5%	82.0%	8.2%	87.8%
		5	32.0%		47.5%		59.2%	
		6	23.1%		23.0%		20.4%	
	Critical	7	14.1%	28.2%	4.9%	8.2%	6.1%	8.1%
		8	11.5%		3.3%		2.0%	
		9	2.6%		0.0%		0.0%	
Importance	Median		6.0		5.0		5.0	
	Range		2-9		2-8		3-8	
	Mean		5.7		5.1		5.2	
	SD		1.5		1.2		0.9	
	Mean Rank		56		57		58	

= Consensus

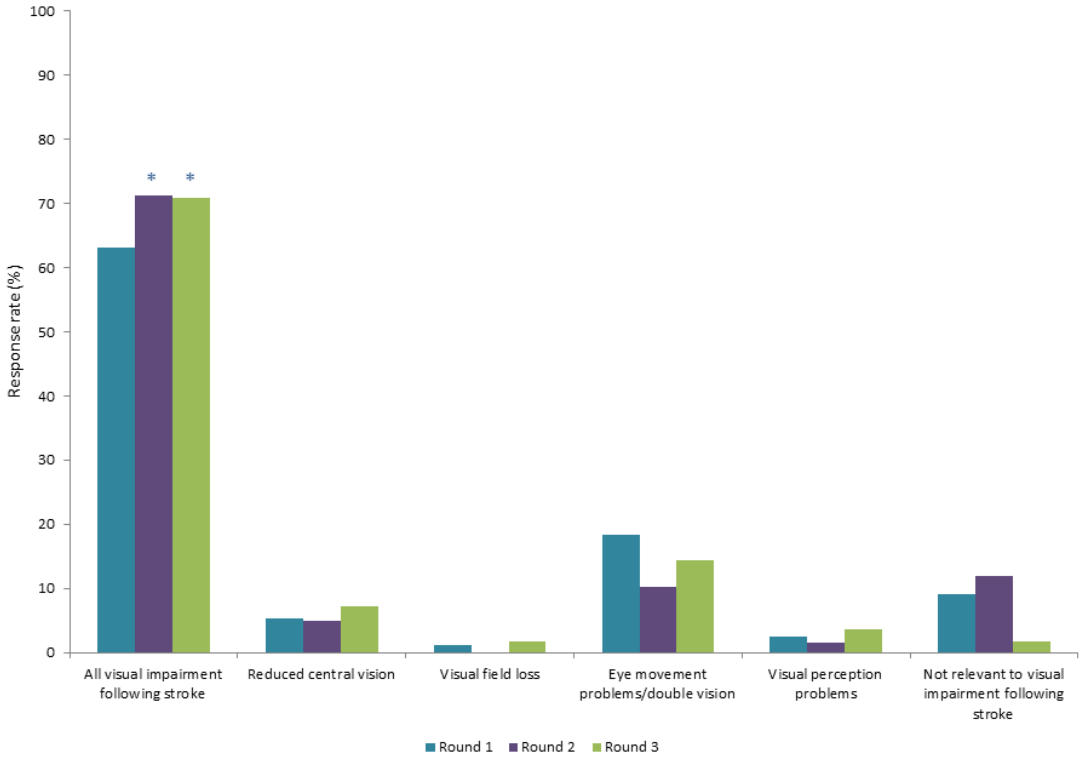


Figure 8.15: Agreement of application of 'tired eyes' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.10: Agreement and importance values for the 'eyes seeing differently' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	2.6%	11.6%	0.0%	8.3%	0.0%	4.1%
		2	0.0%		0.0%		0.0%	
		3	9.0%		8.3%		4.1%	
	Important but not critical	4	3.8%	42.2%	1.7%	45.1%	0.0%	38.8%
		5	14.1%		11.7%		10.2%	
		6	24.3%		31.7%		28.6%	
	Critical	7	28.2%	46.2%	41.6%	46.6%	46.9%	57.1%
		8	15.4%		5.0%		10.2%	
		9	2.6%		0.0%		0.0%	
Importance	Median		6.0		6.0		7.0	
	Range		1-9		3-8		3-8	
	Mean		6.1		6.1		6.5	
	SD		1.7		1.3		1.1	
	Mean Rank		=46		48		=45	

= Consensus

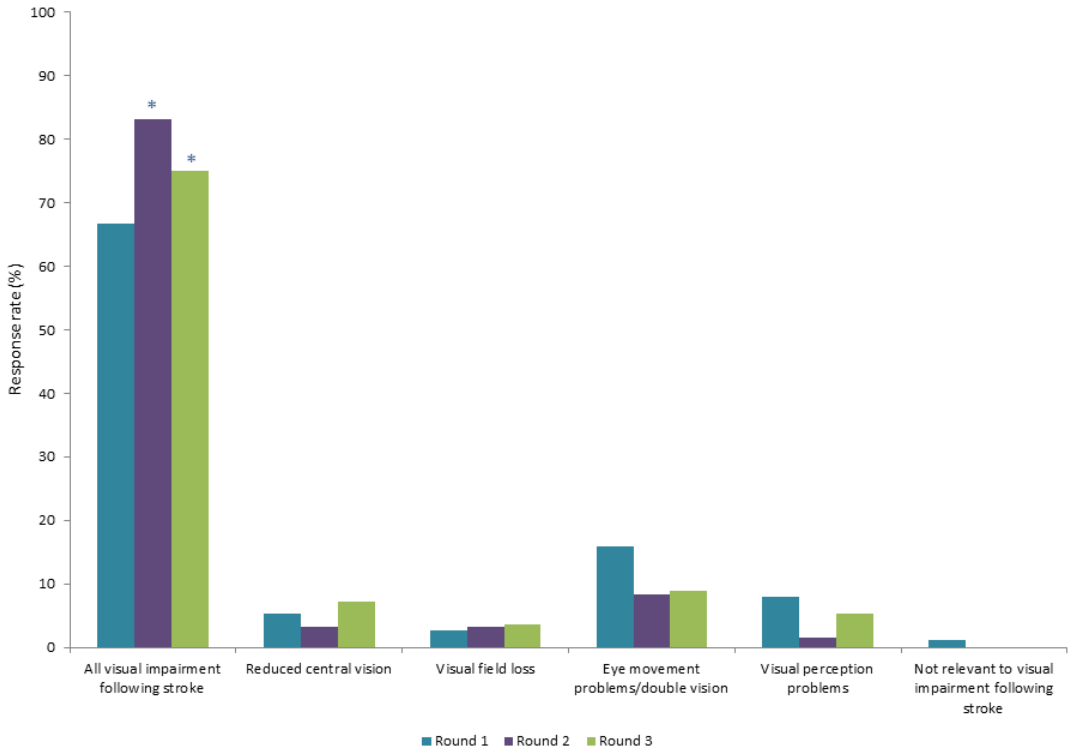


Figure 8.16: Agreement of application of 'eyes seeing differently' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.11: Agreement and importance values for the 'double vision' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	2.6%	9.1%	1.7%	1.7%	0.0%	0.0%
		2	2.6%		0.0%		0.0%	
		3	3.9%		0.0%		0.0%	
	Important but not critical	4	0.0%	23.0%	0.0%	21.7%	0.0%	8.2%
		5	5.1%		1.7%		2.1%	
		6	17.9%		20.0%		6.1%	
	Critical	7	16.7%	67.9%	10.0%	76.6%	16.3%	91.8%
		8	33.3%		55.0%		61.2%	
		9	17.9%		11.6%		14.3%	
Importance	Median		8.0		8.0		8.0	
	Range		1-9		1-9		5-9	
	Mean		6.8		7.5		7.8	
	SD		1.9		1.3		0.8	
	Mean Rank		12		7		7	

= Consensus

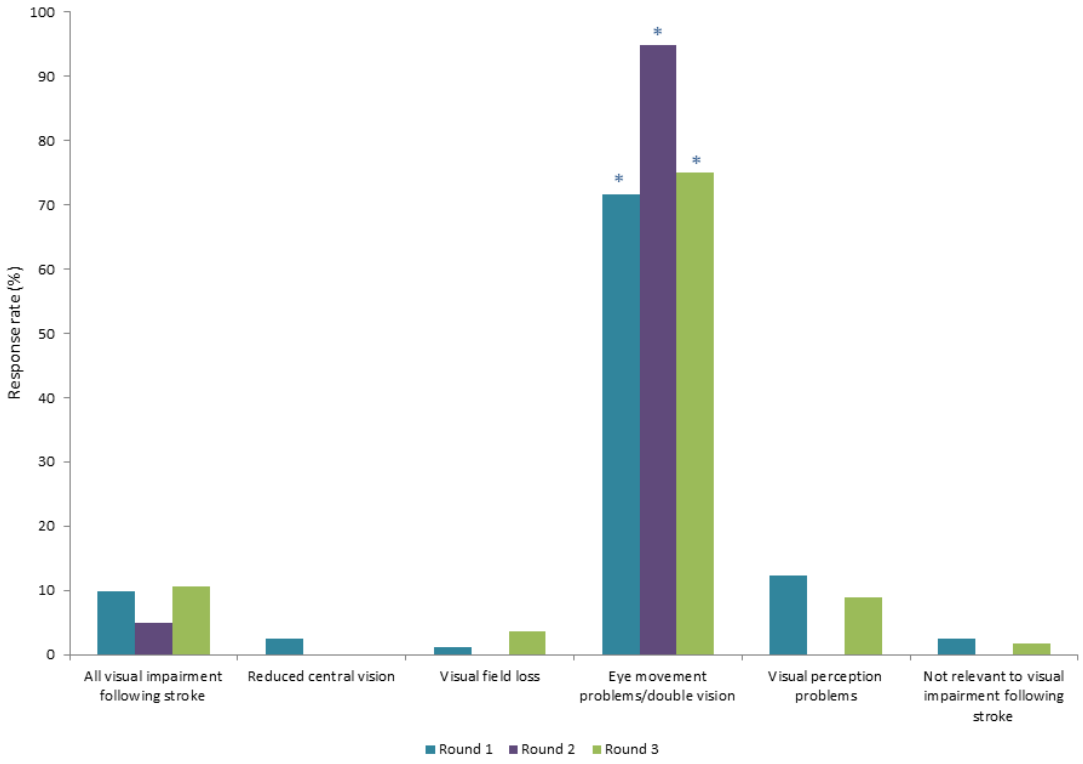


Figure 8.17: Agreement of application of 'double vision' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.12: Agreement and importance values for the 'judging distances' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	1.3%	1.3%	0.0%	0.0%	0.0%	0.0%
		2	0.0%		0.0%		0.0%	
		3	0.0%		0.0%		0.0%	
	Important but not critical	4	2.6%	34.6%	0.0%	26.6%	2.0%	26.6%
		5	12.8%		3.3%		2.2%	
		6	19.2%		23.3%		22.4%	
	Critical	7	29.5%	64.1%	38.3%	73.3%	32.7%	73.5%
		8	29.5%		31.7%		40.8%	
		9	5.1%		3.3%		0.0%	
Importance	Median		7.0		7.0		7.0	
	Range		1-9		5-9		4-8	
	Mean		6.8		7.1		7.1	
	SD		1.4		0.9		1.0	
	Mean Rank		25		=19		24	

= Consensus

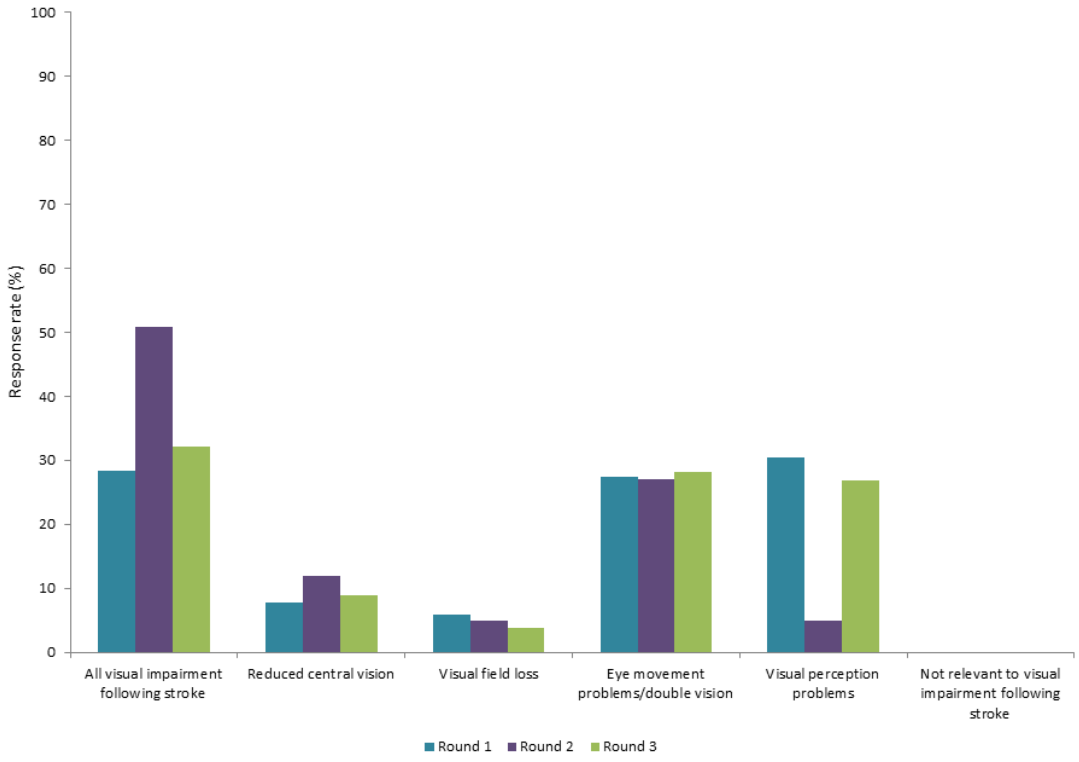


Figure 8.18: Agreement of application of 'judging distances' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.13: Agreement and importance values for the 'unusual appearance' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	5.1%	25.6%	3.3%	13.3%	2.1%	12.3%
		2	9.0%		6.7%		6.1%	
		3	11.5%		3.3%		4.1%	
	Important but not critical	4	12.8%	55.2%	21.7%	81.7%	14.3%	77.5%
		5	32.1%		41.7%		36.7%	
		6	10.3%		18.3%		26.5%	
	Critical	7	14.1%	19.2%	3.3%	5.0%	6.1%	10.2%
		8	3.8%		1.7%		4.1%	
		9	1.3%		0.0%		0.0%	
Importance	Median		5.0		5.0		5.0	
	Range		1-9		1-8		1-8	
	Mean		4.7		4.7		5.0	
	SD		1.8		1.4		1.5	
	Mean Rank		61		61		59	

= Consensus

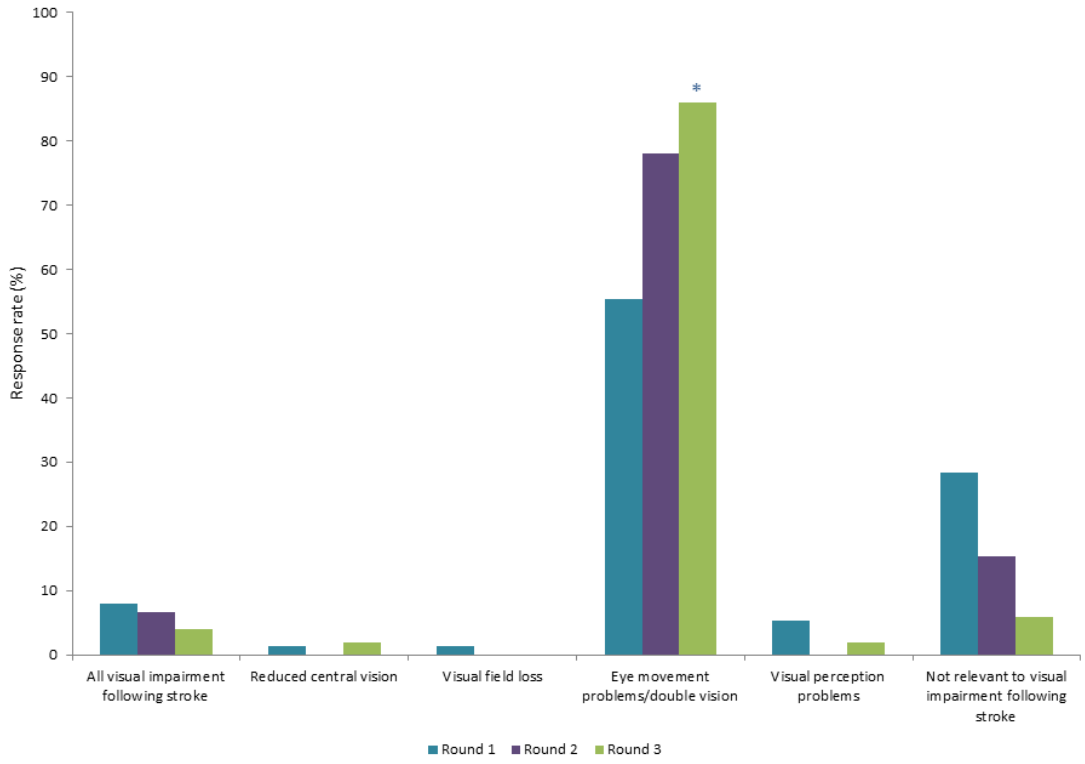


Figure 8.19: Agreement of application of 'unusual appearance' item to a category of visual impairment. When and where consensus is reached shown by *

8.3.3.12*: 'Seeing far side of a room'*

No consensus to either include or exclude this item was reached within the three rounds (Table 8.14). An increasing proportion responded using the 'critical' options; initially 52.6% in the first to 59.2% in the third round. The range interval and standard deviation slightly decreased across the three rounds (by 1 and 0.4 respectively), indicating convergence. Despite the mean remaining the same, the rank decreased from 35th initially to 41st in the final round.

A consensus (72.9%) that 'seeing far side of a room' was relevant to 'all visual impairment following stroke' was reached in the second round (Figure 8.20). This consensus was lost in the third round (60.3%), with an increase in the selection of the 'visual field loss', 'eye movement problem/double vision' and 'visual perception problems' categories.

8.3.3.13*: 'Seeing something far away'*

No consensus to either include or exclude this item was reached within the three rounds (Table 8.15). Most participants responded to this item as 'important but not critical'; 73.6% in the third round. The range interval and standard deviation decreased across the three rounds (by 2 and 0.4 respectively), indicating convergence. The mean remained the same in the first and third rounds whereas the rank dropped slightly from 52nd initially to 54th in the final round.

No consensus was reached on which category of visual impairment 'seeing something far away' was most relevant to (Figure 8.21). The only category that did not receive any responses was the 'not relevant' category. This indicated agreement that it is a relevant item for stroke survivors with visual impairment. The most popular category in all three rounds was 'all visual impairment following stroke'.

8.3.3.14*: 'Seeing faces'*

Consensus (75.6%) to include the item was reached in the third round (Table 8.16). The range interval and standard deviation decreased (by 3 and 0.8 respectively), demonstrating convergence. The mean continued to increase across the three rounds, whereas, the rank decreased in the second round from 36th to 39th and then increased to 35th in the final round.

No consensus was reached on which category of visual impairment 'seeing faces' was most relevant to (Figure 8.22). The focus in the second round was between 'all visual impairment'

(57.6%) and 'reduced central vision' (40.7%) categories. This diverged again in the third round with an increase in the selection of the 'eye movement problems/double vision' and 'visual perception problems' categories.

8.3.3.15*: 'Writing'*

No consensus to either include or exclude this item was reached within the three rounds (Table 8.17). This was due to the proportion of participants who selected an 'important but not critical' option; 40.8% in the final round. The range interval and standard deviation decreased across the three rounds (by 4 and 0.4 respectively), indicating convergence. The mean continued to increase across the three rounds, whereas, the rank increased in the second from 42nd to 41st then dropped to 43rd in the final round.

A consensus (83.1%) that 'writing' was relevant to 'all visual impairment following stroke' was reached in the second round (Figure 8.23). The strength of the consensus decreased in the third round (76.8%) with an increase in the use of the 'eye movement problems/double vision' and 'visual perception problems' categories.

8.3.3.16*: 'Close-up vision'*

A consensus was not reached to include or exclude the item within the three rounds (Table 8.18). Decreasing range interval and standard deviation did demonstrate convergence towards a consensus across the three rounds (by 5 and 0.5 respectively). The mean consistently increased across the process, whereas the rank decreased in the second round from 29th to 31st and subsequently increased to 28th in the final round.

No consensus was reached on which category of visual impairment 'close-up vision' was most relevant to (Figure 8.24). The decision was mainly split between the 'all visual impairment', 'reduced central vision' and 'eye movement problems/double vision' categories. The 'all visual impairment' remained the most popular (50.8%) in the final round.

Table 8.14: Agreement and importance values for the 'seeing far side of a room' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	0.0%	3.8%	0.0%	0.0%	0.0%	2.0%
		2	0.0%		0.0%		0.0%	
		3	3.8%		0.0%		2.0%	
	Important but not critical	4	2.6%	43.6%	1.7%	51.7%	0.0%	38.8%
		5	16.7%		20.0%		10.2%	
		6	24.3%		30.0%		28.6%	
	Critical	7	28.2%	52.6%	36.6%	48.3%	51.0%	59.2%
		8	21.8%		10.0%		8.2%	
		9	2.6%		1.7%		0.0%	
Importance	Median		7.0		6.0		7.0	
	Range		3-9		4-9		3-8	
	Mean		6.5		6.4		6.5	
	SD		1.3		1.0		0.9	
	Mean Rank		35		42		41	

= Consensus

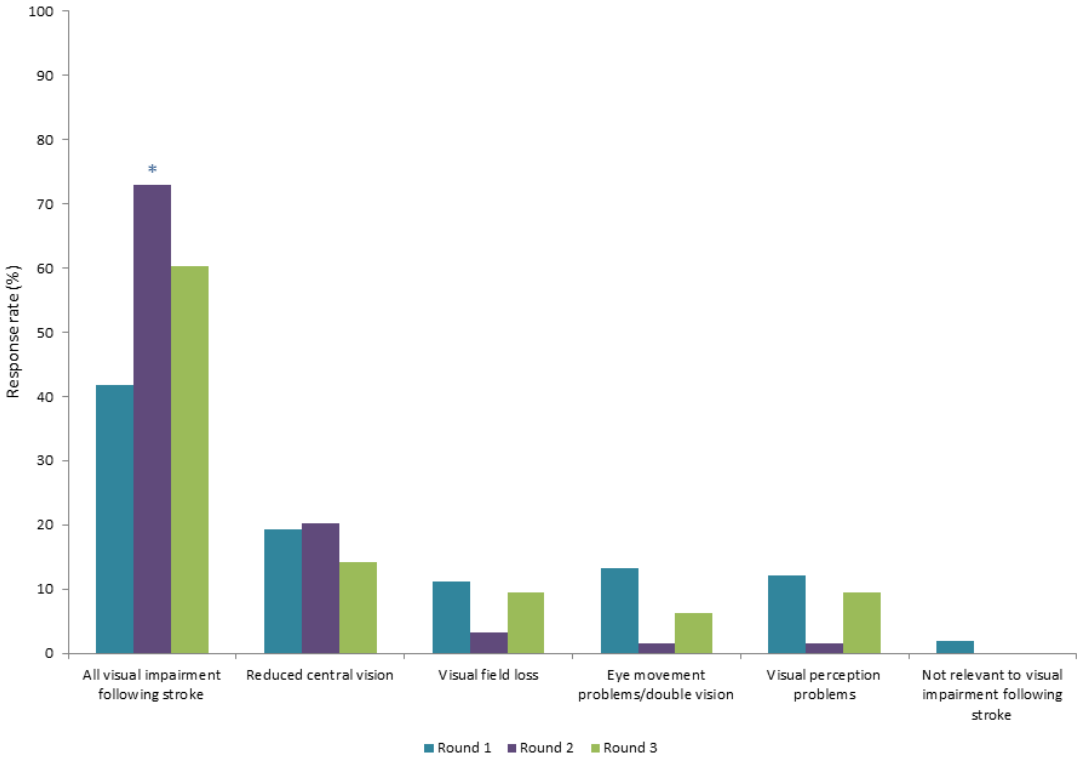


Figure 8.20: Agreement of application of 'seeing far side of a room' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.15: Agreement and importance values for the 'seeing something far away' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	1.3%	5.2%	0.0%	0.0%	0.0%	2.0%
		2	1.3%		0.0%		0.0%	
		3	2.6%		0.0%		2.0%	
	Important but not critical	4	10.3%	59.0%	14.8%	73.8%	2.0%	73.6%
		5	28.2%		34.4%		43.0%	
		6	20.5%		24.6%		28.6%	
	Critical	7	24.3%	35.8%	23.0%	26.2%	20.4%	24.4%
		8	7.7%		1.6%		2.0%	
		9	3.8%		1.6%		2.0%	
Importance	Median		6.0		6.0		6.0	
	Range		1-9		4-9		3-9	
	Mean		5.8		5.7		5.8	
	SD		1.5		1.1		1.1	
	Mean Rank		52		54		54	

= Consensus

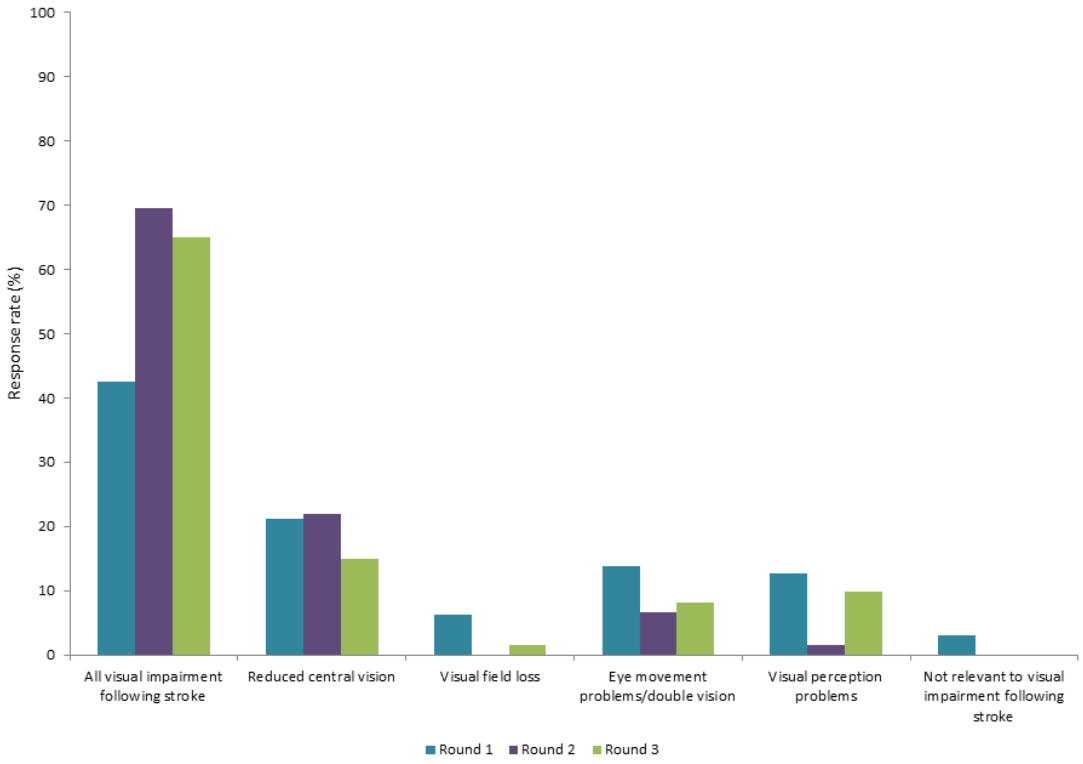


Figure 8.21: Agreement of application of 'seeing something far away' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.16: Agreement and importance values for the 'seeing faces' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	1.3%	6.5%	0.0%	0.0%	0.0%	2.0%
		2	3.9%		0.0%		0.0%	
		3	1.3%		0.0%		2.0%	
	Important but not critical	4	6.4%	33.3%	6.6%	41.0%	2.0%	22.4%
		5	12.8%		14.7%		2.0%	
		6	14.1%		19.7%		18.4%	
	Critical	7	33.3%	60.2%	44.3%	59.0%	57.2%	75.6%
		8	19.2%		14.7%		18.4%	
		9	7.7%		0.0%		0.0%	
Importance	Median		7.0		7.0		7.0	
	Range		1-9		4-8		3-8	
	Mean		6.4		6.5		6.8	
	SD		1.8		1.1		1.0	
	Mean Rank		=36		39		35	

= Consensus

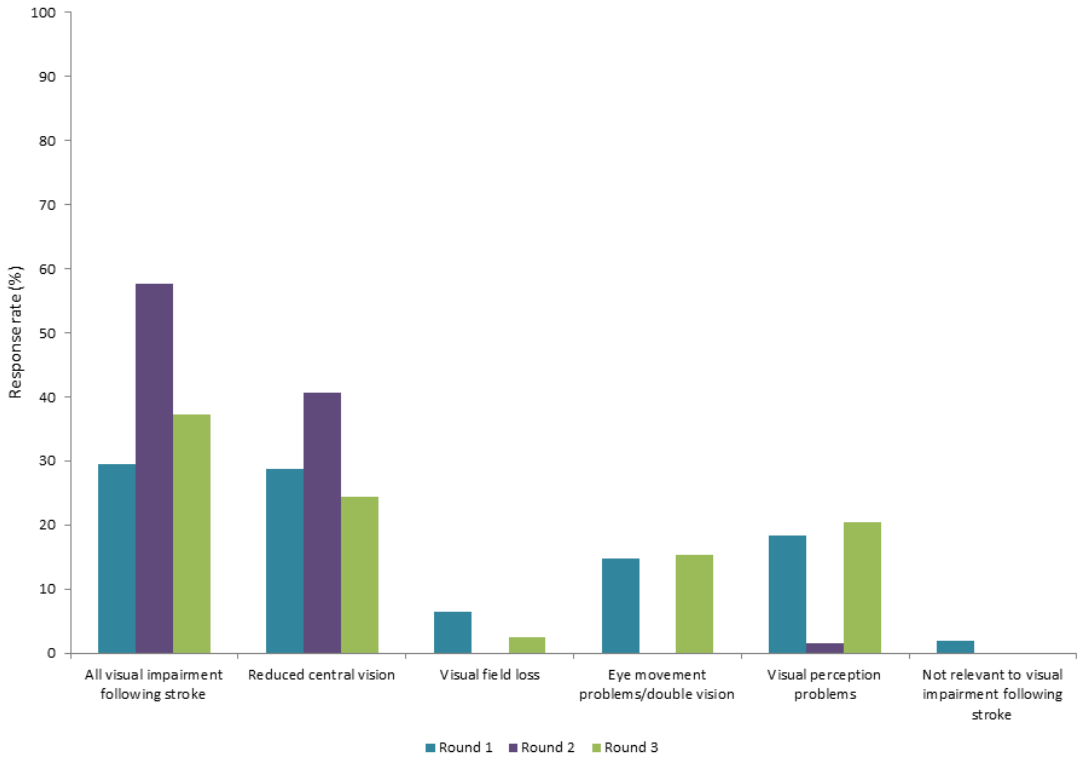


Figure 8.22: Agreement of application of 'seeing faces' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.17: Agreement and importance values for the 'writing' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	1.3%	2.6%	0.0%	0.0%	0.0%	0.0%
		2	0.0%		0.0%		0.0%	
		3	1.3%		0.0%		0.0%	
	Important but not critical	4	5.1%	47.4%	3.3%	46.7%	2.0%	40.8%
		5	20.5%		11.7%		18.4%	
		6	21.8%		31.7%		20.4%	
	Critical	7	35.9%	50.0%	45.0%	53.3%	49.0%	59.2%
		8	11.5%		8.3%		10.2%	
		9	2.6%		0.0%		0.0%	
Importance	Median		6.5		7.0		7.0	
	Range		1-9		4-8		4-8	
	Mean		6.3		6.4		6.5	
	SD		1.4		0.9		1.0	
	Mean Rank		42		41		=43	

= Consensus

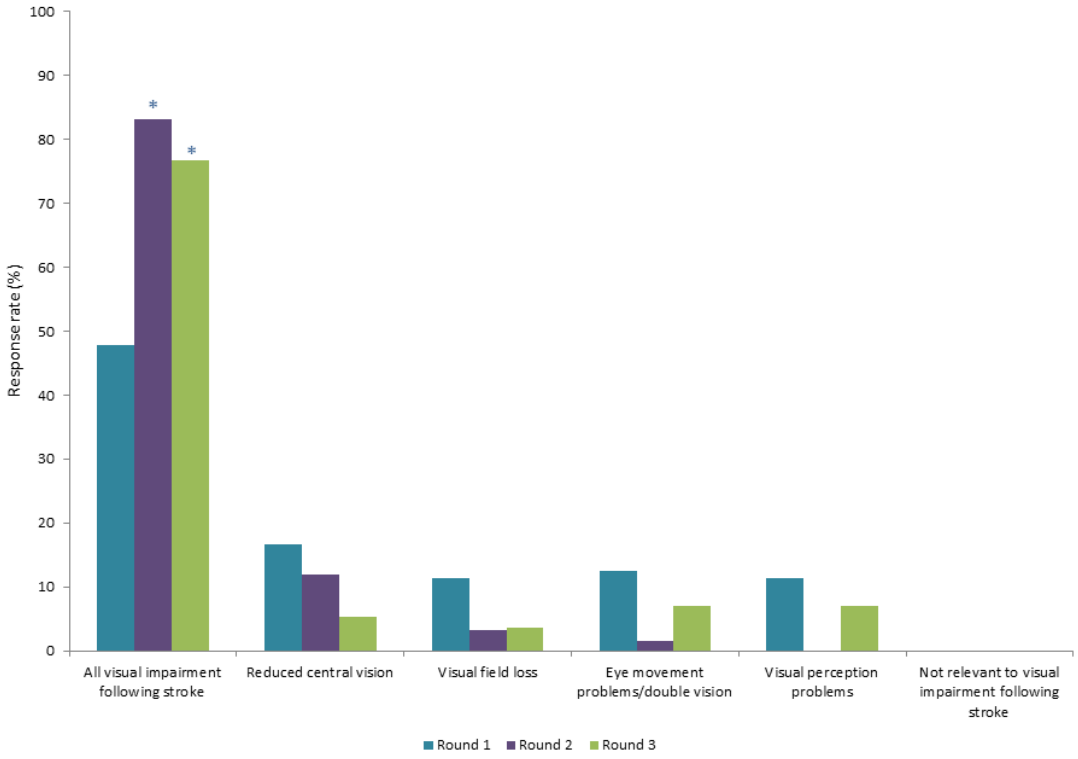


Figure 8.23: Agreement of application of 'writing' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.18: Agreement and importance values for the 'close-up vision' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	1.3%	2.6%	0.0%	0.0%	0.0%	0.0%
		2	0.0%		0.0%		0.0%	
		3	1.3%		0.0%		0.0%	
	Important but not critical	4	3.8%	39.7%	4.9%	37.7%	0.0%	32.6%
		5	11.5%		6.6%		6.1%	
		6	24.4%		26.2%		26.5%	
	Critical	7	32.1%	57.7%	37.7%	62.3%	32.7%	67.4%
		8	21.8%		23.0%		34.7%	
		9	3.8%		1.6%		0.0%	
Importance	Median		7.0		7.0		7.0	
	Range		1-9		4-9		5-8	
	Mean		6.6		6.7		7.0	
	SD		1.4		1.1		0.9	
	Mean Rank		=29		31		=28	

= Consensus

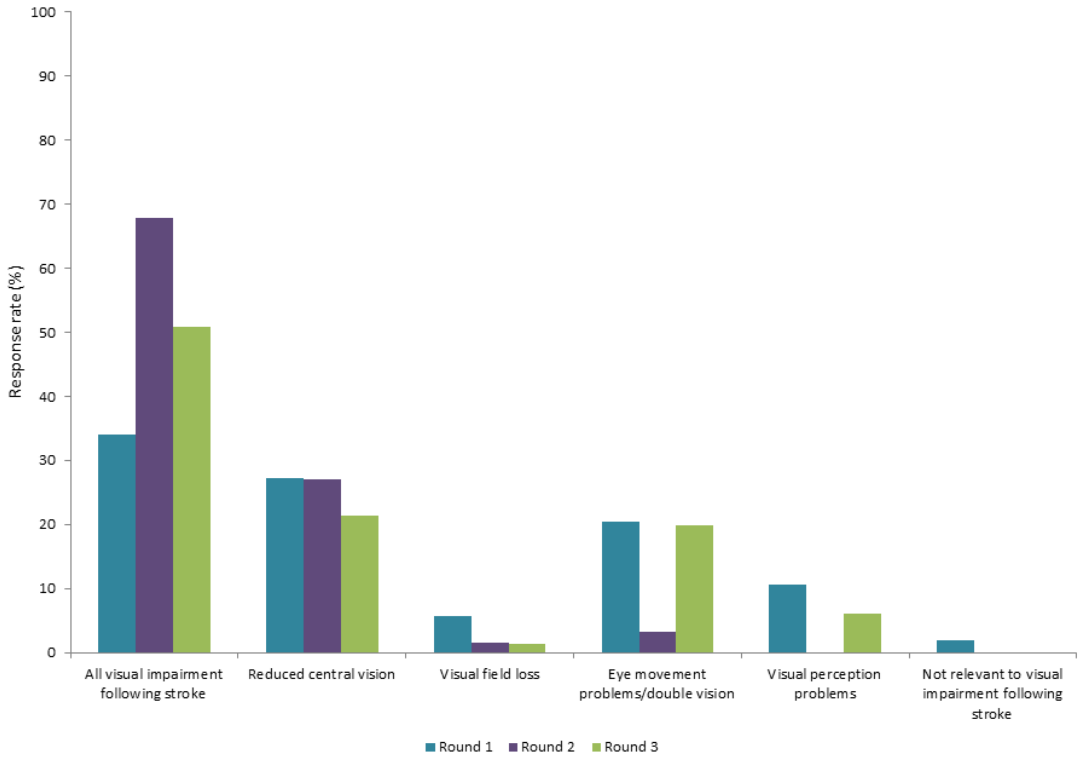


Figure 8.24: Agreement of application of 'close-up vision' item to a category of visual impairment. When and where consensus is reached shown by *

8.3.3.17*: 'Finding something'*

No consensus to either include or exclude this item was reached within the process (Table 8.19). This was due to the majority of participants being split between option '6' (36.7%) and '7' (34.7%) and this being the threshold between 'important but not critical' and 'critical'. The range interval and standard deviation decreased across the three rounds (by 4 and 0.5 respectively), indicating convergence. The mean increased slightly in the third round whilst the rank dropped from 43rd initially to 48th in the final round.

A consensus (74.6%) that 'finding something' was relevant to 'all visual impairment following stroke' was reached in the second round (Figure 8.25). This continued to strengthen in the third round to 89.6%.

8.3.3.18*: 'Using a computer'*

No consensus to either include or exclude this item was reached (Table 8.20). The majority of participants (77.6%) selected an option from the 'important but not critical' category. The range interval and standard deviation decreased across the three rounds (by 2 and 0.5 respectively), indicating convergence. The mean and rank increased across the three round from 55th initially to 49th in the final round.

A consensus (93.2%) that 'using a computer' was relevant to 'all visual impairment following stroke' was reached in the second round (Figure 8.26). The strength of the consensus weakened in the third round (86.3%).

8.3.3.19*: 'Following a line of print'*

Consensus (71.6%) to include the item was reached in the second round and continued to strengthen in the third (83.7%) (Table 8.21). The range interval and standard deviation both decreased across the three rounds (by 2 and 0.7, respectively), indicating convergence. The mean across the three rounds increased, whereas the rank decreased from 13th initially to 25th in the final round.

A consensus (79.7%) that 'following a line of print' was relevant to 'all visual impairment following stroke' was reached in second round (Figure 8.27). This consensus was lost in the third round, with an increase in participants selecting the 'eye movement problems/double vision' and 'visual perception problems' categories.

Table 8.19: Agreement and importance values for the 'finding something' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	1.3%	5.1%	0.0%	1.7%	0.0%	0.0%
		2	0.0%		0.0%		0.0%	
		3	3.8%		1.7%		0.0%	
	Important but not critical	4	3.8%	50.0%	0.0%	57.6%	2.0%	57.1%
		5	18.0%		27.1%		18.4%	
		6	28.2%		30.5%		36.7%	
	Critical	7	28.2%	44.9%	32.2%	40.7%	34.7%	42.9%
		8	15.4%		8.5%		8.2%	
		9	1.3%		0.0%		0.0%	
Importance	Median		6.0		6.0		6.0	
	Range		1-9		3-8		4-8	
	Mean		6.2		6.2		6.3	
	SD		1.4		1.0		0.9	
	Mean Rank		43		46		48	

= Consensus

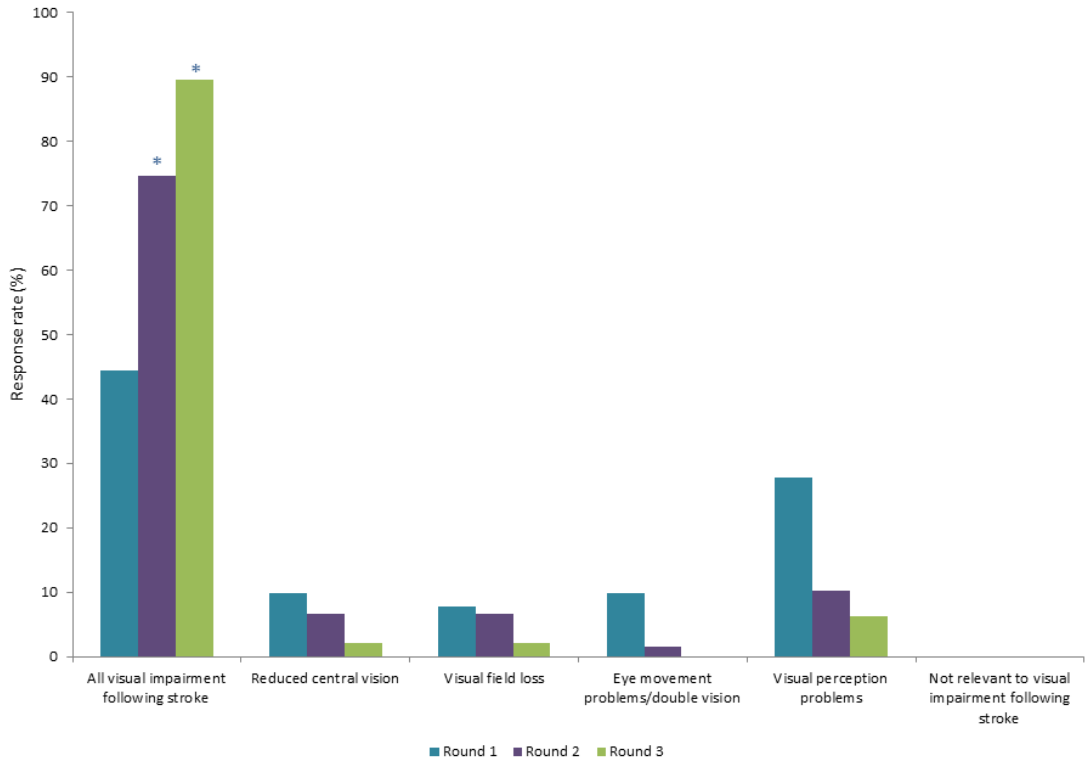


Figure 8.25: Agreement of application of 'finding something' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.20: Agreement and importance values for the 'using a computer' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	0.0%	6.4%	0.0%	3.3%	0.0%	0.0%
		2	1.3%		0.0%		0.0%	
		3	5.1%		3.3%		0.0%	
	Important but not critical	4	10.3%	65.4%	1.7%	78.4%	6.1%	77.6%
		5	28.2%		31.7%		16.4%	
		6	26.9%		45.0%		55.1%	
	Critical	7	19.2%	28.2%	13.3%	18.3%	18.4%	22.4%
		8	6.4%		5.0%		2.0%	
		9	2.6%		0.0%		2.0%	
Importance	Median		6.0		6.0		6.0	
	Range		2-9		3-8		4-9	
	Mean		5.7		5.8		6.0	
	SD		1.4		1.0		0.9	
	Mean Rank		55		50		49	

= Consensus

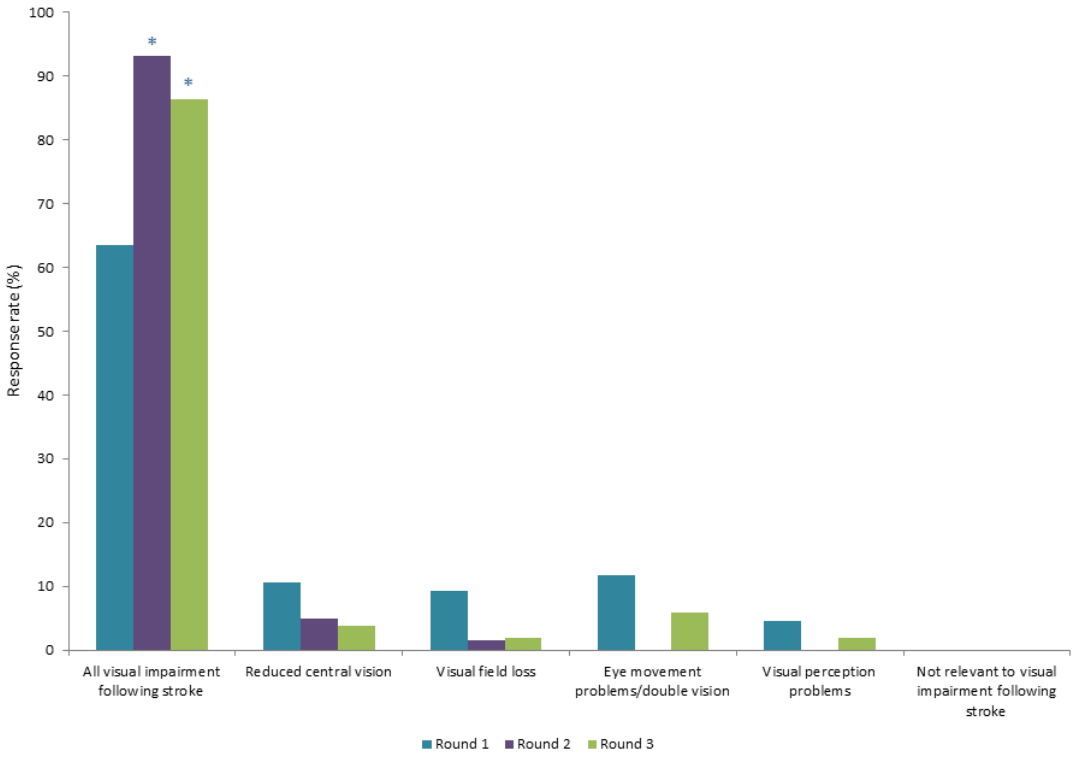


Figure 8.26: Agreement of application of 'using a computer' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.21: Agreement and importance values for the 'following a line of print' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	0.0%	2.6%	0.0%	0.0%	0.0%	0.0%
		2	0.0%		0.0%		0.0%	
		3	2.6%		0.0%		0.0%	
	Important but not critical	4	3.9%	29.5%	1.7%	28.4%	0.0%	16.3%
		5	5.1%		6.7%		2.0%	
		6	20.5%		20.0%		14.3%	
	Critical	7	30.8%	67.9%	46.6%	71.6%	61.3%	83.7%
		8	25.6%		21.7%		20.4%	
		9	11.5%		3.3%		2.0%	
Importance	Median		7.0		7.0		7.0	
	Range		3-9		4-9		5-9	
	Mean		7.0		6.9		7.1	
	SD		1.4		1.0		0.7	
	Mean Rank		=13		27		=25	

= Consensus

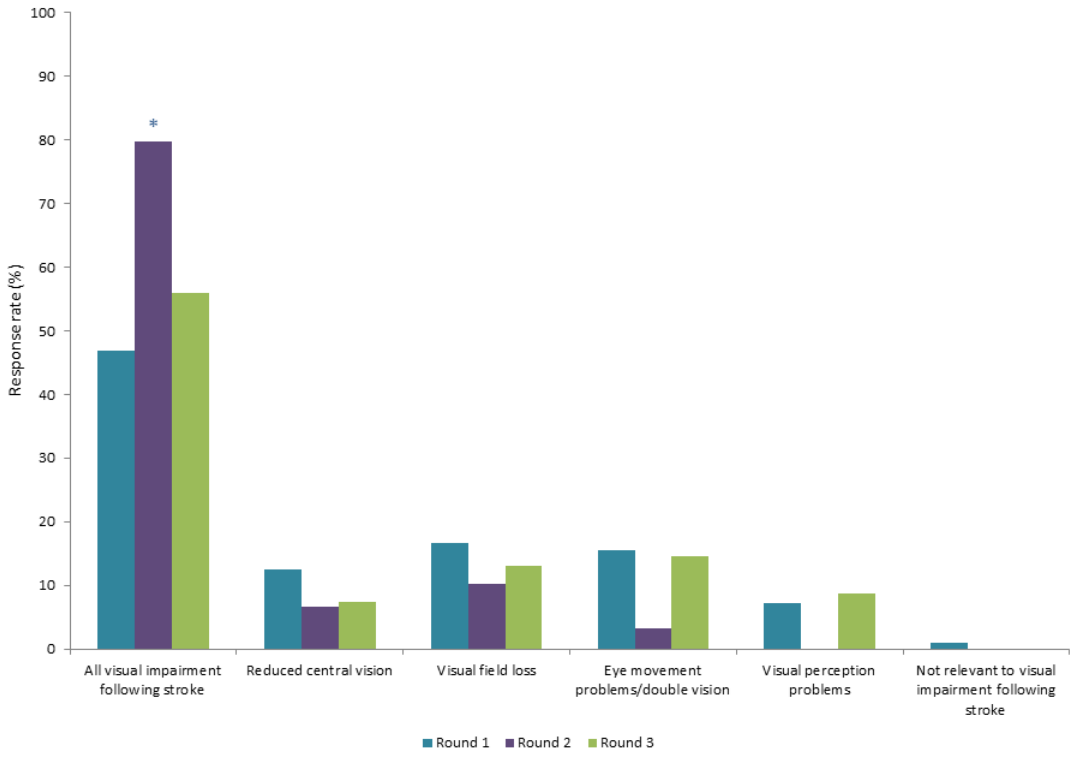


Figure 8.27: Agreement of application of 'following a line of print' item to a category of visual impairment. When and where consensus is reached shown by *

8.3.3.20*: 'Reading same print size'*

No consensus to either include or exclude this item was reached (Table 8.22). Most participants selected an 'important but not critical' option; 75.6% in the final round. The range interval remained the same in the first and third rounds. The standard deviation decreased across the three rounds (by 0.4). The mean and rank decreased across the three rounds, from 49th initially to 56th in the final round.

No consensus was reached on which category of visual impairment 'reading same print size' was most relevant to (Figure 8.28). 'All visual impairment following stroke' was the most popular option with 53.8% in the final round. 'Reduced central vision' was also a consistently popular option between 20.0-30.5%.

8.3.3.21*: 'Objects suddenly appearing'*

Consensus (77.1%) to include the item was reached in the second round and strengthened into the third (79.6%) (Table 8.23). The range interval and standard deviation decreased across the three rounds (by 1 and 0.4 respectively), indicating convergence. Despite the mean increasing across the three rounds, the rank decreased from 24th initially to 30th in the final round.

A two-category consensus (79.1%) that 'objects suddenly appearing' was relevant to 'visual field loss' and 'visual perception problems' was achieved in the third round (Figure 8.29). In the previous rounds 'all visual impairment' prevented the consensus (15.0% and 20.3%).

8.3.3.22*: 'Missing patches of vision'*

Consensus (72.9%) to include the item was reached in the second round and strengthened into the third (79.6%) (Table 8.24). The range interval and standard deviation decreased across the three rounds (by 4 and 0.7 respectively), indicating convergence. The mean increased over the three rounds. Despite this the rank dropped from 23rd initially to 25th in the final round.

A two-category consensus (74.1%) that 'missing patches of vision' was relevant to 'reduced central vision' and 'visual field loss' was reached in the first round (Figure 8.30). During the second round this mainly focused onto 'visual field loss' (76.3%). In the third round this split again between 'reduced central vision' (32.0%) and 'visual field loss' (42.0%), with an increase in the 'visual perception problems' (18.0%) category. This creates a consensus

between the three categories (92.0%). These changes suggest instability; a consensus has been present in all three rounds but the included categories have changed in each.

8.3.3.23*: 'Noticing objects off to the side'*

Consensus (70.5%) to include the item was reached in the first round which strengthened to 91.9% in the final round (Table 8.25). The range interval and standard deviation decreased across the three rounds (by 4 and 0.5 respectively), indicating convergence. The mean increased over the three rounds with the rank remaining stable at 17th.

A two-category consensus (73.8%) that 'noticing objects off to the side' was relevant to 'visual field loss' and 'visual perception problems' was reached in the first round (Figure 8.31). During the second round this mainly focused onto 'visual field loss' (89.8%). In the third round this split again between 'visual field loss' and 'visual perception problems', to reform a two-category consensus (75.7%).

8.3.3.24*: 'Seeing in poor or dim light'*

No consensus to either include or exclude this item was reached within the process (Table 8.26). This was due to the majority of participants being split between option '6' (30.6%) and '7' (44.9%) in the final round; this being the threshold between 'important but not critical' and 'critical'. The range interval and standard deviation slightly decreased across the three rounds (by 1 and 0.3 respectively), indicating convergence. The mean increased over the three rounds, however the rank decreased from 40th initially to 47th in the final round.

No consensus was reached on which category of visual impairment 'seeing in poor or dim light' was most relevant to (Figure 8.32). A high proportion of participants selected 'all visual impairment', however the other two popular categories were 'reduced central vision' and 'visual perception problems'.

Table 8.22: Agreement and importance values for the 'reading same print size' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	0.0%	7.7%	0.0%	1.7%	0.0%	8.1%
		2	1.3%		0.0%		2.0%	
		3	6.4%		1.7%		6.1%	
	Important but not critical	4	6.4%	51.3%	11.7%	73.3%	0.0%	75.6%
		5	24.4%		31.6%		47.0%	
		6	20.5%		30.0%		28.6%	
	Critical	7	25.6%	41.0%	23.3%	25.0%	14.3%	16.3%
		8	10.3%		0.0%		0.0%	
		9	5.1%		1.7%		2.0%	
Importance	Median		6.0		6.0		5.0	
	Range		2-9		3-9		2-9	
	Mean		6.0		5.7		5.5	
	SD		1.6		1.1		1.2	
	Mean Rank		=49		53		56	

= Consensus

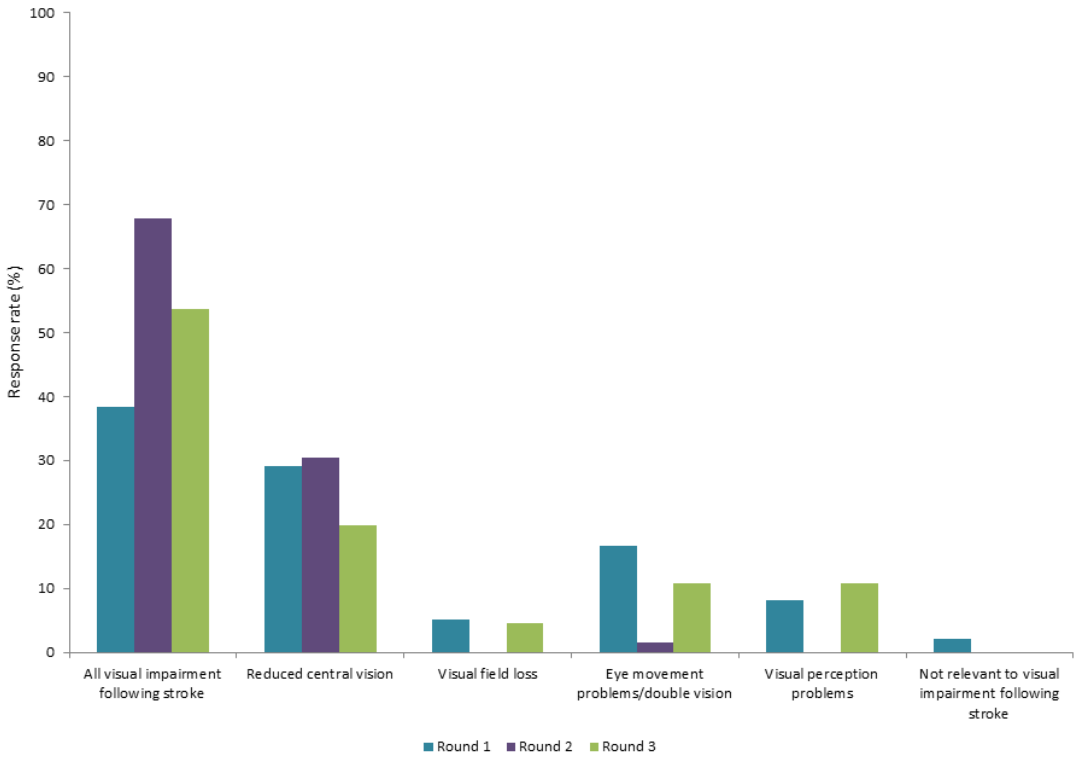


Figure 8.28: Agreement of application of 'reading same print size' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.23: Agreement and importance values for the 'objects suddenly appearing' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	0.0%	2.6%	0.0%	3.2%	0.0%	2.0%
		2	2.6%		1.6%		2.0%	
		3	0.0%		1.6%		0.0%	
	Important but not critical	4	3.8%	29.5%	0.0%	19.7%	0.0%	18.4%
		5	10.3%		6.6%		4.1%	
		6	15.4%		13.1%		14.3%	
	Critical	7	29.5%	67.9%	41.0%	77.1%	53.1%	79.6%
		8	33.3%		34.5%		26.5%	
		9	5.1%		1.6%		0.0%	
Importance	Median		7.0		7.0		7.0	
	Range		2-9		2-9		2-8	
	Mean		6.8		7.0		6.9	
	SD		1.4		1.2		1.0	
	Mean Rank		24		=22		=30	

= Consensus

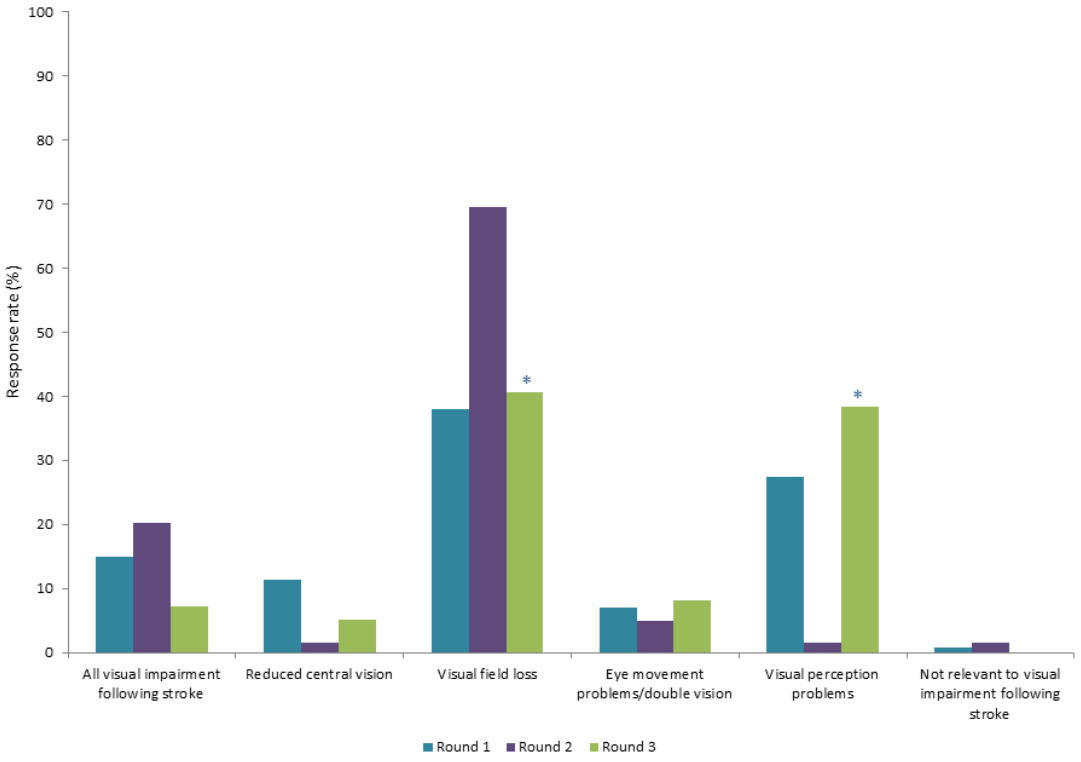


Figure 8.29: Agreement of application of 'objects suddenly appearing' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.24: Agreement and importance values for the 'missing patches of vision' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	1.3%	3.9%	1.7%	1.7%	0.0%	0.0%
		2	1.3%		0.0%		0.0%	
		3	1.3%		0.0%		0.0%	
	Important but not critical	4	3.8%	26.9%	1.7%	25.4%	0.0%	20.4%
		5	7.7%		3.4%		4.1%	
		6	15.4%		20.3%		16.3%	
	Critical	7	34.6%	69.2%	44.1%	72.9%	53.1%	79.6%
		8	23.1%		23.7%		22.4%	
		9	11.5%		5.1%		4.1%	
Importance	Median		7.0		7.0		7.0	
	Range		1-9		1-9		5-9	
	Mean		6.9		6.9		7.1	
	SD		1.6		1.3		0.9	
	Mean Rank		23		26		=25	

= Consensus

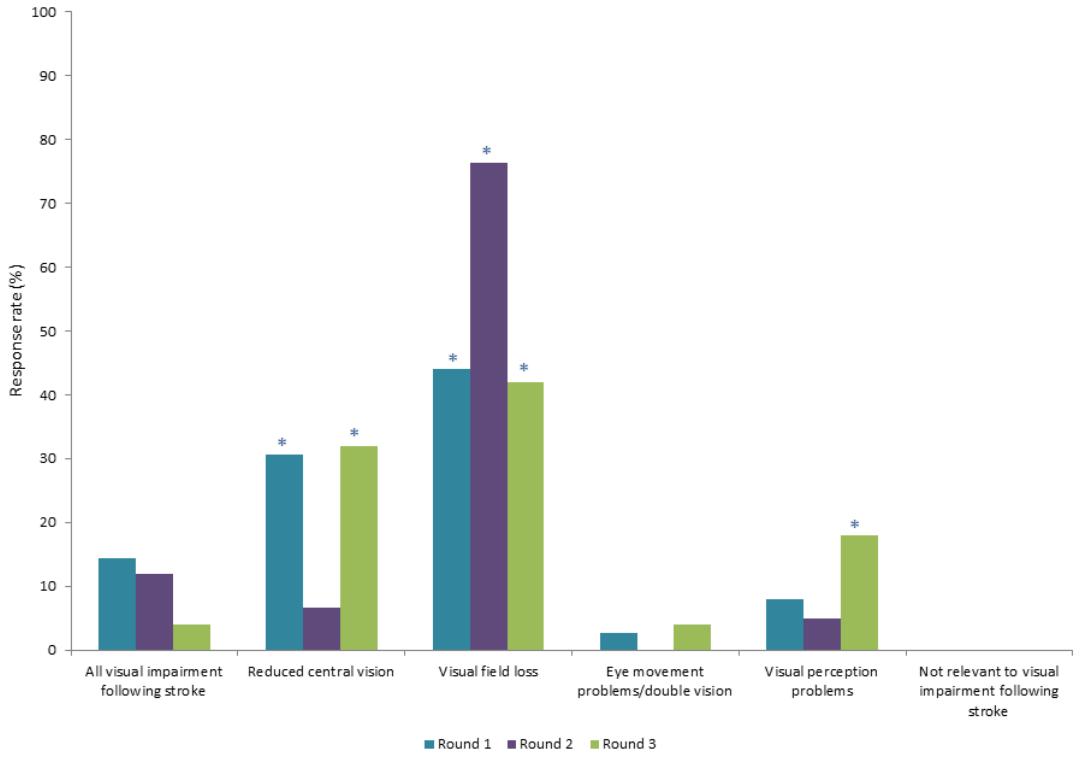


Figure 8.30: Agreement of application of 'missing patches of vision' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.25: Agreement and importance values for the 'noticing objects off to the side' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	1.3%	1.3%	0.0%	0.0%	0.0%	0.0%
		2	0.0%		0.0%		0.0%	
		3	0.0%		0.0%		0.0%	
	Important but not critical	4	0.0%	28.1%	0.0%	25.0%	0.0%	8.1%
		5	10.3%		6.7%		2.0%	
		6	17.9%		18.3%		6.1%	
	Critical	7	37.2%	70.5%	36.7%	75.0%	55.1%	91.9%
		8	28.2%		33.3%		32.7%	
		9	5.1%		5.0%		4.1%	
Importance	Median		7.0		7.0		7.0	
	Range		1-9		5-9		5-9	
	Mean		6.9		7.1		7.3	
	SD		1.2		1.0		0.7	
	Mean Rank		=17		=16		17	

= Consensus

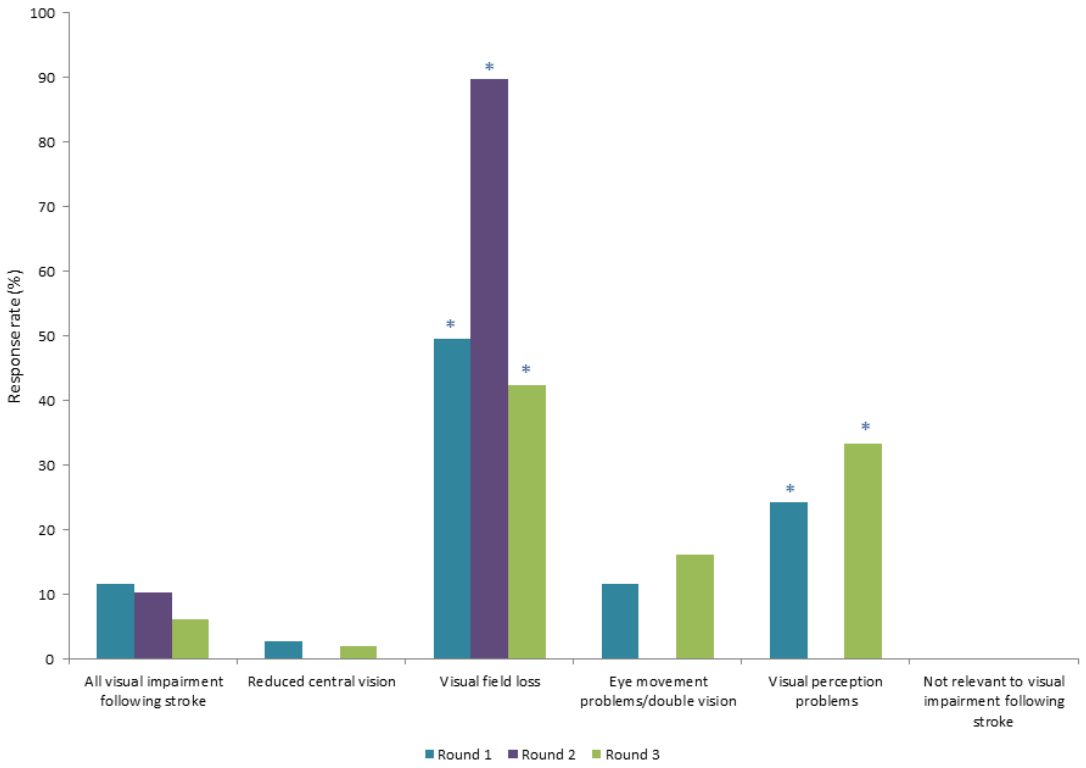


Figure 8.31: Agreement of application of 'noticing objects off to the side' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.26: Agreement and importance values for the 'seeing in poor or dim light' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	0.0%	3.8%	0.0%	1.7%	0.0%	2.0%
		2	0.0%		0.0%		0.0%	
		3	3.8%		1.7%		2.0%	
	Important but not critical	4	5.1%	43.6%	6.7%	41.7%	4.1%	42.9%
		5	21.8%		13.3%		8.2%	
		6	16.7%		21.7%		30.6%	
	Critical	7	35.9%	52.5%	51.7%	56.7%	44.9%	55.1%
		8	11.5%		3.3%		10.2%	
		9	5.1%		1.7%		0.0%	
Importance	Median		7.0		7.0		7.0	
	Range		1-9		5-9		5-9	
	Mean		6.9		7.1		7.3	
	SD		1.2		1.0		0.7	
	Mean Rank		=17		=16		17	

= Consensus

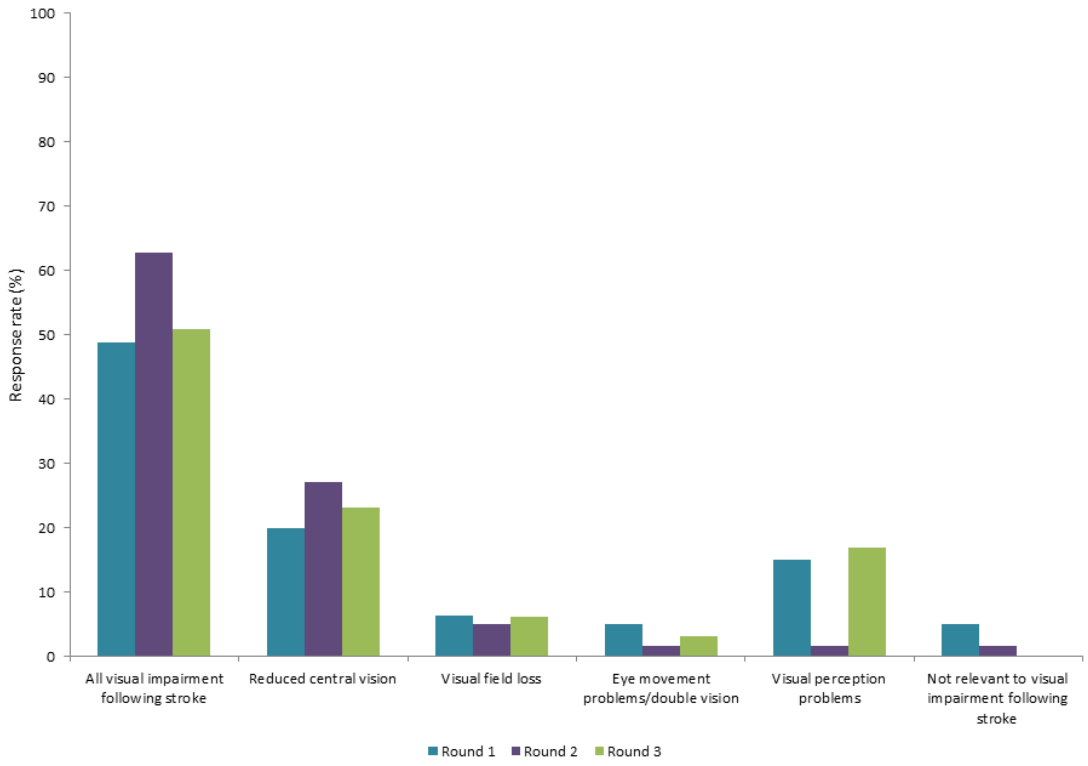


Figure 8.32: Agreement of application of 'seeing in poor or dim light' item to a category of visual impairment. When and where consensus is reached shown by *

8.3.3.25*: 'Seeing in bright light'*

No consensus to either include or exclude this item was reached within the process (Table 8.27). This was due to the majority of participants selecting an 'important but not critical' option; 81.6% in the final round. The range interval and standard deviation decreased across the three rounds (by 4 and 0.8 respectively), indicating convergence. The rank remained low but did increase throughout the rounds along with the mean finishing at 51st in the final round.

No consensus was reached on which category of visual impairment 'seeing in bright light' was most relevant to (Figure 8.33). A high proportion of participants selected 'all visual impairment', which increased across the three rounds to 52.5% in the final round. The other two popular categories were 'reduced central vision' and 'visual perception problems'.

8.3.3.26*: 'Adjusting to differing lighting'*

No consensus to either include or exclude this item was reached within the process (Table 8.28). This was due to the majority of participants selecting an 'important but not critical' option; 79.7% in the final round. The range interval and standard deviation slightly decreased across the three rounds (by 2 and 0.4 respectively), indicating convergence. The mean remained stable across the three rounds whereas the rank remained low, but increased slightly from 57th initially to 55th in the final round.

No consensus was reached on which category of visual impairment 'adjusting to differing light' was most relevant to (Figure 8.34). A high proportion of participants selected 'all visual impairment'. The other two popular categories were 'visual perception problems' and 'reduced central vision'.

8.3.3.27*: 'Change in colour perception'*

No consensus to either include or exclude this item was reached within the process (Table 8.29). This was due to the majority of participants selecting an 'important but not critical' option; 77.6% in the final round. It must be noted that 10.2% selected a 'not important' option. The range interval and standard deviation decreased across the three rounds (by 1 and 0.4 respectively), indicating convergence. This is a low ranked item, the mean

increased from the first round to the third but the rank dropped one place to be 60th after the third round.

A two-category consensus (72.8%) that 'change in colour perception' was relevant to 'reduced central vision' and 'visual perception problems' was reached in the first round (Figure 8.35). During the second round this mainly focused onto 'visual perception problems' (79.7%). In the third round this split again between 'visual field loss' and 'visual perception problems' reaching a stronger two-category consensus (90.8%).

8.3.3.28*: 'Dry eyes'*

No consensus to either include or exclude this item was reached within the process (Table 8.30). This was due to the majority of participants selecting an 'important but not critical' option; 79.6% in the final round. It must be noted that 14.3% selected a 'not important' option and 6.1% selected a 'critical' option. The range interval and standard deviation decreased across the three rounds (by 1 and 0.5 respectively), indicating convergence. This is a very low ranked item; the mean increased across into the second round but dropped one place to 61st after the third round.

A consensus (83.3%) that 'dry eyes' was 'not relevant to visual impairment following stroke' was reached in the third round (Figure 8.36), indicating there may be a mandate to exclude this item.

8.3.3.29*: 'Watery eyes'*

No consensus to either include or exclude this item was reached within the process (Table 8.31). This was due to most participants selecting an 'important but not critical' option; 77.6% in the final round. It must be noted that 16.3% selected a 'not important' option and 6.1% selected a 'critical' option. The range interval and standard deviation decreased across the three rounds (by 2 and 0.4 respectively), indicating convergence. This item consistently had the lowest rank; 62nd despite the slight increase of the mean.

A consensus (70.0%) that 'watery eyes' was 'not relevant to visual impairment following stroke' was reached in the third round (Figure 8.37); indicating there may be a mandate to exclude this item.

Table 8.27: Agreement and importance values for the 'seeing in bright light' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	1.3%	10.3%	1.6%	3.2%	0.0%	0.0%
		2	1.3%		1.6%		0.0%	
		3	7.7%		0.0%		0.0%	
	Important but not critical	4	6.4%	57.7%	4.9%	85.3%	2.0%	81.6%
		5	24.4%		32.8%		28.6%	
		6	26.9%		47.6%		51.0%	
	Critical	7	16.7%	32.1%	9.9%	11.5%	14.3%	18.4%
		8	12.8%		1.6%		4.1%	
		9	2.6%		0.0%		0.0%	
Importance	Median		6.0		6.0		6.0	
	Range		1-9		1-8		4-8	
	Mean		5.8		5.6		5.9	
	SD		1.6		1.1		0.8	
	Mean Rank		54		56		51	

= Consensus

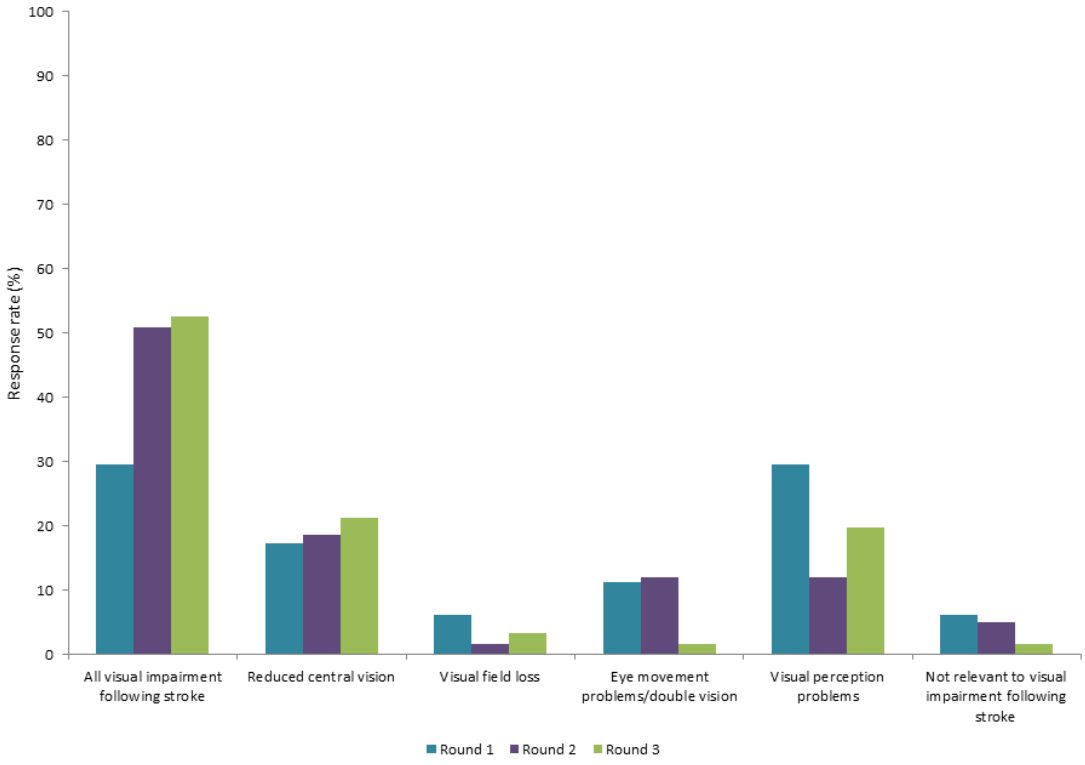


Figure 8.33: Agreement of application of 'seeing in bright light' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.28: Agreement and importance values for the 'adjusting to differing lighting' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	1.3%	7.7%	0.0%	3.3%	0.0%	2.0%
		2	1.3%		0.0%		0.0%	
		3	5.1%		3.3%		2.0%	
	Important but not critical	4	6.4%	65.4%	13.1%	73.7%	8.2%	79.7%
		5	28.2%		27.8%		28.6%	
		6	30.8%		32.8%		42.9%	
	Critical	7	19.2%	26.9%	19.7%	23.0%	16.3%	18.3%
		8	7.7%		3.3%		2.0%	
		9	0.0%		0.0%		0.0%	
Importance	Median		6.0		6.0		6.0	
	Range		1-8		3-8		3-8	
	Mean		5.7		5.6		5.7	
	SD		1.4		1.1		1.0	
	Mean Rank		57		55		55	

= Consensus

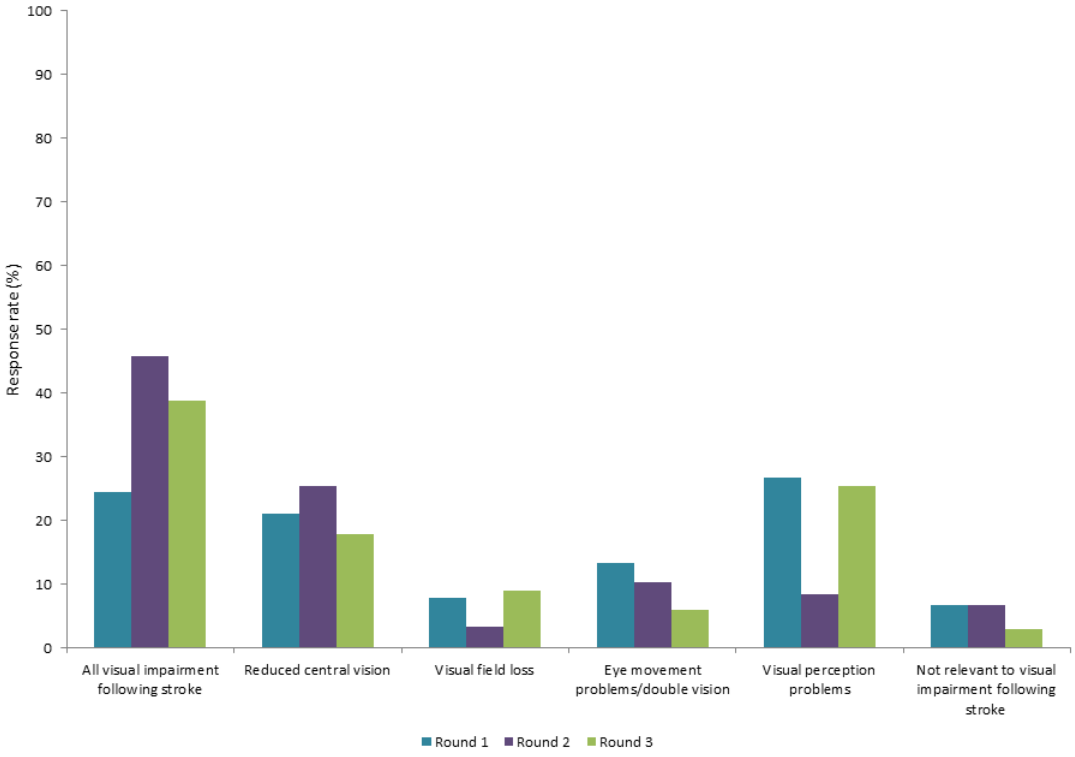


Figure 8.34: Agreement of application of 'adjusting to differing lighting' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.29: Agreement and importance values for the 'change in colour perception' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	5.1%	24.4%	0.0%	18.7%	0.0%	10.2%
		2	2.6%		8.5%		4.1%	
		3	16.7%		10.2%		6.1%	
	Important but not critical	4	19.2%	57.6%	23.7%	71.1%	28.6%	77.6%
		5	20.5%		27.1%		30.6%	
		6	17.9%		20.3%		18.4%	
	Critical	7	15.4%	18.0%	8.5%	10.2%	10.2%	12.2%
		8	2.6%		1.7%		2.0%	
		9	0.0%		0.0%		0.0%	
Importance	Median		5.0		5.0		5.0	
	Range		1-8		2-8		2-8	
	Mean		4.8		4.7		4.9	
	SD		1.7		1.4		1.3	
	Mean Rank		59		60		60	

= Consensus

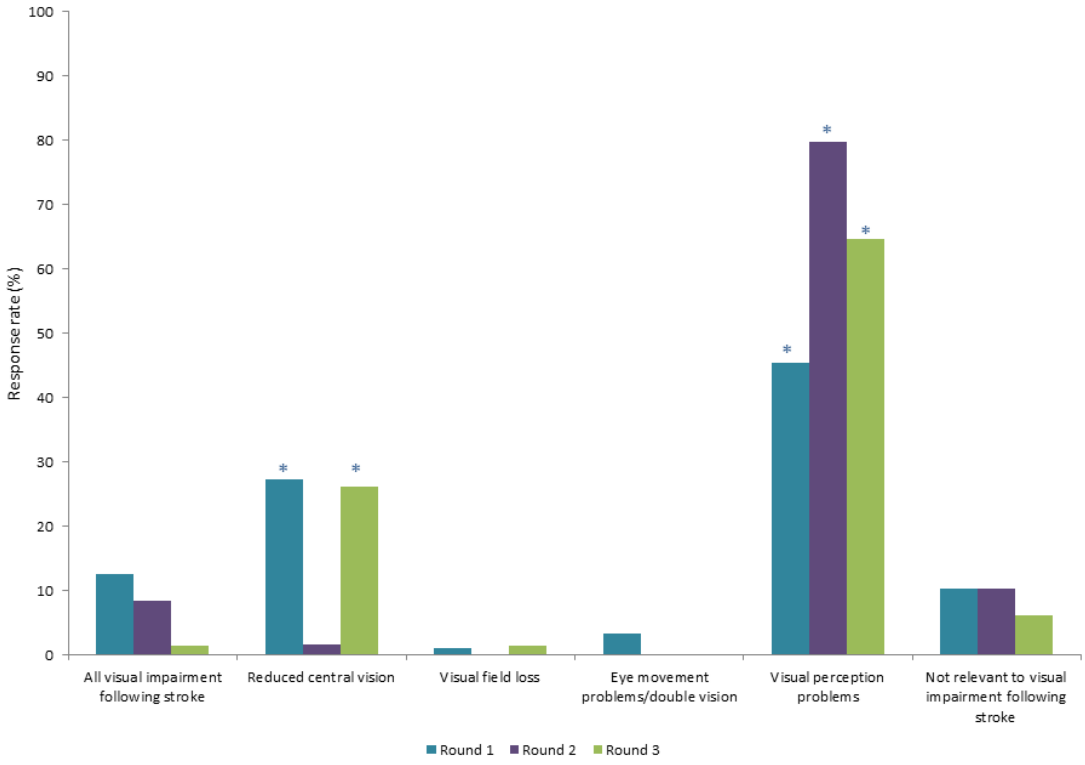


Figure 8.35: Agreement of application of 'change in colour perception' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.30: Agreement and importance values for the 'dry eyes' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	6.4%	21.8%	5.1%	13.6%	2.0%	14.3%
		2	5.1%		3.4%		4.1%	
		3	10.3%		5.1%		8.2%	
	Important but not critical	4	11.5%	64.0%	13.6%	77.9%	10.2%	79.6%
		5	34.6%		45.7%		59.2%	
		6	17.9%		18.6%		10.2%	
	Critical	7	12.8%	14.1%	8.5%	8.5%	6.1%	6.1%
		8	1.3%		0.0%		0.0%	
		9	0.0%		0.0%		0.0%	
Importance	Median		5.0		5.0		5.0	
	Range		1-8		1-7		1-7	
	Mean		4.7		4.8		4.8	
	SD		1.7		1.4		1.2	
	Mean Rank		60		59		61	

= Consensus

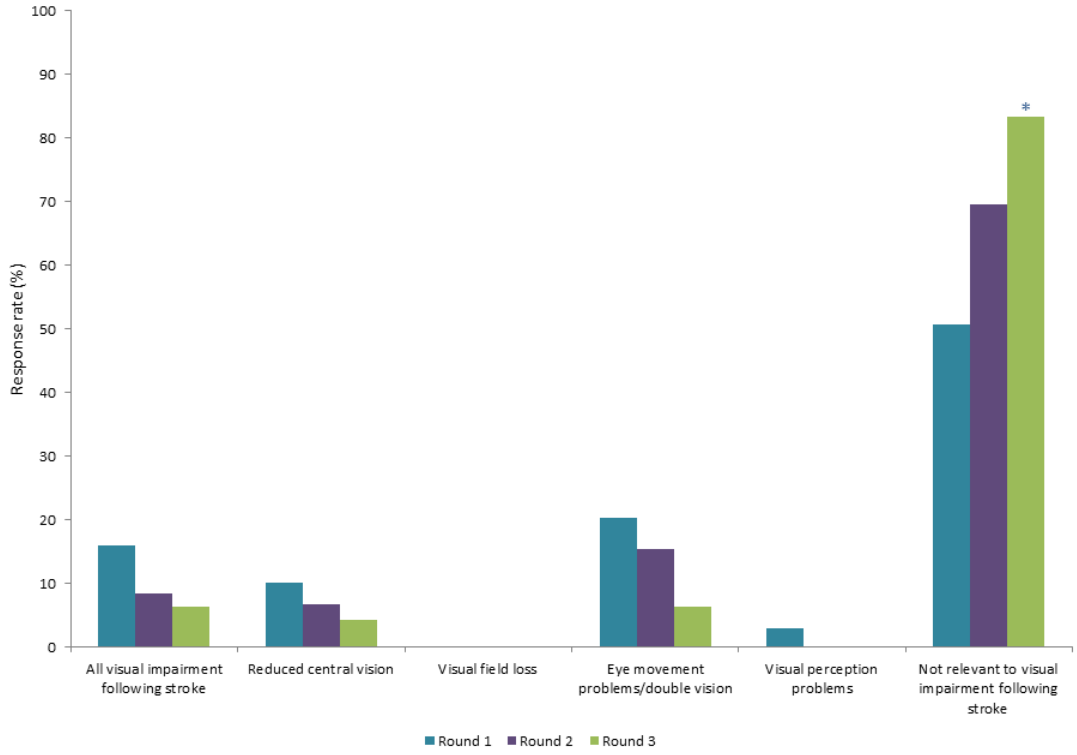


Figure 8.36: Agreement of application of 'dry eyes' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.31: Agreement and importance values for the 'watery eyes' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	3.8%	26.9%	3.4%	20.4%	2.0%	16.3%
		2	14.1%		8.5%		6.1%	
		3	9.0%		8.5%		8.2%	
	Important but not critical	4	17.9%	62.8%	23.7%	74.5%	24.5%	75.6%
		5	29.5%		32.2%		40.8%	
		6	15.4%		18.6%		12.3%	
	Critical	7	7.7%	10.3%	3.4%	5.1%	6.1%	6.1%
		8	1.3%		0.0%		0.0%	
		9	1.3%		1.7%		0.0%	
Importance	Median		5.0		5.0		5.0	
	Range		1-9		1-9		1-7	
	Mean		4.5		4.5		4.6	
	SD		1.7		1.5		1.3	
	Mean Rank		62		62		62	

= Consensus

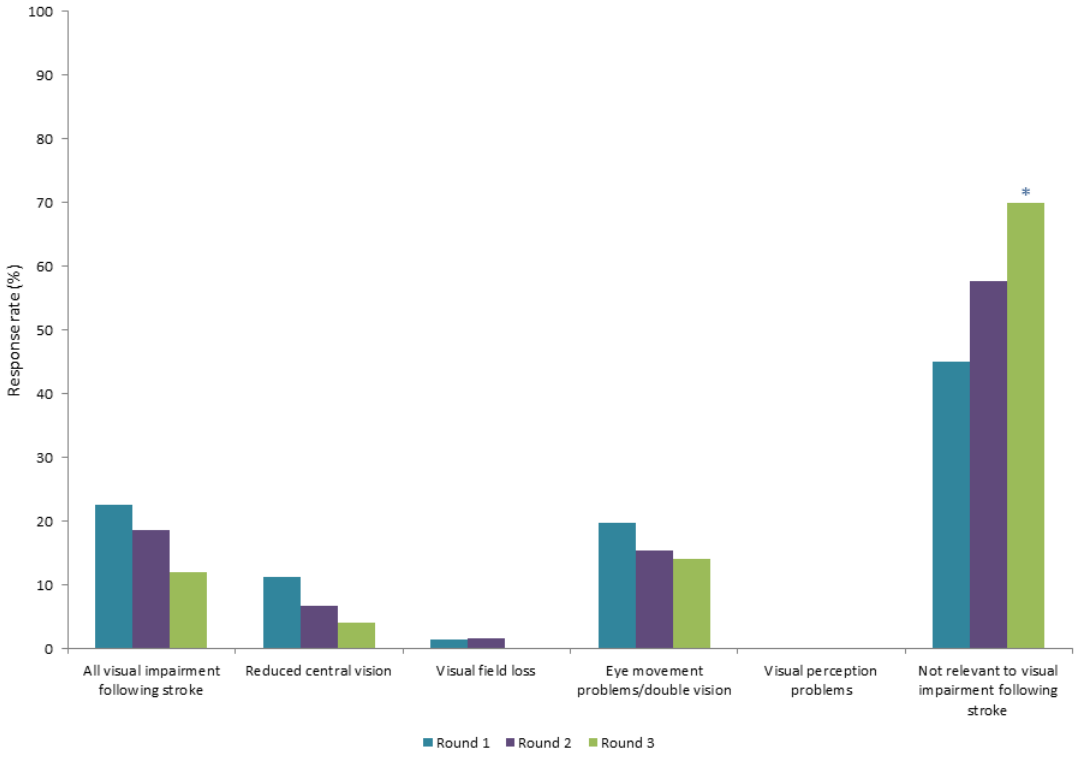


Figure 8.37: Agreement of application of 'watery eyes' item to a category of visual impairment. When and where consensus is reached shown by *

8.3.3.30*: 'Moving around on uneven ground'*

Consensus (79.5%) to include the item was reached in the first round and strengthened with each subsequent round to 96.0% in the third (Table 8.32). The range interval and standard deviation decreased across the three rounds (by 3 and 0.7 respectively), indicating convergence. Despite the mean increasing, the rank which was initially high at 5th dropped to 13th in the final round.

A consensus (88.1%) that 'moving around on uneven ground' was relevant to 'all visual impairment following stroke' was reached in the second round (Figure 8.38). This continued to strengthen in the third round to 90.4%.

8.3.3.31*: 'Trips and falls'*

Consensus (88.4%) to include the item was reached in the first round and strengthened with each subsequent round to 98.0% in the final round (Table 8.33). The range interval and standard deviation decreased between the first and second round (by 4 and 0.6 respectively) indicating convergence. However, subsequently they increased in the third round (by 3 and 0.2 respectively) indicating divergence. Two percent selected 'not critical' in the third round. This selection had not been present in the second round and may account for the appearance of divergence of opinion. This is a high ranked item. It was initially the most important item in the first and second rounds and dropped to 3rd in the final round, despite the mean increasing.

A consensus that 'trips and falls' was relevant to 'all visual impairment following stroke' was achieved in the first round (91.5%) (Figure 8.39). This strengthened in the second round (96.6%) with a subsequent drop in the third (85.5%) in favour of 'visual perceptual problems'.

8.3.3.32*: 'Crossing the road'*

Consensus (84.6%) to include the item was reached in the first round and strengthened with each subsequent round to 96.0% in the third (Table 8.34). The range interval and standard deviation slightly decreased (by 1 and 0.3 respectively), indicating convergence. This is a high ranked item. It was listed 3rd in the first and second rounds and dropped to 6th in the third, despite the mean increasing slightly.

A consensus that 'crossing the road' was relevant to 'all visual impairment following stroke' was achieved in the first round (75.9%) (Figure 8.40). This strengthened in the second round (96.6%) with a subsequent drop in the third (85.5%)

8.3.3.33*: 'Moving around in familiar areas'*

Consensus (74.4%) to include the item was reached in the first round and strengthened with each subsequent round to 87.8% in the third (Table 8.35). The range interval and standard deviation decreased (by 3 and 0.7 respectively), indicating convergence. The mean increased over the three rounds, however the rank dropped from 13th initially to 16th in the final round.

A consensus (83.1%) that 'moving around in familiar areas' was relevant to 'all visual impairment following stroke' was achieved in the second round (Figure 8.41). This weakened slightly in the third round (81.5%).

8.3.3.34*: 'Moving around in unfamiliar areas'*

Consensus (70.5%) to include the item was reached in the second round and strengthened in the third round to 87.7% (Table 8.36). The range interval and standard deviation decreased (by 3 and 0.6 respectively), indicating convergence. The mean increased over the three rounds with the rank remaining stable at 21st.

A consensus (83.8%) that 'moving around in unfamiliar areas' was relevant to 'all visual impairment following stroke' was achieved in the first round (Figure 8.42). This strengthened in the second round (94.9%) with a slight drop in the third (92.2%).

Table 8.32: Agreement and importance values for the 'moving around on uneven ground' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	0.0%	1.3%	0.0%	0.0%	0.0%	0.0%
		2	1.3%		0.0%		0.0%	
		3	0.0%		0.0%		0.0%	
	Important but not critical	4	5.1%	19.2%	0.0%	15.3%	0.0%	4.0%
		5	3.8%		5.1%		2.0%	
		6	10.3%		10.2%		2.0%	
	Critical	7	23.1%	79.5%	30.5%	84.8%	42.9%	96.0%
		8	41.0%		49.2%		49.0%	
		9	15.4%		5.1%		4.1%	
Importance	Median		8.0		8.0		8.0	
	Range		2-9		5-9		5-9	
	Mean		7.3		7.4		7.5	
	SD		1.4		0.9		0.7	
	Mean Rank		5		9		13	

= Consensus

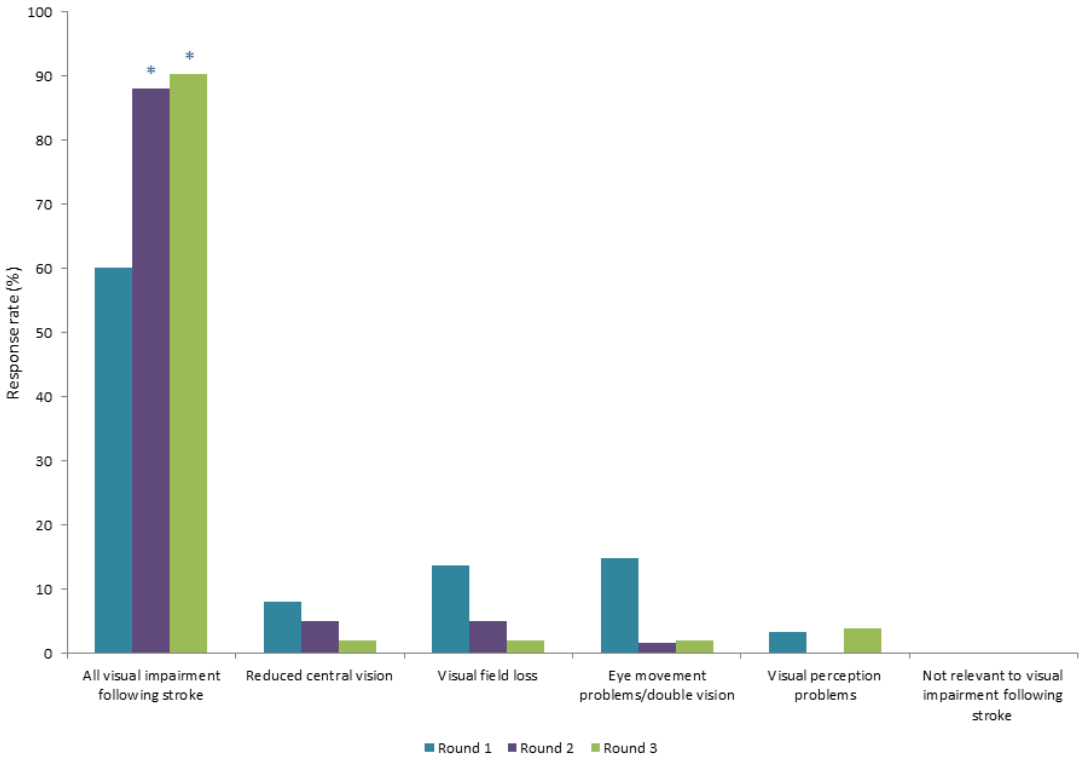


Figure 8.38: Agreement of application of 'moving around on uneven ground' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.33: Agreement and importance values for the 'trips and falls' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	1.3%	2.6%	0.0%	0.0%	0.0%	2.0%
		2	0.0%		0.0%		2.0%	
		3	1.3%		0.0%		0.0%	
	Important but not critical	4	1.3%	9.0%	0.0%	5.1%	0.0%	0.0%
		5	2.6%		1.7%		0.0%	
		6	5.1%		3.4%		0.0%	
	Critical	7	15.4%	88.4%	17.0%	94.9%	10.2%	98.0%
		8	41.0%		55.9%		65.3%	
		9	32.0%		22.0%		22.5%	
Importance	Median		8.0		8.0		8.0	
	Range		1-9		5-9		2-9	
	Mean		7.8		7.9		8.0	
	SD		1.4		0.8		1.0	
	Mean Rank		1		1		3	

= Consensus

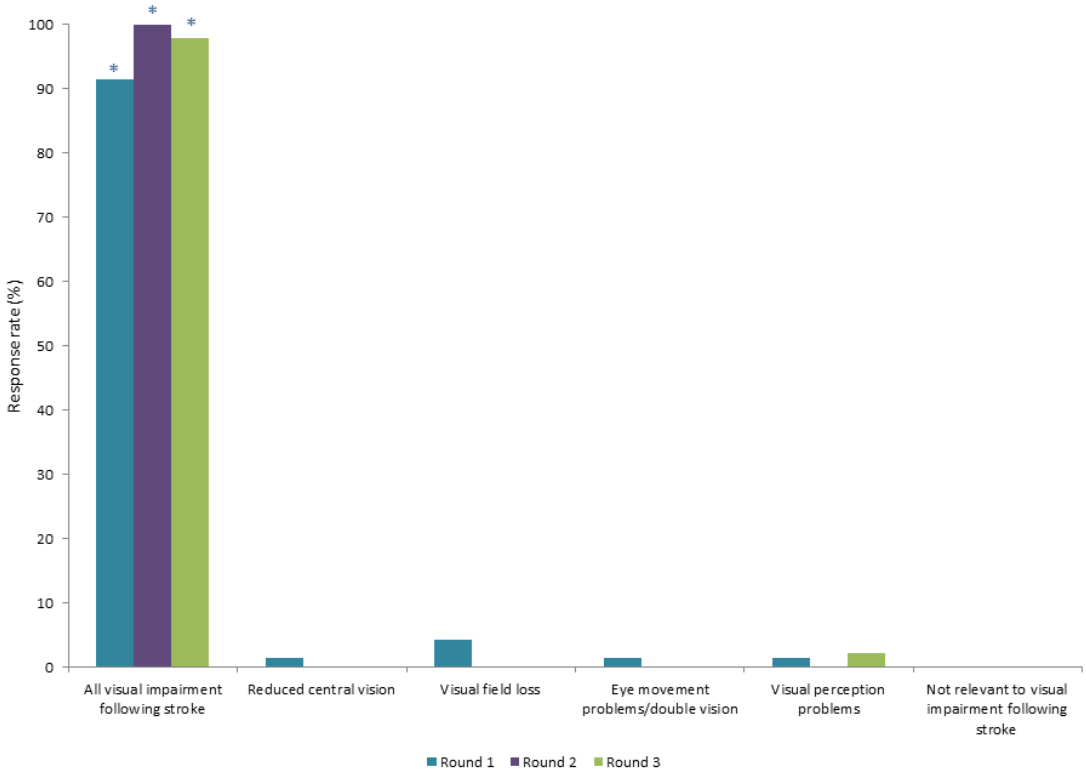


Figure 8.39: Agreement of application of 'trips and falls' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.34: Agreement and importance values for the 'crossing the road' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	0.0%	0.0%	0.0%	0.0%	0.0%	2.0%
		2	0.0%		0.0%		0.0%	
		3	0.0%		0.0%		2.0%	
	Important but not critical	4	3.9%	15.4%	1.7%	6.7%	0.0%	2.0%
		5	6.4%		0.0%		0.0%	
		6	5.1%		5.0%		2.0%	
	Critical	7	20.5%	84.6%	23.3%	93.3%	18.4%	96.0%
		8	41.0%		50.0%		63.3%	
		9	23.1%		20.0%		14.3%	
Importance	Median		8.0		8.0		8.0	
	Range		4-9		4-9		3-9	
	Mean		7.6		7.8		7.8	
	SD		1.3		0.9		1.0	
	Mean Rank		3		3		6	

= Consensus

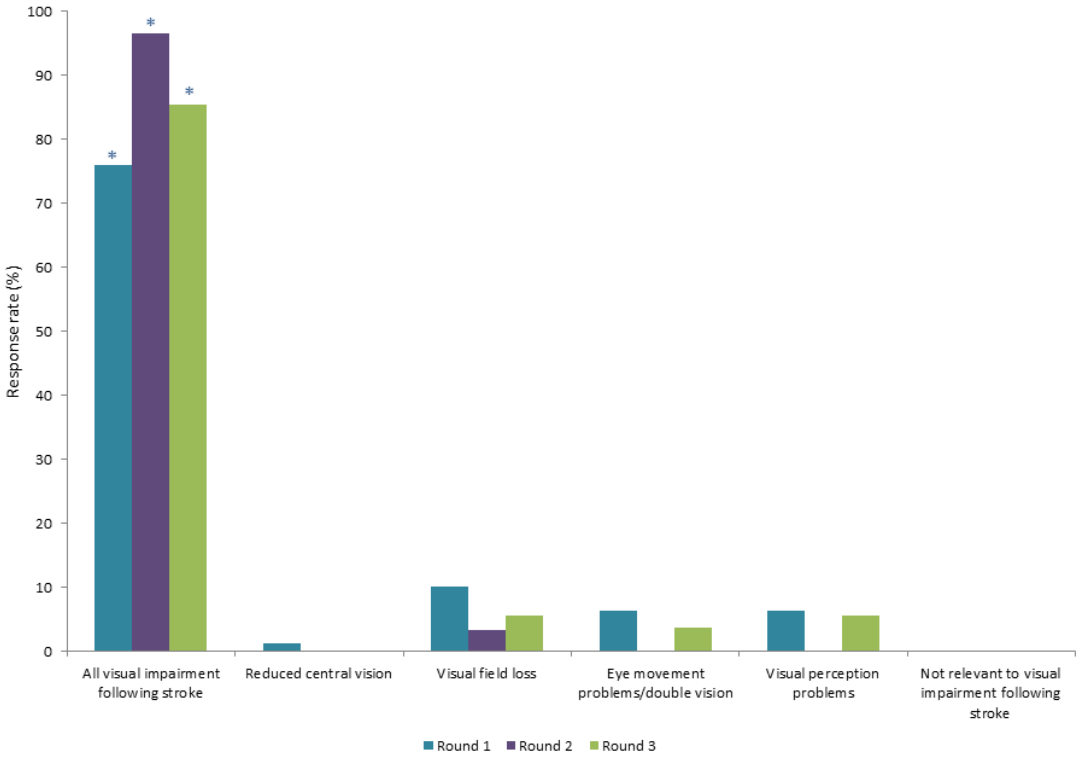


Figure 8.40: Agreement of application of 'crossing the road' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.35: Agreement and importance values for the 'moving around in familiar areas' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	1.3%	5.2%	0.0%	1.7%	0.0%	0.0%
		2	1.3%		1.7%		0.0%	
		3	2.6%		0.0%		0.0%	
	Important but not critical	4	3.8%	20.5%	0.0%	13.5%	2.0%	12.2%
		5	6.4%		3.4%		2.0%	
		6	10.3%		10.2%		8.2%	
	Critical	7	30.8%	74.4%	39.0%	84.8%	40.8%	87.8%
		8	32.1%		39.0%		42.9%	
		9	11.5%		6.8%		4.1%	
Importance	Median		7.0		7.0		7.0	
	Range		1-9		2-9		4-9	
	Mean		7.0		7.3		7.3	
	SD		1.6		1.1		0.9	
	Mean Rank		=13		=12		16	

= Consensus

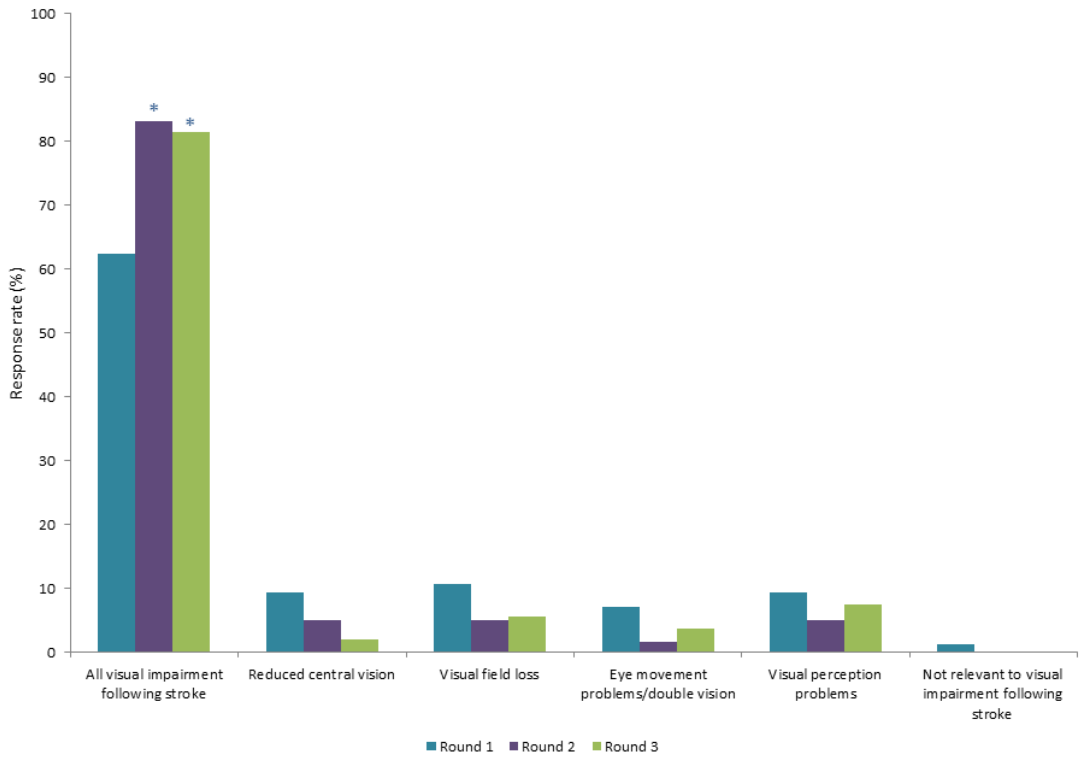


Figure 8.41: Agreement of application of 'moving around in familiar areas' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.36: Agreement and importance values for the 'moving around in unfamiliar areas' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	0.0%	1.3%	0.0%	0.0%	0.0%	0.0%
		2	1.3%		0.0%		0.0%	
		3	0.0%		0.0%		0.0%	
	Important but not critical	4	2.6%	33.3%	1.6%	29.5%	0.0%	12.3%
		5	11.5%		9.9%		4.1%	
		6	19.2%		18.0%		8.2%	
	Critical	7	29.5%	65.4%	37.7%	70.5%	59.2%	87.7%
		8	26.9%		26.2%		26.5%	
		9	9.0%		6.6%		2.0%	
Importance	Median		7.0		7.0		0.7	
	Range		2-9		4-9		5-9	
	Mean		6.9		7.0		7.1	
	SD		1.4		1.1		0.8	
	Mean Rank		21		=22		=21	

= Consensus

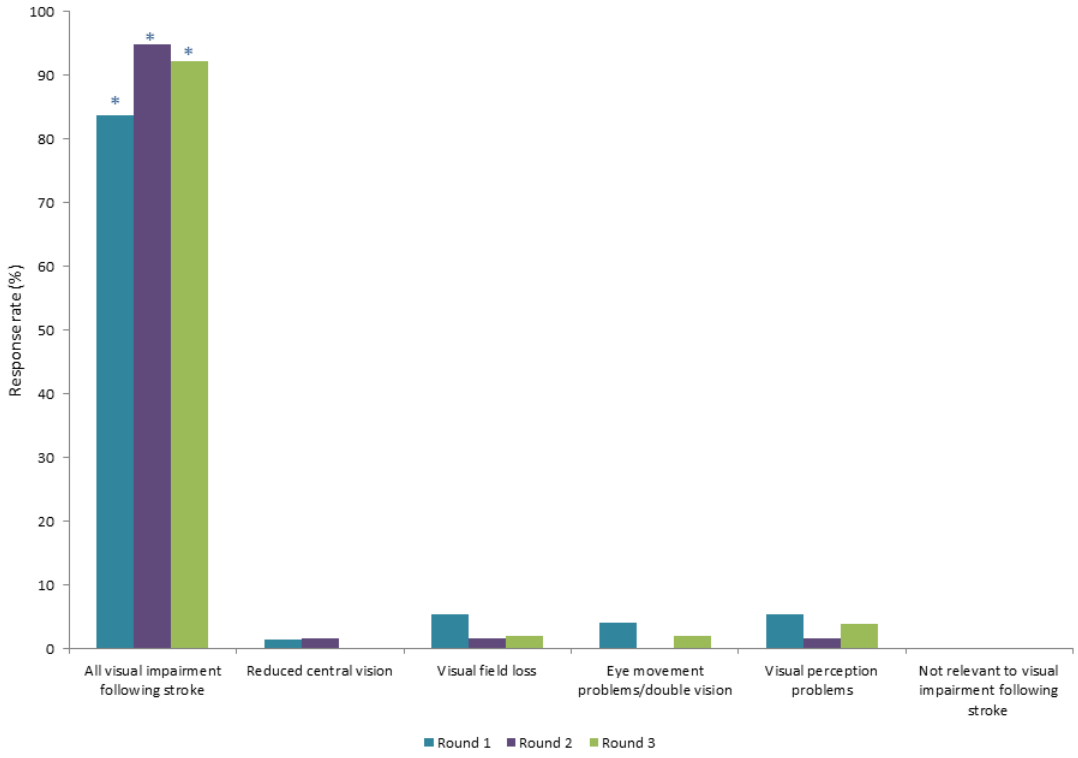


Figure 8.42: Agreement of application of 'moving around in unfamiliar areas' item to a category of visual impairment. When and where consensus is reached shown by *

8.3.3.35*: 'Bumps into or against objects or people in crowded areas'*

Consensus (81.7%) to include the item was reached in the third round (Table 8.37). The range interval and standard deviation decreased (by 4 and 0.7 respectively), indicating convergence. Both the mean and rank increased into the third round with the rank 19th initially rising to 18th by the final round.

A consensus (71.2%) that 'bumps into or against objects or people in crowded areas' was relevant to 'all visual impairment following stroke' was reached in the second round (Figure 8.43). This was eroded in the third round with a large increase in the selection of the 'visual field loss', 'eye movement problems/double vision' and 'visual perception problems' categories. This resulted in no consensus in the third round.

8.3.3.36*: 'Moving around indoors'*

Consensus (74.3%) to include the item was reached in the first round and strengthened with each subsequent round to 89.8% in the final round (Table 8.38). The range interval and standard deviation decreased across all three rounds (by 4 and 0.7 respectively), indicating convergence. The mean increased across the three rounds. The rank dipped in the second round to 18th then returned to 11th in the final round.

A consensus that 'moving around indoors' was relevant to 'all visual impairment following stroke' was reached in the second round (89.8%) (Figure 8.44). Consensus was almost achieved in round one (69.1%) and strengthened in each subsequent round to 90.2% in the third.

8.3.3.37*: 'Moving around outdoors'*

Consensus (73.0%) to include the item was reached in the first round and strengthened with each subsequent round to 85.8% in the final round (Table 8.39). The range interval and standard deviation decreased the three rounds (by 3 and 0.5 respectively), indicating convergence. The mean increased slightly across the three rounds, however the rank dropped from 16th initially to 21st in the final round.

A consensus that 'moving around outdoors' was relevant to 'all visual impairment following stroke' was reached in the first round (75.6%) (Figure 8.45). This initially strengthened in the second round (94.9%) and dropped slightly in the third (92.0%).

8.3.3.38*: 'Travelling as a passenger'*

No consensus to either include or exclude this item was reached within the process (Table 8.40). This was due to the majority of participants selecting an 'important but not critical' option; 75.5% in the final round. It must also be noted that 10.2% selected a 'not important' option. The range interval and standard deviation decreased slightly between the first and second rounds (by 1 and 0.4 respectively), indicating convergence. This is a low ranked item; the mean decreased slightly across the three rounds but the rank did increase by one place to 57th in the third round.

A consensus (72.9%) that 'travelling as a passenger' was relevant to 'all visual impairment following stroke' was initially reached in the second round (Figure 8.46). This consensus was lost in the third round, with a particular increase in participants selecting the 'eye movement problems/double vision' and 'visual perception problems' categories.

8.3.3.39*: 'Making eye contact'*

No consensus to either include or exclude this item was reached within the process (Table 8.41). This was due to the majority of participants selecting an 'important but not critical' option; 63.3% in the final round. The range interval and standard deviation decreased across the three rounds (by 3 and 0.6 respectively), indicating convergence. This is a low ranked item; the mean and rank increased over the three rounds to 50th after the third round.

No consensus was reached on which category of visual impairment 'making eye contact' was most relevant to (Figure 8.47). A high proportion of participants selected 'all visual impairment', which varied across the three rounds. The other two popular categories were 'reduced central vision' and 'eye movement problems/double vision'.

Table 8.37: Agreement and importance values for the 'bumps into or against objects or people in crowded areas' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	1.3%	5.1%	0.0%	0.0%	0.0%	0.0%
		2	0.0%		0.0%		0.0%	
		3	3.8%		0.0%		0.0%	
	Important but not critical	4	1.3%	29.5%	0.0%	34.4%	0.0%	18.3%
		5	9.0%		4.9%		2.0%	
		6	19.2%		29.5%		16.3%	
	Critical	7	24.4%	65.4%	29.5%	65.6%	36.8%	81.7%
		8	26.9%		31.2%		40.8%	
		9	14.1%		4.9%		4.1%	
Importance	Median		7.0		7.0		7.0	
	Range		1-9		5-9		5-9	
	Mean		6.9		7.0		7.3	
	SD		1.6		1.0		0.9	
	Mean Rank		19		21		18	

= Consensus

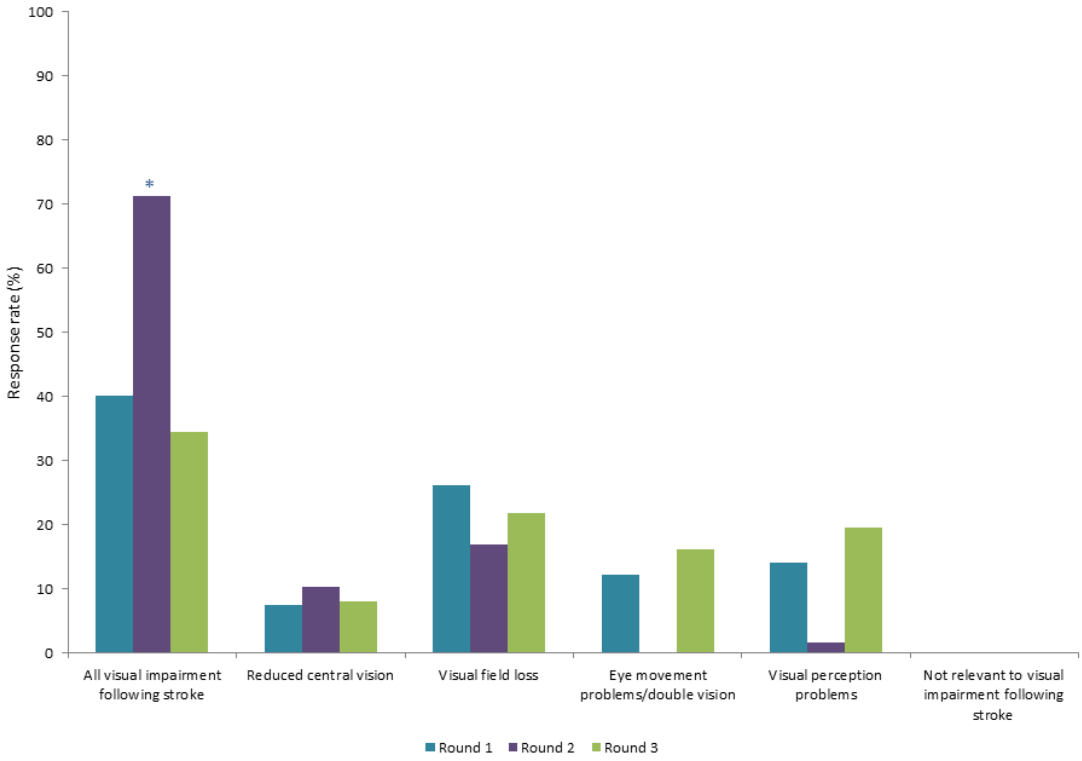


Figure 8.43: Agreement of application of 'bumps into or against objects or people in crowded areas' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.38: Agreement and importance values for the 'moving around indoors' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	2.6%	3.9%	0.0%	3.3%	0.0%	0.0%
		2	1.3%		3.3%		0.0%	
		3	0.0%		0.0%		0.0%	
	Important but not critical	4	0.0%	21.8%	0.0%	18.4%	0.0%	10.2%
		5	5.1%		6.7%		2.0%	
		6	16.7%		11.7%		8.2%	
	Critical	7	29.5%	74.3%	30.0%	78.3%	26.5%	89.8%
		8	34.6%		45.0%		59.2%	
		9	10.2%		3.3%		4.1%	
Importance	Median		7.0		7.0		8.0	
	Range		1-9		2-9		5-9	
	Mean		7.1		7.1		7.6	
	SD		1.5		1.3		0.8	
	Mean Rank		11		18		11	

= Consensus

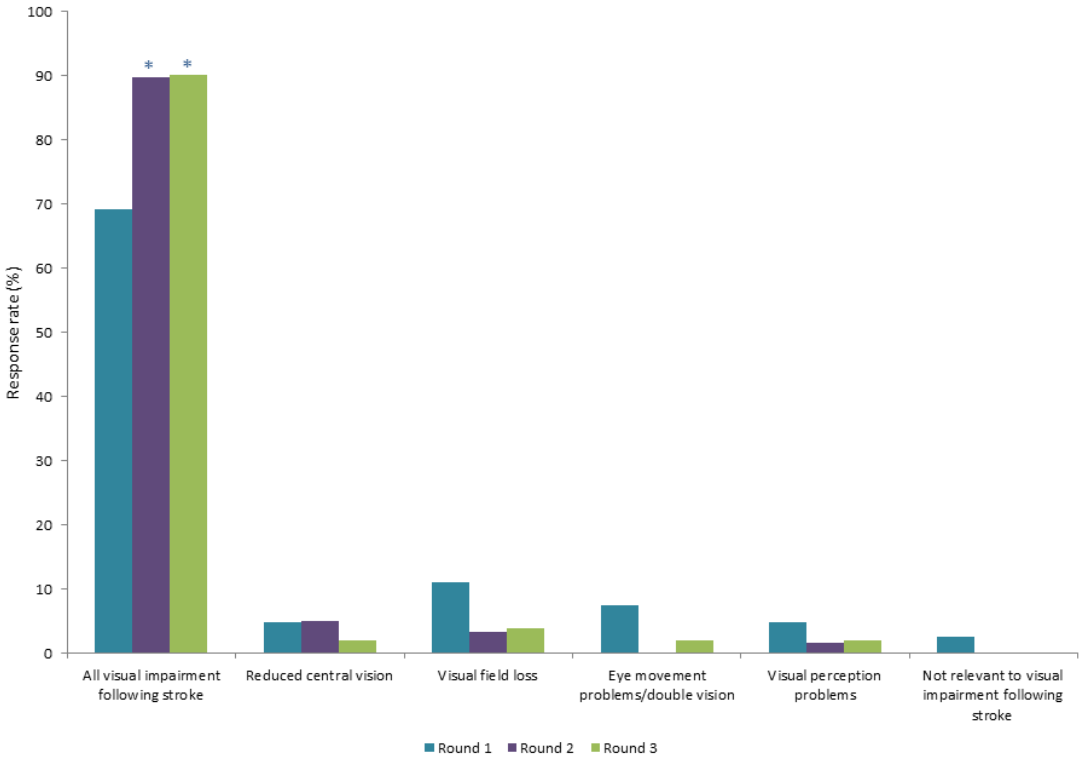


Figure 8.44: Agreement of application of 'moving around indoors' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.39: Agreement and importance values for the 'moving around outdoors' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	1.3%	1.3%	0.0%	0.0%	0.0%	2.0%
		2	0.0%		0.0%		0.0%	
		3	0.0%		0.0%		2.0%	
	Important but not critical	4	5.2%	25.7%	0.0%	18.7%	0.0%	12.2%
		5	7.7%		6.8%		2.0%	
		6	12.8%		11.9%		10.2%	
	Critical	7	33.3%	73.0%	47.4%	81.3%	49.0%	85.8%
		8	33.3%		30.5%		36.8%	
		9	6.4%		3.4%		0.0%	
Importance	Median		7.0		7.0		7.0	
	Range		1-9		5-9		3-8	
	Mean		7.0		7.1		7.1	
	SD		1.4		0.9		0.9	
	Mean Rank		16		=16		=21	

= Consensus

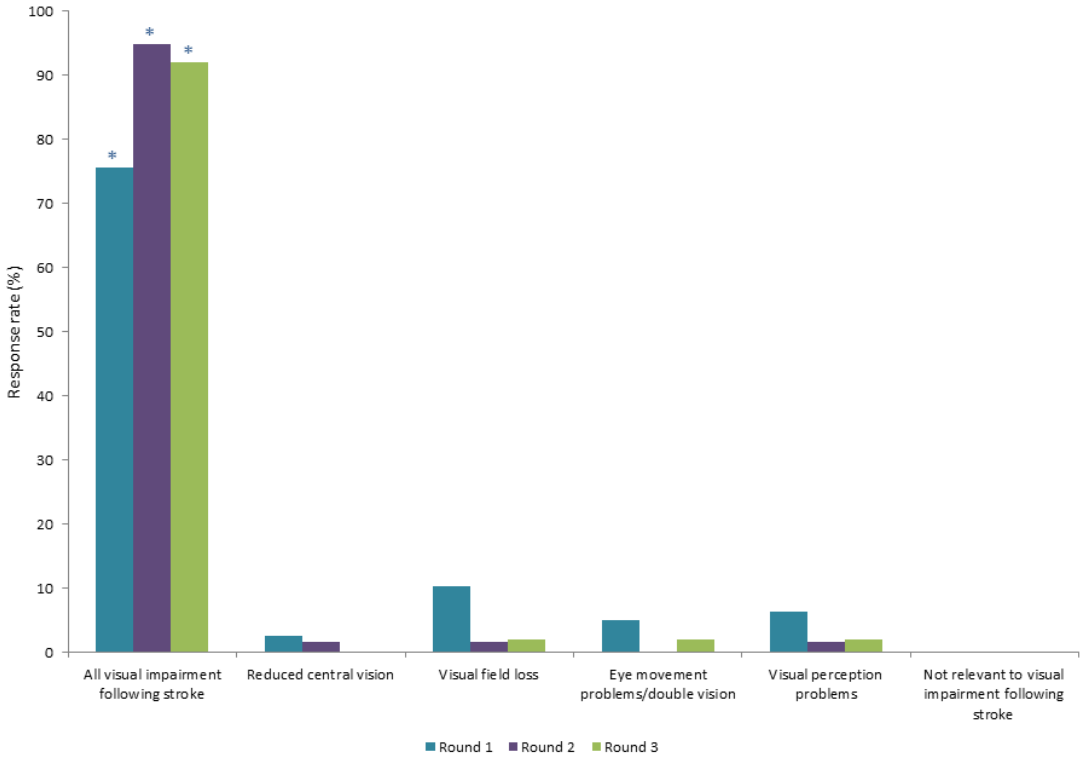


Figure 8.45: Agreement of application of 'moving around outdoors' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.40: Agreement and importance values for the 'travelling as a passenger' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	3.8%	12.7%	1.6%	11.5%	2.0%	10.2%
		2	3.8%		3.3%		4.1%	
		3	5.1%		6.6%		4.1%	
	Important but not critical	4	16.7%	61.6%	19.7%	75.4%	8.2%	75.5%
		5	28.2%		39.3%		40.8%	
		6	16.7%		16.4%		26.5%	
	Critical	7	11.6%	25.7%	8.2%	13.1%	8.2%	14.3%
		8	12.8%		4.9%		6.1%	
		9	1.3%		0.0%		0.0%	
Importance	Median		5.0		5.0		5.0	
	Range		1-9		1-8		1-8	
	Mean		5.3		5.0		5.2	
	SD		1.8		1.4		1.4	
	Mean Rank		58		58		57	

= Consensus

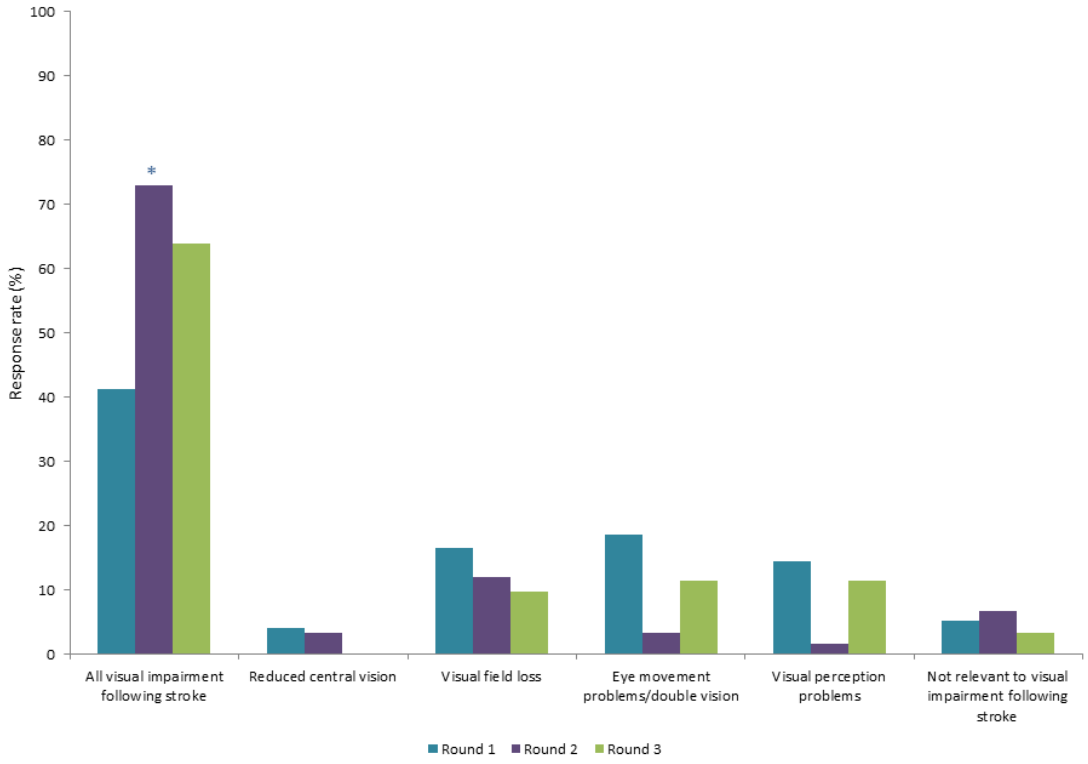


Figure 8.46: Agreement of application of 'travelling as a passenger' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.41: Agreement and importance values for the 'making eye contact' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	1.3%	11.5%	1.7%	5.1%	0.0%	2.0%
		2	0.0%		1.7%		2.0%	
		3	10.2%		1.7%		0.0%	
	Important but not critical	4	7.7%	51.3%	10.0%	64.9%	4.1%	63.3%
		5	16.7%		21.6%		22.5%	
		6	26.9%		33.3%		36.7%	
	Critical	7	23.1%	37.2%	28.3%	31.0%	34.7%	34.7%
		8	12.8%		1.7%		0.0%	
		9	1.3%		0.0%		0.0%	
Importance	Median		6.0		6.0		6.0	
	Range		1-9		1-8		2-7	
	Mean		5.8		5.7		6.0	
	SD		1.6		1.3		1.0	
	Mean Rank		52		52		50	

= Consensus

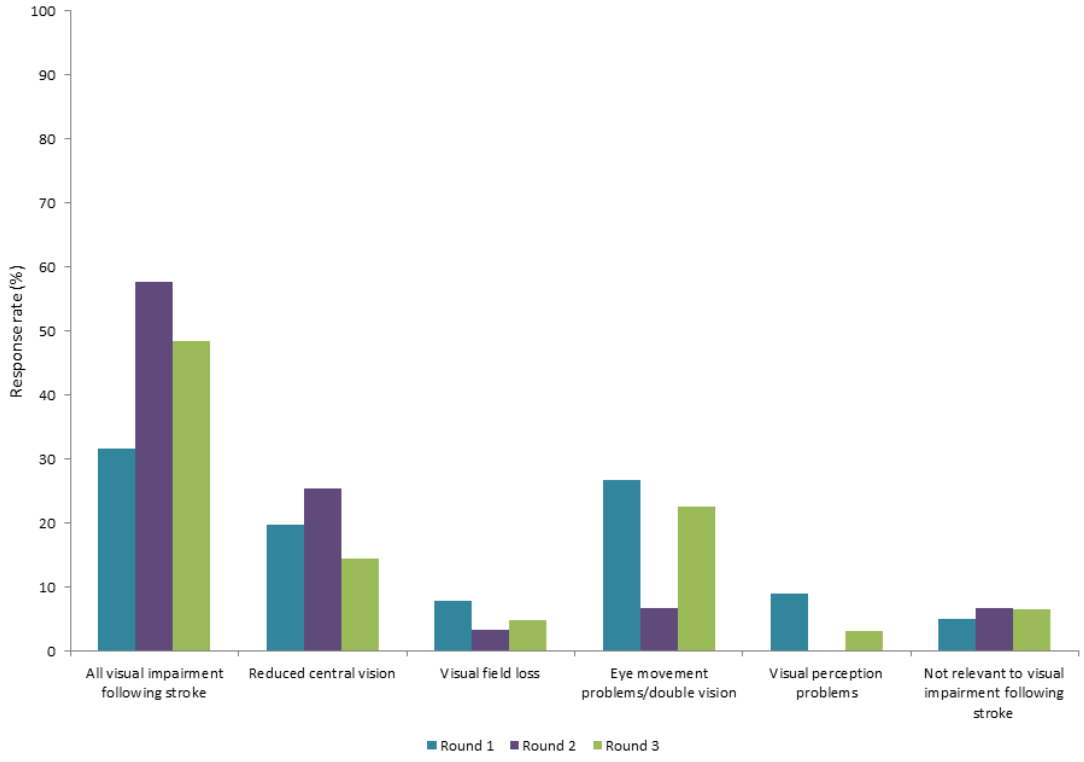


Figure 8.47: Agreement of application of 'making eye contact' item to a category of visual impairment. When and where consensus is reached shown by *

8.3.3.40*: 'Dealing with strangers'*

No consensus to either include or exclude this item was reached within the process (Table 8.42). This was due to the majority of participants being split between option '6' (24.5%) and '7' (40.8%); this being the threshold between 'important but not critical' and 'critical'. The range interval and standard deviation decreased across the three rounds (by 3 and 0.5 respectively), indicating convergence. The mean and rank increased across the three rounds from 45th initially to 39th in the final round.

A consensus that 'dealing with strangers' was relevant to 'all visual impairment following stroke' was reached in the second round (88.1%) (Figure 8.48). Consensus was almost achieved in the first round (68.8%) and dropped slightly in the third (82.7%).

8.3.3.41*: 'Participating in indoor social activities'*

No consensus to either include or exclude this item was reached within the process (Table 8.43). This was due to the proportion of participants who selected option '6' in the 'important but not critical' category; 34.7% in the final round. The range interval and standard deviation decreased mainly in the second round (by 3 and 0.6 respectively), indicating convergence. Despite the mean increasing, the rank dropped from 29th initially to 36th in the final round.

A consensus that 'participating in indoor social activities' was relevant to 'all visual impairment following stroke' was reached in the first round (84.7%) (Figure 8.49). The consensus strengthened into the second round (94.9%) and remained stable in the third (94.1%).

8.3.3.42*: 'Participating in outdoor social activities'*

No consensus to either include or exclude this item was reached within the process (Table 8.44). This was prevented by the proportion of participants who selected option '6' in the 'important but not critical' category; 22.4% in the final round. The range interval decreased in the second round (by 1), whereas the standard deviation decreased across the three rounds (by 0.4), indicating some convergence. Both the mean and rank increased across the three rounds from initially 38th to 36th in the final round.

A consensus that 'participating in outdoor social activities' was relevant to 'all visual impairment following stroke' was reached in the first round (78.9%) (Figure 8.50). The

consensus strengthened in subsequent rounds, with complete consensus achieved in the third round (100%).

8.3.3.43*: 'Loss of confidence'*

Consensus (71.8%) to include the item was reached in the first round and strengthened with each subsequent round to 89.8% in the final round (Table 8.45). The range interval decreased in the second round (by 1) whereas the standard deviation decreased across the three rounds (by 0.5), indicating convergence. The mean and rank increased over the three rounds, jumping from 22nd to 10th in the second round which was then maintained.

A consensus that 'loss of confidence' was relevant to 'all visual impairment following stroke' was reached in the first round (92.8%) (Figure 8.51). The consensus strengthened in the second round to achieve complete consensus (100%) which was maintained in the third round.

8.3.3.44*: 'Accomplishing as much as would like'*

Consensus (73.5%) to include the item was reached in the third round (Table 8.46). The range interval decreased in the second round (by 2), whereas the standard deviation decreased across the three rounds (by 0.3), indicating convergence. Despite the mean increasing across the three rounds, the rank dropped by one place to 28th in the final round.

A consensus that 'accomplishing as much as would like' was relevant to 'all visual impairment following stroke' was reached in the first round (87.7%) (Figure 8.52). The consensus strengthened in the second round to achieve complete consensus (100%) which was maintained in the third round.

Table 8.42: Agreement and importance values for the 'dealing with strangers' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	1.3%	6.5%	0.0%	1.7%	0.0%	0.0%
		2	2.6%		0.0%		0.0%	
		3	2.6%		1.7%		0.0%	
	Important but not critical	4	3.8%	48.6%	3.3%	45.0%	2.0%	36.7%
		5	25.6%		18.4%		10.2%	
		6	19.2%		23.3%		24.5%	
	Critical	7	23.1%	44.9%	35.0%	53.3%	40.8%	63.3%
		8	18.0%		15.0%		18.4%	
		9	3.8%		3.3%		4.1%	
Importance	Median		6.0		7.0		7.0	
	Range		1-9		3-9		4-9	
	Mean		6.1		6.5		6.8	
	SD		1.6		1.2		1.1	
	Mean Rank		45		40		39	

= Consensus

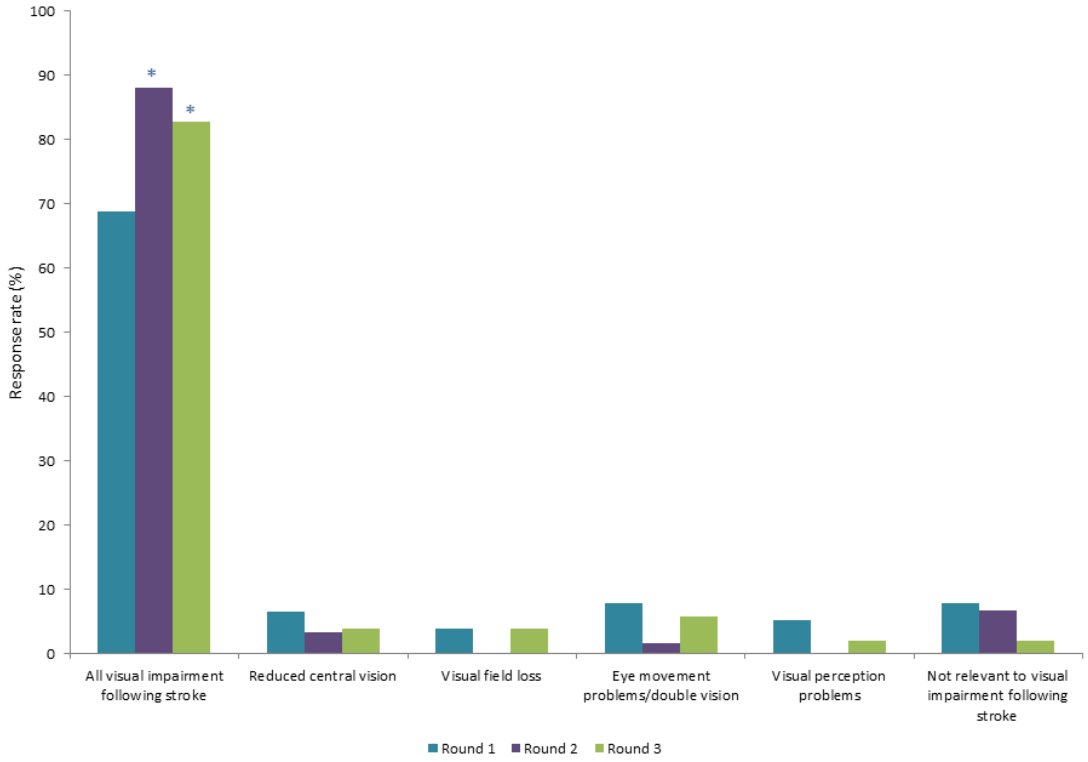


Figure 8.48: Agreement of application of 'dealing with strangers' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.43: Agreement and importance values for the 'participating in indoor social activities' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	1.3%	1.3%	0.0%	0.0%	0.0%	0.0%
		2	0.0%		0.0%		0.0%	
		3	0.0%		0.0%		0.0%	
	Important but not critical	4	6.4%	47.4%	5.0%	51.6%	2.0%	38.7%
		5	12.8%		3.3%		2.0%	
		6	28.2%		43.3%		34.7%	
	Critical	7	23.1%	51.3%	36.7%	48.4%	40.9%	61.3%
		8	17.9%		10.0%		18.4%	
		9	10.3%		1.7%		2.0%	
Importance	Median		7.0		6.0		7.0	
	Range		1-9		4-9		4-9	
	Mean		6.6		6.5		6.8	
	SD		1.5		1.0		0.9	
	Mean Rank		=29		36		=36	

= Consensus

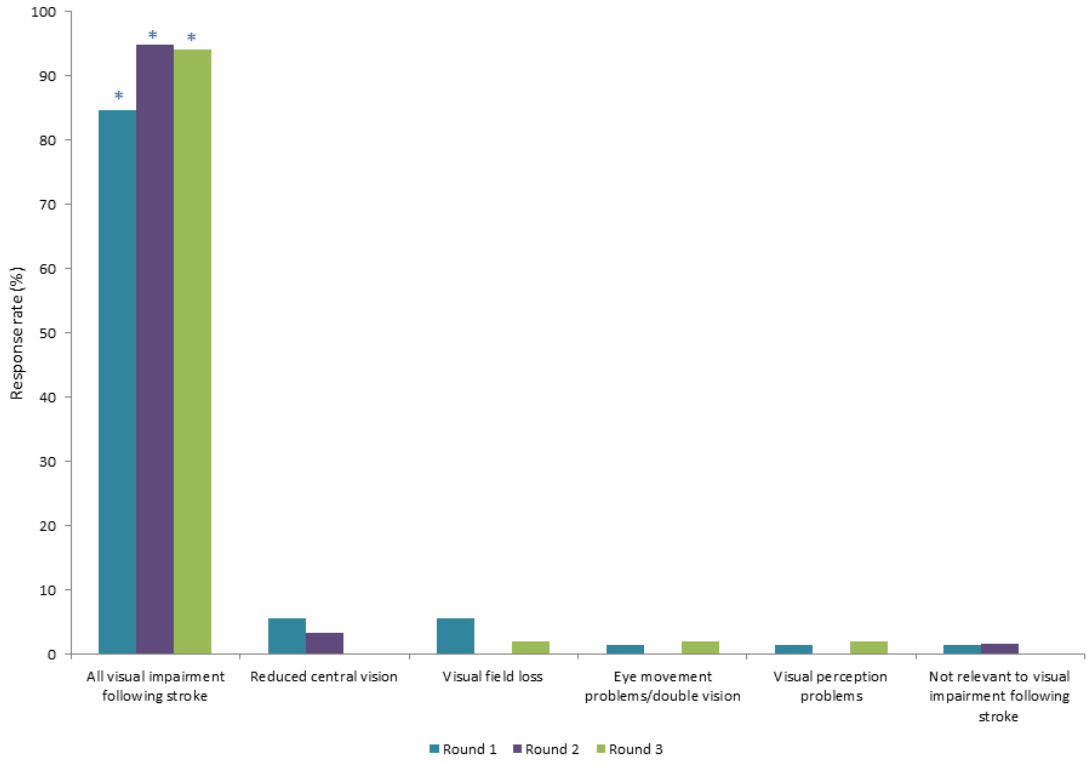


Figure 8.49: Agreement of application of 'participating in indoor social activities' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.44: Agreement and importance values for the 'participating in outdoor social activities' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	0.0%	1.3%	0.0%	0.0%	0.0%	0.0%
		2	0.0%		0.0%		0.0%	
		3	1.3%		0.0%		0.0%	
	Important but not critical	4	7.7%	47.5%	3.4%	47.4%	2.0%	32.7%
		5	23.1%		22.0%		8.2%	
		6	16.7%		22.0%		22.5%	
	Critical	7	26.9%	51.2%	32.2%	52.6%	46.9%	67.3%
		8	19.2%		17.0%		18.4%	
		9	5.1%		3.4%		2.0%	
Importance	Median		7.0		7.0		7.0	
	Range		3-9		4-9		4-9	
	Mean		6.4		6.5		6.8	
	SD		1.4		1.2		1.0	
	Mean Rank		38		=37		=36	

= Consensus

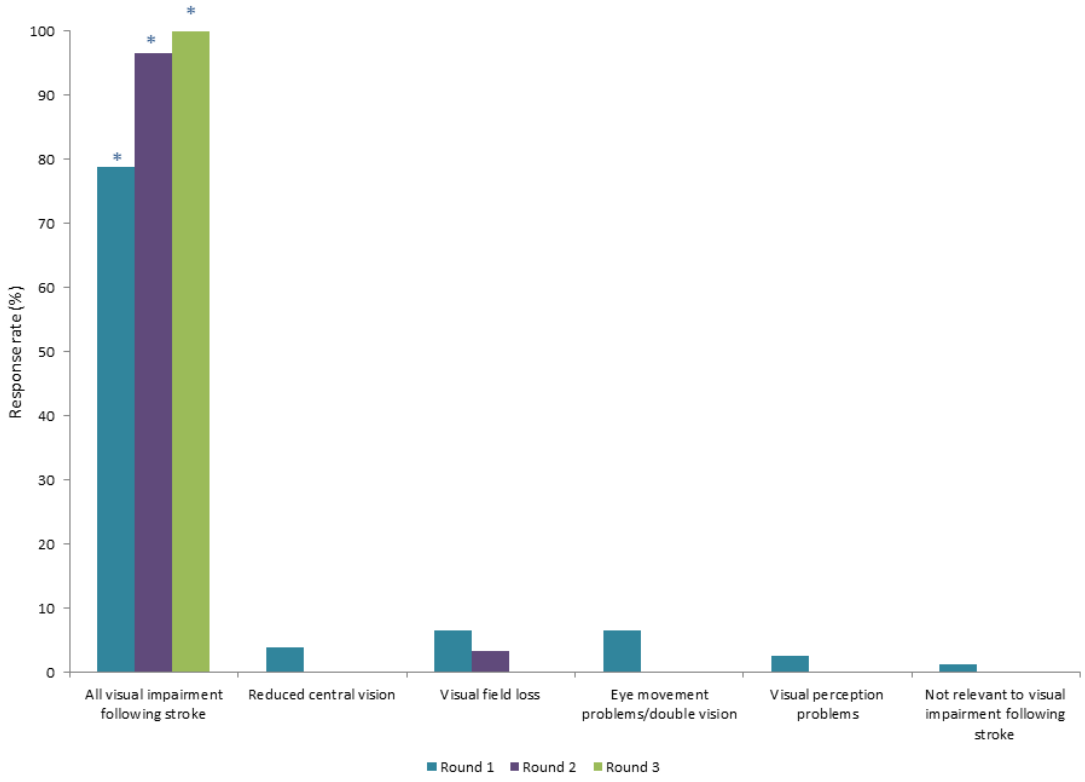


Figure 8.50: Agreement of application of 'participating in outdoor social activities' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.45: Agreement and importance values for the 'loss of confidence' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	0.0%	3.9%	0.0%	1.7%	0.0%	2.0%
		2	1.3%		0.0%		0.0%	
		3	2.6%		1.7%		2.0%	
	Important but not critical	4	5.1%	24.3%	1.7%	15.3%	0.0%	8.1%
		5	9.0%		3.4%		2.0%	
		6	10.2%		10.2%		6.1%	
	Critical	7	29.5%	71.8%	25.4%	83.0%	18.4%	89.9%
		8	37.2%		54.2%		63.3%	
		9	5.1%		3.4%		8.2%	
Importance	Median		7.0		8.0		8.0	
	Range		2-9		3-9		3-9	
	Mean		6.9		7.3		7.6	
	SD		1.5		1.1		1.0	
	Mean Rank		22		10		10	

= Consensus

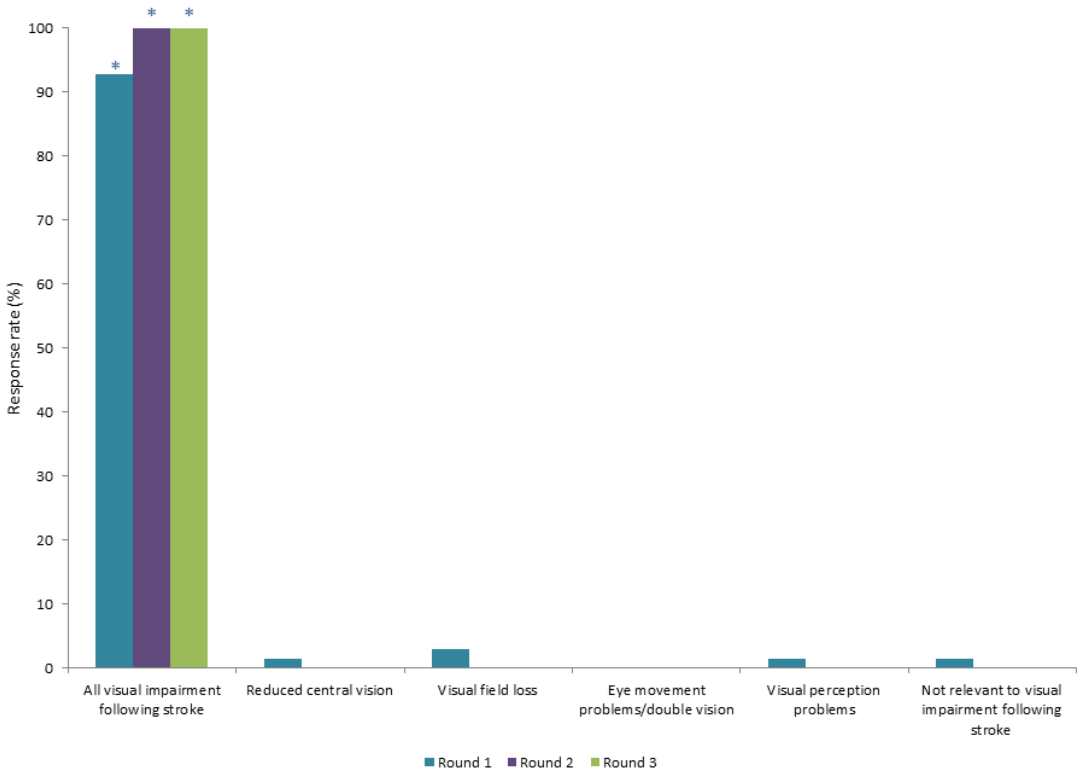


Figure 8.51: Agreement of application of 'loss of confidence' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.46: Agreement and importance values for the 'accomplishing as much as would like' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	0.0%	2.6%	0.0%	0.0%	0.0%	0.0%
		2	1.3%		0.0%		0.0%	
		3	1.3%		0.0%		0.0%	
	Important but not critical	4	1.3%	37.2%	1.6%	34.4%	2.0%	26.5%
		5	19.2%		19.7%		8.2%	
		6	16.7%		13.1%		16.3%	
	Critical	7	26.9%	60.2%	37.7%	65.6%	44.9%	73.5%
		8	25.6%		23.0%		22.5%	
		9	7.7%		4.9%		6.1%	
Importance	Median		7.0		7.0		7.0	
	Range		2-9		4-9		4-9	
	Mean		6.7		6.8		7.0	
	SD		1.4		1.2		1.1	
	Mean Rank		27		30		=28	

= Consensus

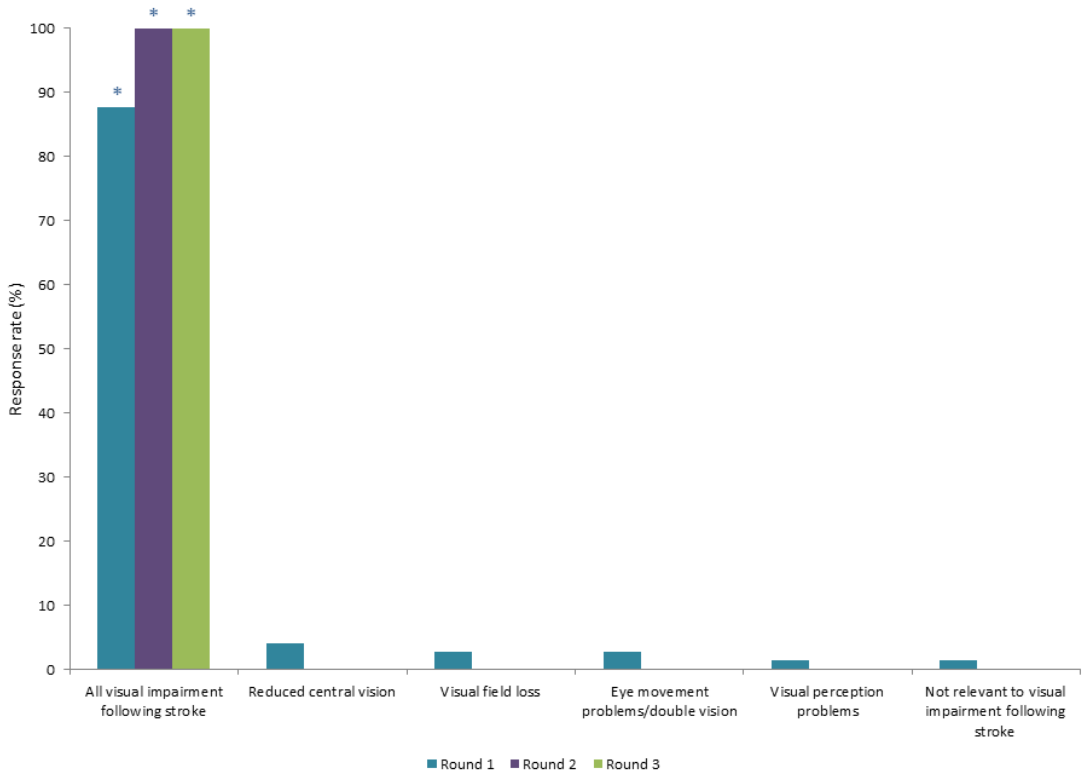


Figure 8.52: Agreement of application of 'accomplishing as much as would like' item to a category of visual impairment. When and where consensus is reached shown by *

8.3.3.45*: 'Limit of how long activities can be done for'*

No consensus to either include or exclude this item was reached within the process (Table 8.47). This was due to the proportion of participants who selected an 'important but not critical' option; 49.0% in the final round. The range interval decreased in the third round (by 1) whereas the standard deviation decreased across the three rounds (by 0.4), indicating convergence. Both the mean and rank increased across the three rounds from 46th initially to 43rd in the final round.

A consensus that 'limit of how long activities can be done for' was relevant to 'all visual impairment following stroke' was reached in the first round (79.5%) (Figure 8.53). The consensus strengthened in subsequent rounds to 91.8% in the third.

8.3.3.46*: 'Usual standard'*

Consensus (73.5%) to include the item was reached in the third round (Table 8.48). The range interval and standard deviation decreased across all three rounds (by 3 and 0.4 respectively), indicating convergence. Despite the mean being stable throughout the process, the rank had a large drop from 26th initially to 40th in the third round.

A consensus that 'usual standard' was relevant to 'all visual impairment following stroke' was reached in the first round (87.5%) (Figure 8.54). The consensus strengthened in the second round to achieve complete consensus (100%) which was maintained in the third round.

8.3.3.47*: 'Toileting'*

Consensus (73.0%) to include the item was reached in the first round and strengthened with each subsequent round to 95.9% in the final round (Table 8.49). The range interval decreased in the third round (by 5) whereas the standard deviation decreased across the three rounds (by 1.1), indicating convergence. The mean and rank increased across the three rounds, from 8th initially to joint 1st in the final round.

A consensus that 'toileting' was relevant to 'all visual impairment following stroke' was reached in the second round (79.7%) and was stable in the final round (79.6%) (Figure 8.55).

8.3.3.48*: 'Getting dressed'*

Consensus (73.5%) to include the item was reached in the third round (Table 8.50). The range interval and SD decreased across the three rounds (by 4 and 0.6, respectively), indicating convergence. The mean increased across all three rounds. The rank returned to 32nd following a drop in the second round.

A consensus that 'getting dressed' was relevant to 'all visual impairment following stroke' was reached in the second round (76.3%) (Figure 8.56). This weakened slightly in the third round (75.4%).

8.3.3.49*: 'Eating'*

Consensus (83.0%) to include the item was reached in the second round, strengthening to 91.9% in the third round (Table 8.51). The range interval and standard deviation decreased across the three rounds (by 3 and 0.5 respectively), indicating convergence. The mean increased across all three rounds. The rank increased between the first and second rounds from 20th to 14th and remained stable in the third.

A consensus that 'eating' was relevant to 'all visual impairment following stroke' was reached in the second round (88.1%) (Figure 8.57). This decreased in the third round (79.6%) in favour of the 'visual field loss' and 'visual perception problems' categories.

8.3.3.50*: 'Taking medication'*

Consensus (75.5%) to include the item was reached in the first round and strengthened with each subsequent round to 87.7% in the final round (Table 8.52). The range interval and standard deviation decreased across the three rounds (by 4 and 0.7 respectively), indicating convergence. The mean increased across all three rounds, whereas the rank decreased dropping from 7th in the first round to 9th in the final round.

A consensus that 'taking medication' was relevant to 'all visual impairment following stroke' was reached in the second round (88.1%) (Figure 8.58). This diminished in the third round (75.9%), with an increase in the uptake of the 'eye movement problems/double vision' and 'visual perception problems' categories.

Table 8.47: Agreement and importance values for the 'limit of how long activities can be done for' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	0.0%	5.1%	0.0%	1.7%	0.0%	0.0%
		2	0.0%		0.0%		0.0%	
		3	5.1%		1.7%		0.0%	
	Important but not critical	4	7.7%	53.9%	1.7%	59.3%	2.0%	49.0%
		5	20.5%		23.7%		12.3%	
		6	25.7%		33.9%		34.7%	
	Critical	7	26.9%	41.0%	32.2%	39.0%	40.8%	51.0%
		8	12.8%		5.1%		8.2%	
		9	1.3%		1.7%		2.0%	
Importance	Median		6.0		6.0		7.0	
	Range		3-9		3-9		4-9	
	Mean		6.1		6.2		6.5	
	SD		1.4		1.1		1.0	
	Mean Rank		=46		47		=43	

= Consensus

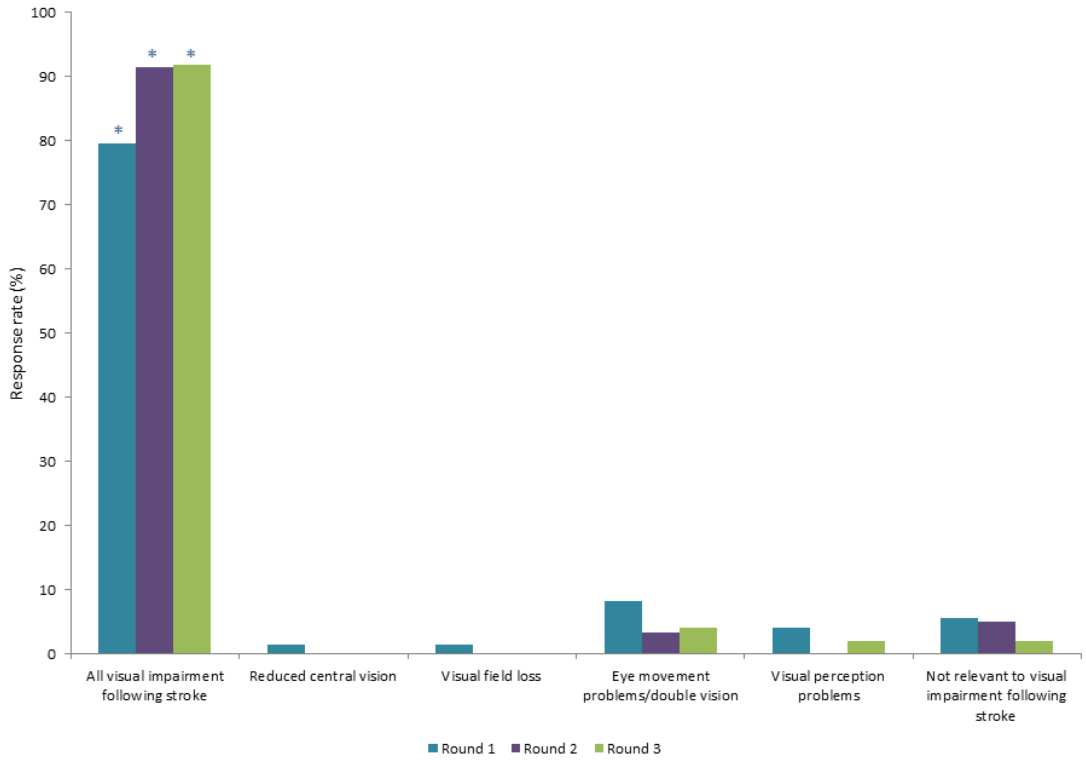


Figure 8.53: Agreement of application of 'limit of how long activities can be done for' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.48: Agreement and importance values for the 'usual standard' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	0.0%	2.6%	0.0%	0.0%	0.0%	0.0%
		2	1.3%		0.0%		0.0%	
		3	1.3%		0.0%		0.0%	
	Important but not critical	4	2.5%	38.4%	3.4%	37.3%	4.1%	26.5%
		5	12.8%		11.9%		10.2%	
		6	23.1%		22.0%		12.2%	
	Critical	7	28.2%	59.0%	42.4%	62.7%	55.1%	73.5%
		8	21.8%		18.6%		18.4%	
		9	9.0%		1.7%		0.0%	
Importance	Median		7.0		7.0		7.0	
	Range		2-9		4-9		4-8	
	Mean		6.7		6.7		6.7	
	SD		1.4		1.1		1.0	
	Mean Rank		26		33		40	

= Consensus

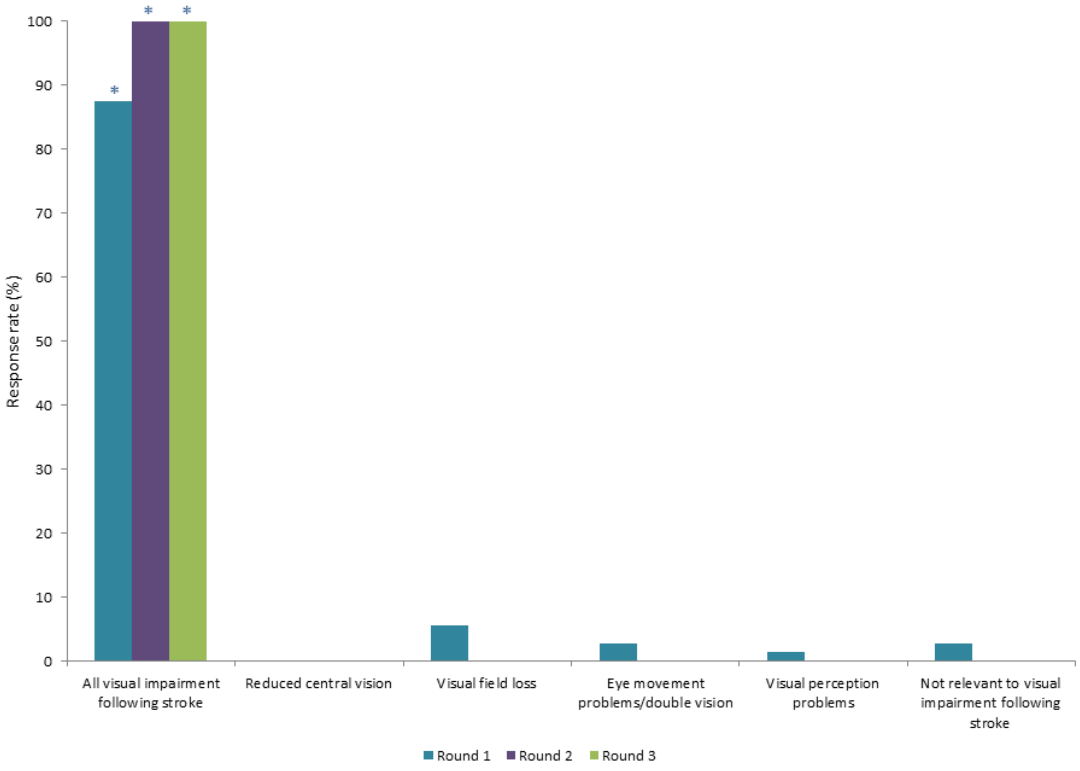


Figure 8.54: Agreement of application of 'usual standard' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.49: Agreement and importance values for the 'toileting' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	5.1%	5.1%	1.7%	1.7%	0.0%	0.0%
		2	0.0%		0.0%		0.0%	
		3	0.0%		0.0%		0.0%	
	Important but not critical	4	2.6%	21.9%	1.7%	8.5%	0.0%	4.1%
		5	9.0%		1.7%		0.0%	
		6	10.3%		5.1%		4.1%	
	Critical	7	11.5%	73.0%	18.6%	89.8%	14.3%	95.9%
		8	41.0%		47.5%		49.0%	
		9	20.5%		23.7%		32.6%	
Importance	Median		8.0		8.0		8.0	
	Range		1-9		1-9		6-9	
	Mean		7.2		7.7		8.1	
	SD		1.9		1.4		0.8	
	Mean Rank		8		4		=1	

= Consensus

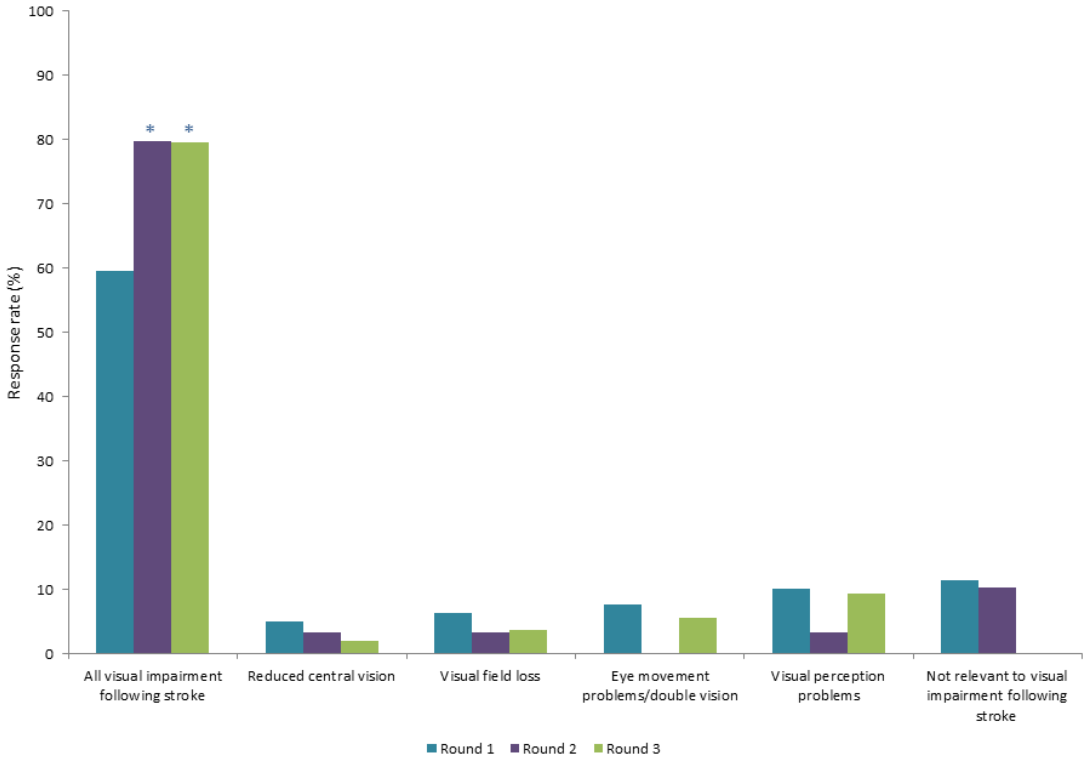


Figure 8.55: Agreement of application of 'toileting' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.50: Agreement and importance values for the 'getting dressed' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	2.6%	2.6%	0.0%	3.4%	0.0%	0.0%
		2	0.0%		1.7%		0.0%	
		3	0.0%		1.7%		0.0%	
	Important but not critical	4	3.8%	39.7%	1.7%	36.6%	0.0%	26.5%
		5	19.2%		18.3%		12.2%	
		6	16.7%		16.6%		14.3%	
	Critical	7	30.8%	57.7%	41.7%	60.0%	51.0%	73.5%
		8	17.9%		16.6%		18.4%	
		9	9.0%		1.7%		4.1%	
Importance	Median		7.0		7.0		7.0	
	Range		1-9		2-9		5-9	
	Mean		6.5		6.5		6.9	
	SD		1.6		1.3		1.0	
	Mean Rank		32		=37		=32	

= Consensus

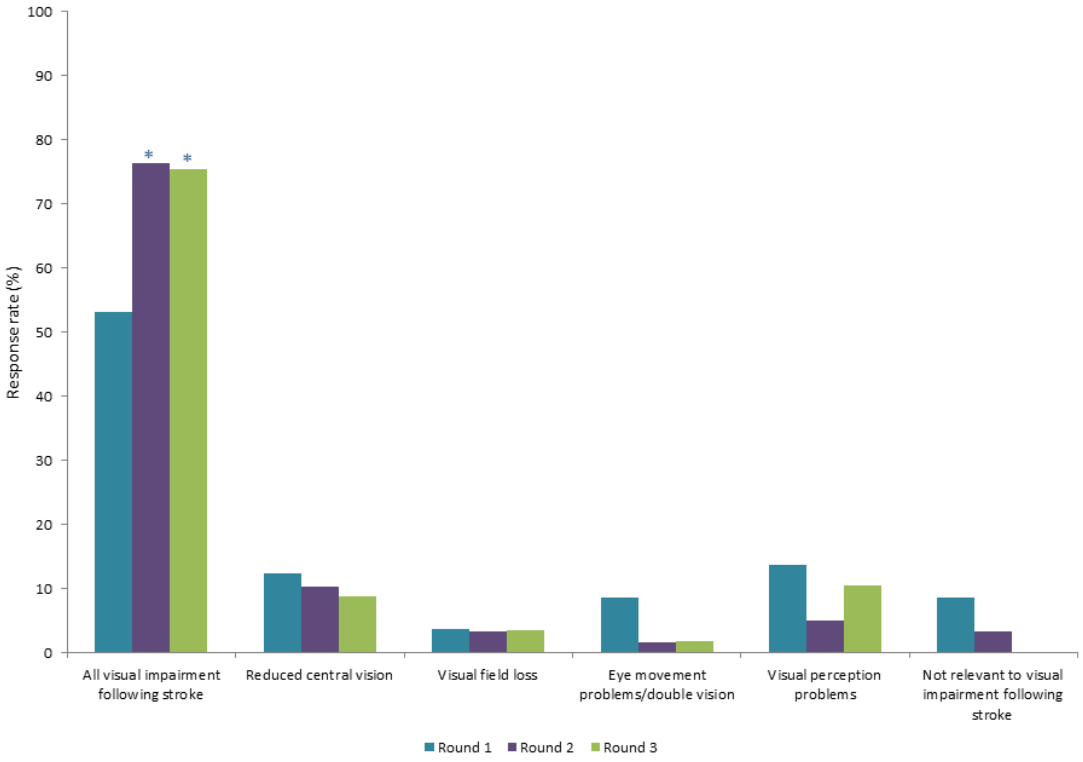


Figure 8.56: Agreement of application of 'getting dressed' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.51: Agreement and importance values for the 'eating' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	2.6%	6.5%	1.7%	1.7%	0.0%	0.0%
		2	1.3%		0.0%		0.0%	
		3	2.6%		0.0%		0.0%	
	Important but not critical	4	1.3%	24.3%	0.0%	15.3%	2.0%	8.1%
		5	10.2%		3.4%		0.0%	
		6	12.8%		11.9%		6.1%	
	Critical	7	25.6%	69.2%	40.6%	83.0%	47.0%	91.9%
		8	28.2%		30.5%		34.7%	
		9	15.4%		11.9%		10.2%	
Importance	Median		7.0		7.0		7.0	
	Range		1-9		1-9		4-9	
	Mean		6.7		7.3		7.4	
	SD		1.4		1.3		0.9	
	Mean Rank		20		=14		14	

= Consensus

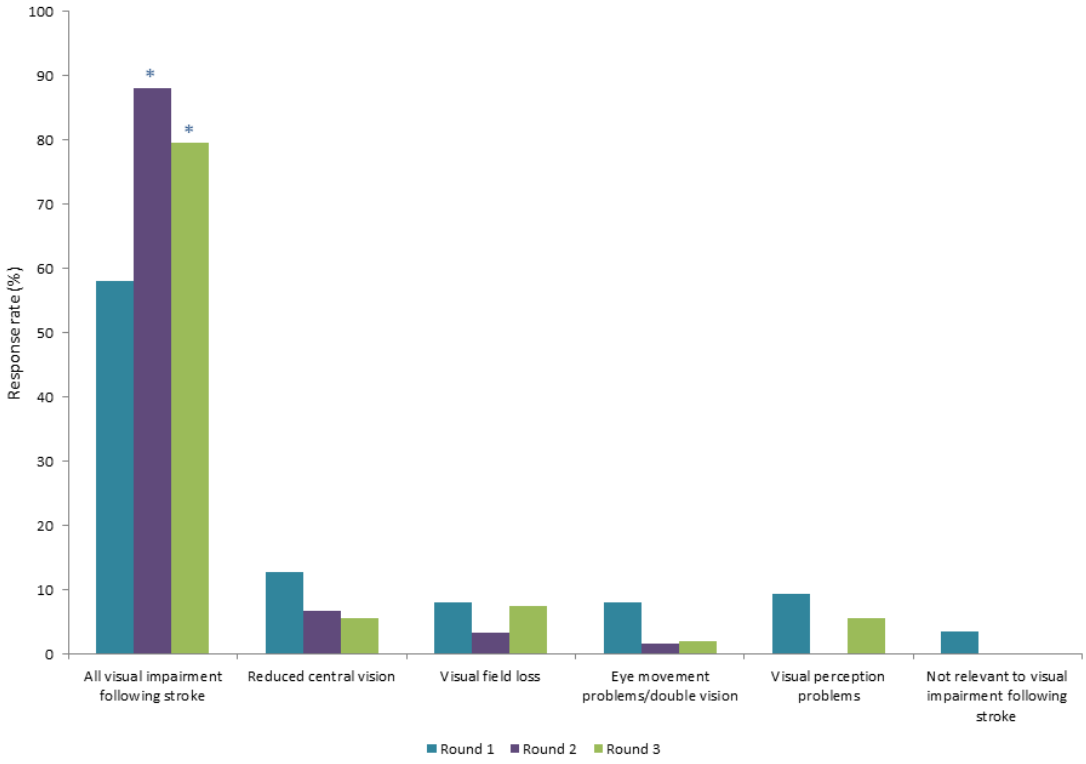


Figure 8.57: Agreement of application of 'eating' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.52: Agreement and importance values for the 'taking medication' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	2.6%	3.9%	0.0%	1.6%	0.0%	0.0%
		2	1.3%		0.0%		0.0%	
		3	0.0%		1.6%		0.0%	
	Important but not critical	4	2.6%	20.6%	1.6%	19.7%	0.0%	12.3%
		5	9.0%		11.5%		8.2%	
		6	9.0%		6.6%		4.1%	
	Critical	7	19.1%	75.5%	21.3%	78.7%	24.5%	87.7%
		8	35.9%		42.6%		42.8%	
		9	20.5%		14.8%		20.4%	
Importance	Median		8.0		8.0		8.0	
	Range		1-9		3-9		5-9	
	Mean		7.2		7.3		7.6	
	SD		1.8		1.4		1.1	
	Mean Rank		7		11		9	

= Consensus

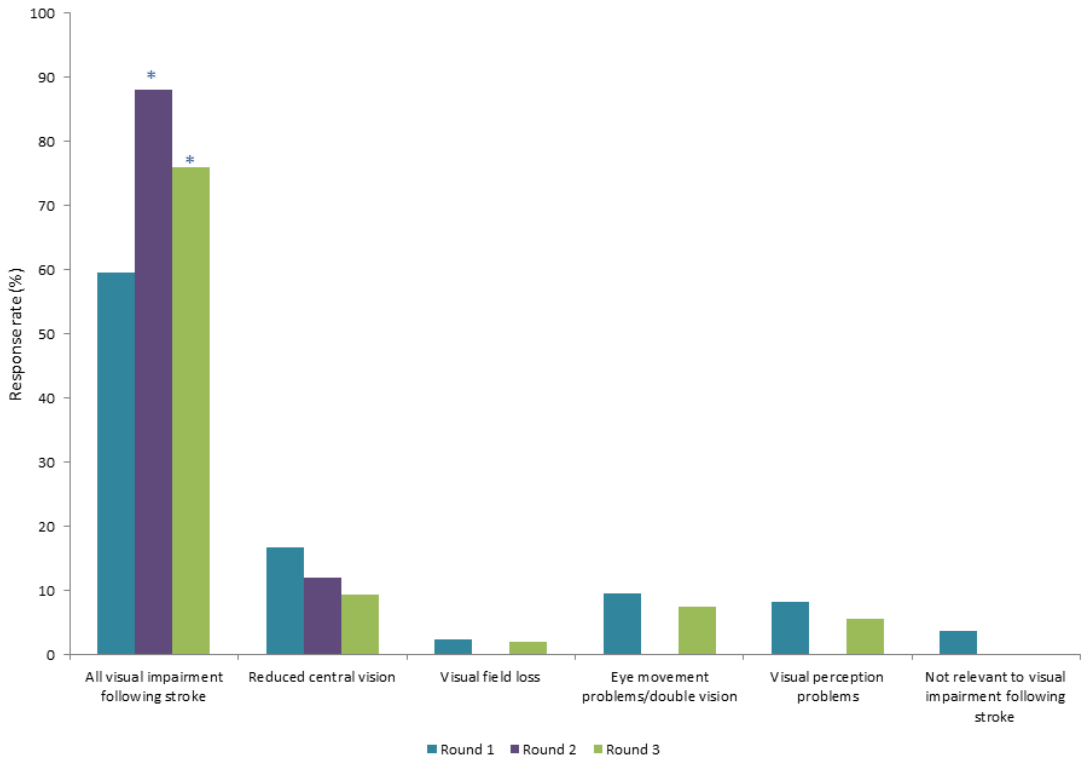


Figure 8.58: Agreement of application of 'taking medication' item to a category of visual impairment. When and where consensus is reached shown by *

8.3.3.51*: 'Pouring a drink'*

No consensus to either include or exclude this item was reached within the process (Table 8.47). This was due to the proportion of participants who selected an 'important but not critical' option; 32.7% in the final round. The range interval and standard deviation decreased across all three rounds (by 4 and 0.5 respectively), indicating convergence.

A consensus that 'pouring a drink' was relevant to 'all visual impairment following stroke' was reached in the second round (81.4%) (Figure 8.59). The consensus weakened in the third round to 76.8%, with an increase in the uptake of the 'eye movement problems/double vision' and 'visual perception problem' categories.

8.3.3.52*: 'Preparing something to eat'*

Consensus (74.6%) to include the item was reached in the second round and strengthened into the third round to 81.6% (Table 8.54). The range interval and standard deviation decreased across the three rounds (by 5 and 0.8 respectively), indicating convergence. The mean and rank increased across the three rounds from 28th initially to 20th in the final round.

A consensus that 'preparing something to eat' was relevant to 'all visual impairment following stroke' was reached in the first round (75.6%) (Figure 8.60). The consensus strengthened in subsequent rounds to 97.9% in the third round.

8.3.3.53*: 'Looking after appearance'*

Consensus (73.5%) to include the item was reached in the third round (Table 8.55). The range interval and standard deviation decreased across the three rounds (by 3 and 0.7 respectively), indicating convergence. The mean and rank increased across the three rounds from 41st initially to 36th in the final round.

A consensus that 'looking after appearance' was relevant to 'all visual impairment following stroke' was reached in the first round (70.9%) (Figure 8.61). This strengthened across subsequent rounds to 90.0% in the third round.

8.3.3.54*: 'Household chores'*

No consensus to either include or exclude this item was reached within the process (Table 8.56). This was due to the majority of participants selecting an 'important but not critical' option; 77.6% in the final round. The range interval and standard deviation decreased across the three rounds (by 3 and 0.6 respectively), indicating convergence. This is a low ranked item; the mean remained stable however the rank dropped one place to 52nd in the final round.

A consensus that 'household chores' was relevant to 'all visual impairment following stroke' was reached in the first round (78.9%) (Figure 8.62). The consensus strengthened in the second round to 91.5% and then weakened slightly in the third round to 84.9%.

8.3.3.55*: 'Shopping'*

No consensus either to include or exclude this item was reached within the process (Table 8.57). This was due to a large proportion of participants selecting an 'important but not critical' option; 40.9% in the third round. The range interval and standard deviation decreased across the three rounds (by 2 and 0.4 respectively), indicating convergence. Both the mean and rank increased across the three rounds from 48th initially to 42nd in the final round.

A consensus that 'shopping' was relevant to 'all visual impairment following stroke' was reached in the first round (89.7%) (Figure 8.63). The consensus strengthened in the second round to 93.2% and subsequently weakened in the third round to 88.2% with an increased selection of the 'eye movement problems/double vision' and 'visual perception problems' categories.

8.3.3.56*: 'Bathing or showering'*

Consensus (76.3%) to include the item was reached in the second round and strengthened in the third (83.7%) (Table 8.58). The range interval and standard deviation decreased (by 6 and 0.9 respectively), indicating convergence. The mean and rank increased across the three rounds from 29th initially to 23rd in the final round.

A consensus (88.1%) that 'bathing or showering' was relevant to 'all visual impairment following stroke' was reached in the second round (Figure 8.42). The consensus strengthened in the third round to 92.2%.

Table 8.53: Agreement and importance values for the 'pouring a drink' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	3.8%	6.4%	0.0%	1.6%	0.0%	0.0%
		2	0.0%		0.0%		0.0%	
		3	2.6%		1.6%		0.0%	
	Important but not critical	4	2.6%	32.1%	3.3%	36.1%	0.0%	32.7%
		5	15.4%		13.1%		8.2%	
		6	14.1%		19.7%		24.5%	
	Critical	7	32.0%	61.5%	41.0%	62.3%	42.8%	67.3%
		8	23.1%		21.3%		24.5%	
		9	6.4%		0.0%		0.0%	
Importance	Median		7.0		7.0		7.0	
	Range		1-9		3-8		5-8	
	Mean		7.6		6.6		6.8	
	SD		1.4		1.2		0.9	
	Mean Rank		33		34		34	

= Consensus

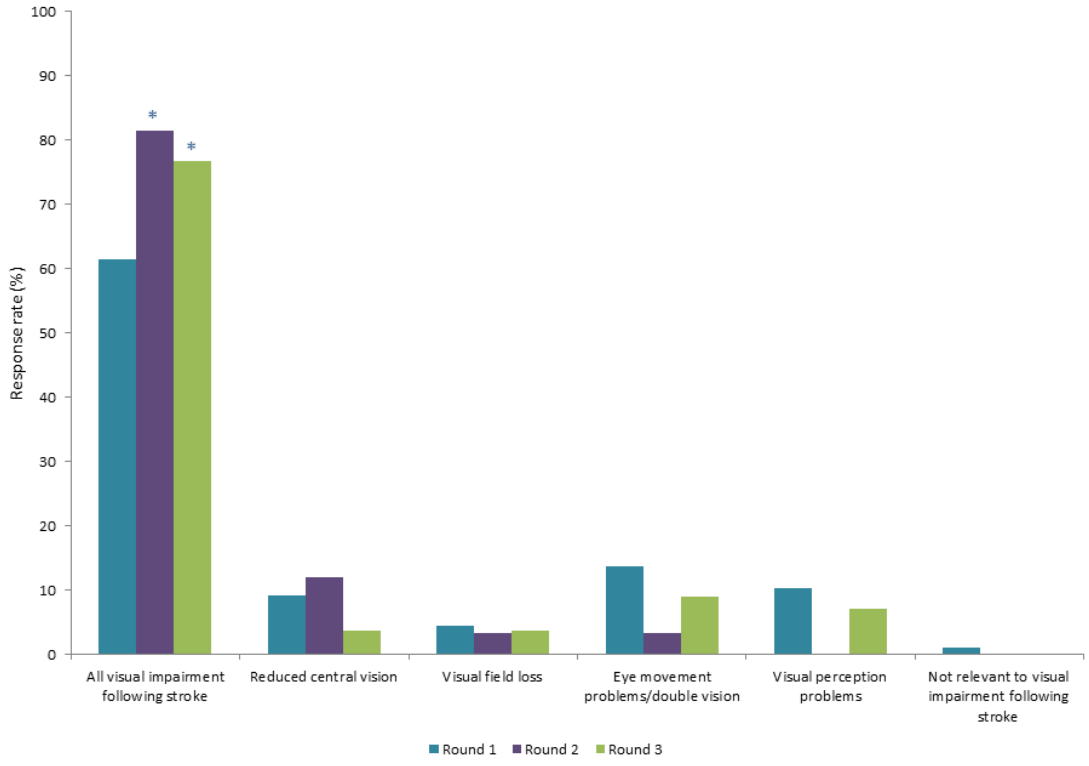


Figure 8.59: Agreement of application of 'pouring a drink' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.54: Agreement and importance values for the 'preparing something to eat' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	2.6%	2.6%	0.0%	1.7%	0.0%	0.0%
		2	0.0%		0.0%		0.0%	
		3	0.0%		1.7%		0.0%	
	Important but not critical	4	6.4%	34.6%	1.7%	23.7%	0.0%	18.4%
		5	11.5%		3.4%		0.0%	
		6	16.7%		18.6%		18.4%	
	Critical	7	34.6%	62.8%	47.5%	74.6%	53.1%	81.6%
		8	23.1%		20.3%		22.4%	
		9	5.1%		6.8%		6.1%	
Importance	Median		7.0		7.0		7.0	
	Range		1-9		3-9		6-9	
	Mean		6.6		7.0		7.2	
	SD		1.6		1.1		0.8	
	Mean Rank		28		=22		20	

= Consensus

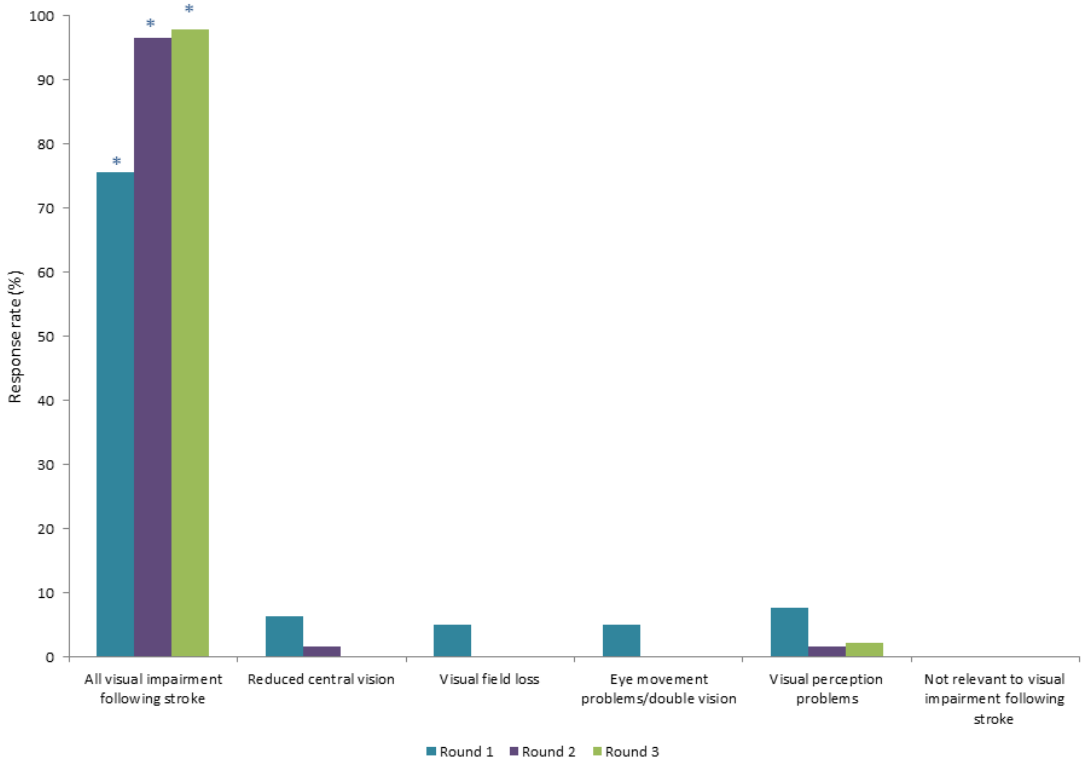


Figure 8.60: Agreement of application of 'preparing something to eat' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.55: Agreement and importance values for the 'looking after appearance' item.

			Round 1		Round 2		Round 3	
Agreement	Not important	1	0.0%	7.7%	0.0%	1.7%	0.0%	0.0%
		2	1.3%		1.7%		0.0%	
		3	6.4%		0.0%		0.0%	
	Important but not critical	4	3.9%	39.7%	3.4%	37.3%	2.0%	26.5%
		5	17.9%		10.2%		6.1%	
		6	17.9%		23.7%		18.4%	
	Critical	7	28.2%	52.6%	42.4%	61.0%	59.2%	73.5%
		8	23.1%		18.6%		14.3%	
		9	1.3%		0.0%		0.0%	
Importance	Median		7.0		7.0		7.0	
	Range		2-9		2-8		4-8	
	Mean		6.3		6.6		6.8	
	SD		1.5		1.2		0.8	
	Mean Rank		41		35		=36	

= Consensus

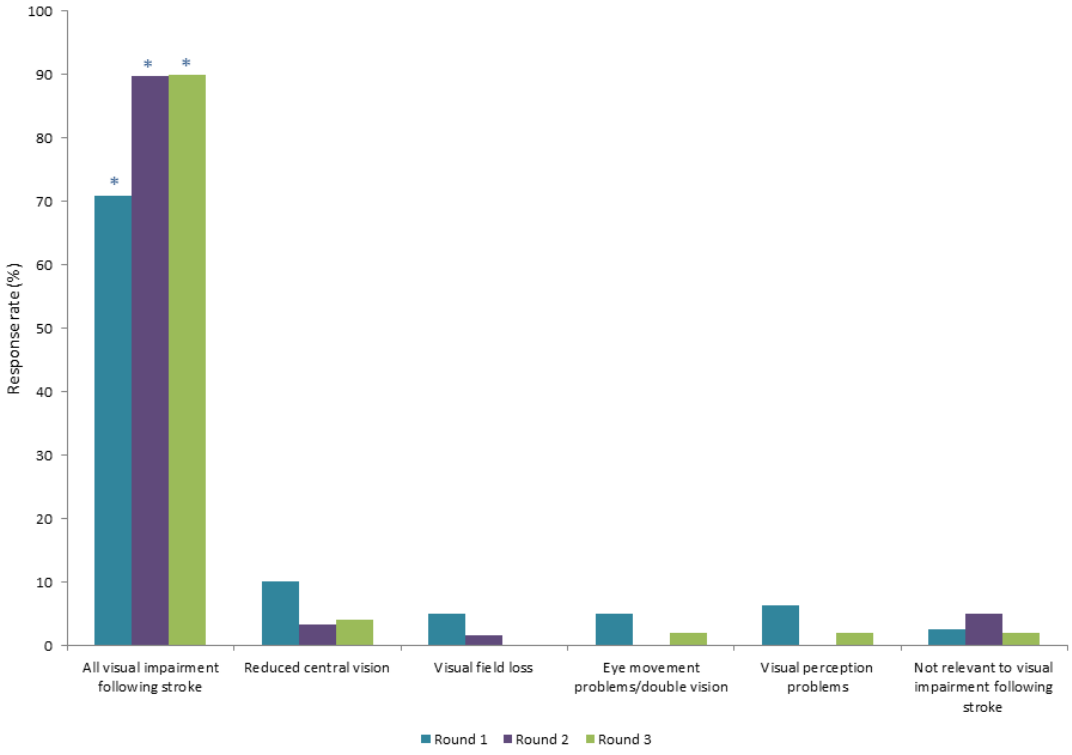


Figure 8.61: Agreement of application of 'looking after appearance' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.56: Agreement and importance values for the 'household chores' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	0.0%	6.5%	0.0%	1.6%	0.0%	0.0%
		2	1.3%		0.0%		0.0%	
		3	5.2%		1.6%		0.0%	
	Important but not critical	4	3.8%	58.9%	6.6%	75.4%	6.1%	77.6%
		5	34.6%		34.4%		32.7%	
		6	20.5%		34.4%		38.8%	
	Critical	7	23.1%	34.6%	18.1%	23.0%	16.3%	22.4%
		8	7.7%		3.3%		6.1%	
		9	3.8%		1.6%		0.0%	
Importance	Median		6.0		6.0		6.0	
	Range		2-9		3-9		4-8	
	Mean		5.8		5.8		5.8	
	SD		1.6		1.1		1.0	
	Mean Rank		51		51		=52	

= Consensus

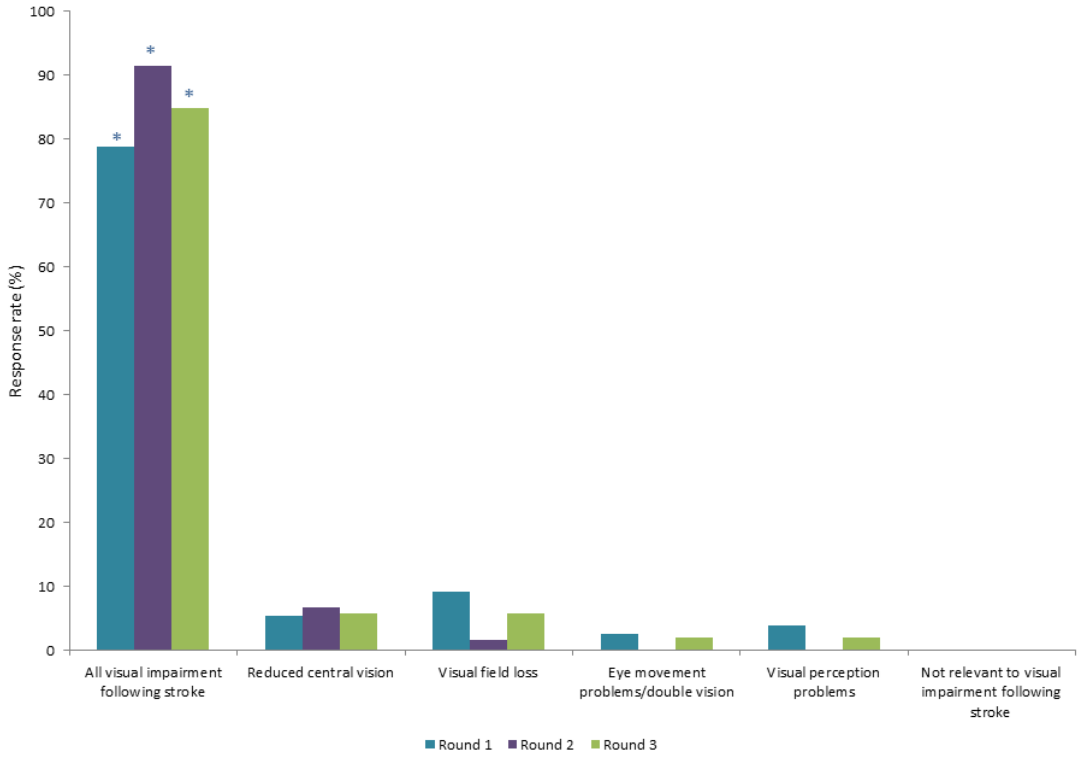


Figure 8.62: Agreement of application of 'household chores' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.57: Agreement and importance values for the 'shopping' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	0.0%	5.1%	0.0%	3.3%	0.0%	0.0%
		2	1.3%		0.0%		0.0%	
		3	3.8%		3.3%		0.0%	
	Important but not critical	4	6.4%	56.4%	1.7%	50.0%	4.1%	40.9%
		5	24.4%		23.3%		14.3%	
		6	25.6%		25.0%		22.5%	
	Critical	7	23.1%	38.5%	38.3%	46.6%	46.9%	59.1%
		8	12.8%		8.3%		12.2%	
		9	2.6%		0.0%		0.0%	
Importance	Median		6.0		6.0		7.0	
	Range		2-9		3-8		4-9	
	Mean		6.0		6.2		6.5	
	SD		1.4		1.1		1.0	
	Mean Rank		48		=44		42	

= Consensus

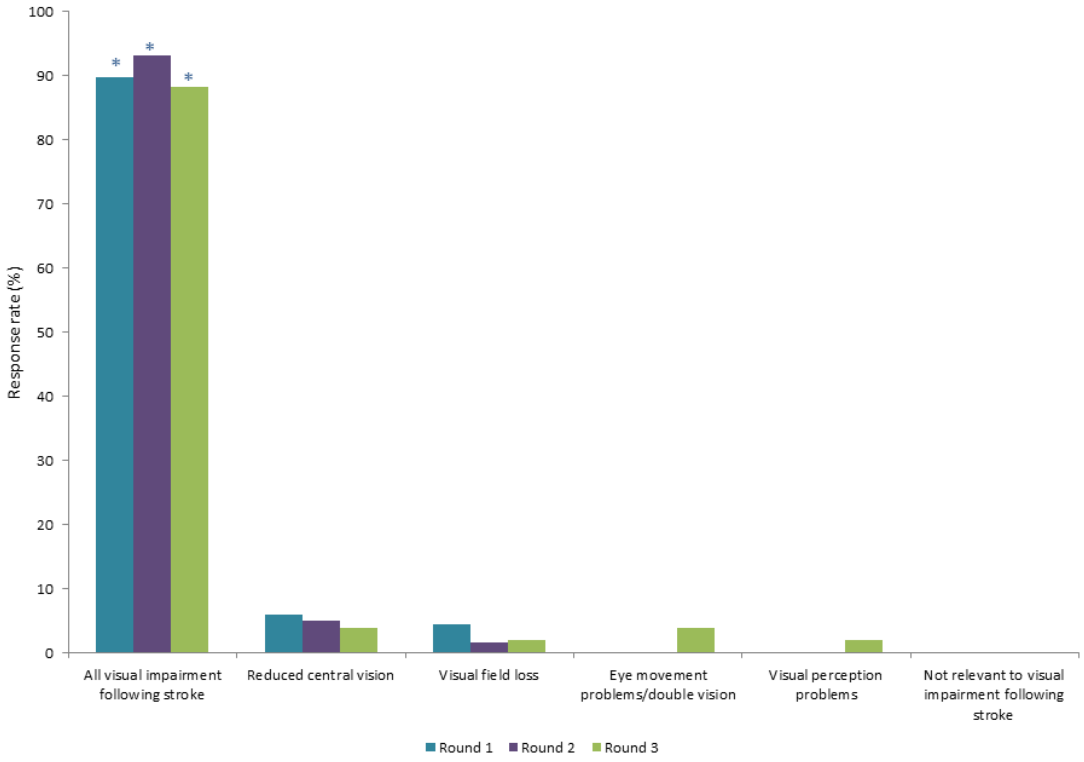


Figure 8.63: Agreement of application of 'shopping' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.58: Agreement and importance values for the 'bathing or showering' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	2.6%	6.4%	0.0%	0.0%	0.0%	0.0%
		2	0.0%		0.0%		0.0%	
		3	3.8%		0.0%		0.0%	
	Important but not critical	4	2.6%	28.3%	0.0%	23.7%	0.0%	16.3%
		5	9.0%		0.0%		0.0%	
		6	16.7%		23.7%		16.3%	
	Critical	7	38.5%	65.4%	57.6%	76.3%	57.2%	83.7%
		8	23.1%		17.0%		26.5%	
		9	3.8%		1.7%		0.0%	
Importance	Median		7.0		7.0		7.0	
	Range		1-9		6-9		6-8	
	Mean		6.6		7.0		7.1	
	SD		1.6		0.7		0.7	
	Mean Rank		=29		=22		23	

= Consensus

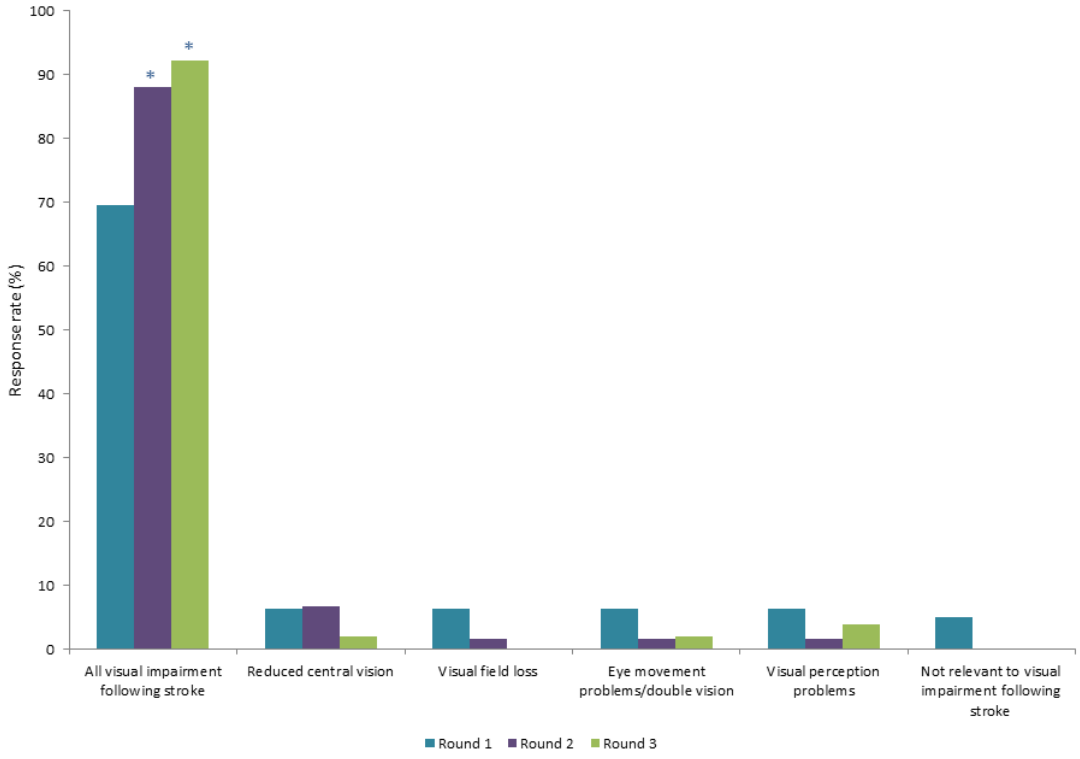


Figure 8.64: Agreement of application of 'bathing or showering' item to a category of visual impairment. When and where consensus is reached shown by *

8.3.3.57*: 'Negative emotions'*

Consensus (77.9%) to include the item was reached in the second round and strengthened in the third round (81.6%) (Table 8.59). The range interval initially decreased in the second round and then rebounded in the third, resulting in no change between the first and third rounds, indicating the presence of disagreement within the group. The standard deviation decreased slightly across the three rounds (by 0.2), indicating some convergence. The mean increased across the three rounds with a slight increase in rank to 12th in the second round which was maintained.

A consensus (89.7%) that 'negative emotions' was relevant to all visual impairment following stroke was achieved in the first round (Figure 8.65). The consensus strengthened across subsequent rounds to 98.0% in the third round.

8.3.3.58*: 'Vulnerable'*

Consensus (79.5%) to include the item was reached in the first round and strengthened with each subsequent round to 94.0% in the final round (Table 8.60). The range interval decreased in the third round (by 1) whereas the standard deviation decreased across the three rounds (by 0.4), indicating convergence. This is a highly-ranked item; the mean increased across all three rounds and the rank increased to 5th in the second and was maintained in the final round.

A consensus that 'vulnerable' was relevant to 'all visual impairment following stroke' was reached in the first round (91.3%) (Figure 8.66). The consensus strengthened across subsequent rounds to 97.9% in the third round.

8.3.3.59*: 'Not coping'*

Consensus (87.2%) to include the item was reached in the first round and strengthened with each subsequent round to complete consensus (100%) in the final round (Table 8.61). The range interval and SD decreased across the three rounds (by 6 and 0.8 respectively), indicating convergence. This is a highly-ranked item. The mean increased across all three rounds and the rank increased by one place to be equal 1st in the final round.

A consensus that 'not coping' was relevant to 'all visual impairment following stroke' was reached in the first round (86.1%) (Figure 8.67). The consensus strengthened in the second round and complete consensus (100%) was achieved in the third round.

8.3.3.60*: 'Self-conscious'*

No consensus to either include or exclude this item was reached within the process (Table 8.62). This was due to a large proportion of participants selecting an 'important but not critical' option; 38.8% in the final round. The range interval and standard deviation decreased across the three rounds (by 2 and 0.2 respectively), indicating convergence. The mean increased in the third round with an associated one place increased of rank to 45th.

A consensus that 'self-conscious' was relevant to 'all visual impairment following stroke' was initially reached in the second round (78.0%) (Figure 8.68). This consensus was lost in the third round, with an increase in participants (16.0%) selecting the 'eye movement problems/double vision'.

8.3.3.61*: 'Burden to others'*

Consensus (74.3%) to include the item was reached in the first round and strengthened with each subsequent round to 87.8% in the final round (Table 8.63). The range interval and standard deviation decreased in the second round (by 3 and 0.5 respectively), indicating convergence. The range interval then slightly diverged (by 1) in the third round. This is a highly-ranked item. The mean increased across all three rounds with the rank increasing to 6th in the second and subsequently dropping to 8th in the final round.

A consensus that 'burden to others' was relevant to 'all visual impairment following stroke' was reached in the first round (80.6%) (Figure 8.69). The consensus strengthened across subsequent rounds to 98.0% in the third round.

8.3.3.62*: 'Stay at home'*

Consensus (83.7%) to include the item was reached in the third round (Table 8.64). The range interval and standard deviation increased between the first and second rounds (by 1 and 0.1 respectively), indicating divergence. This was followed by a slight decrease into the third round (by 1 and 0.3 respectively), indicating convergence. The mean increased across all three rounds and the rank made a large increase from 39th initially to 19th in the final round.

A consensus that 'stay at home' was relevant to 'all visual impairment following stroke' was reached in the first round (75.0%) (Figure 8.70). The consensus strengthened in the second round to 93.2% and then weakened slightly in the third round to 90.2%.

Table 8.59: Agreement and importance values for the 'negative emotions' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	0.0%	0.0%	0.0%	1.7%	0.0%	0.0%
		2	0.0%		0.0%		0.0%	
		3	0.0%		1.7%		0.0%	
	Important but not critical	4	6.4%	32.1%	1.7%	20.4%	2.0%	18.4%
		5	10.3%		8.5%		4.1%	
		6	15.4%		10.2%		12.3%	
	Critical	7	25.6%	67.9%	25.4%	77.9%	18.4%	81.6%
		8	33.3%		39.0%		46.9%	
		9	9.0%		13.5%		16.3%	
Importance	Median		7.0		8.0		8.0	
	Range		4-9		3-9		4-9	
	Mean		7.0		7.3		7.5	
	SD		1.4		1.3		1.2	
	Mean Rank		=13		=12		12	

= Consensus

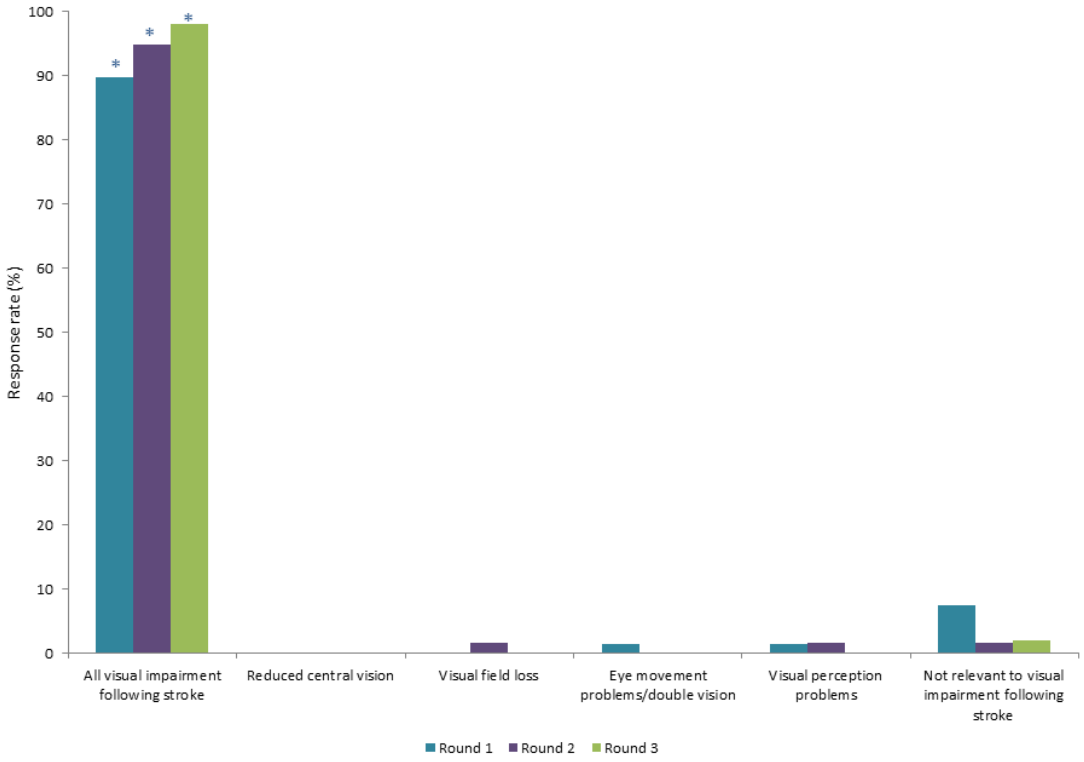


Figure 8.65: Agreement of application of 'negative emotions' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.60: Agreement and importance values for the 'vulnerable' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	0.0%	3.8%	0.0%	1.7%	0.0%	0.0%
		2	0.0%		0.0%		0.0%	
		3	3.8%		1.7%		0.0%	
	Important but not critical	4	2.6%	16.7%	0.0%	10.0%	2.0%	6.0%
		5	3.8%		3.3%		2.0%	
		6	10.3%		6.7%		2.0%	
	Critical	7	26.9%	79.5%	23.3%	88.3%	16.4%	94.0%
		8	38.5%		50.0%		53.1%	
		9	14.1%		15.0%		24.5%	
Importance	Median		8.0		8.0		8.0	
	Range		3-9		3-9		4-9	
	Mean		7.3		7.6		7.9	
	SD		1.4		1.1		1.0	
	Mean Rank		6		5		5	

= Consensus

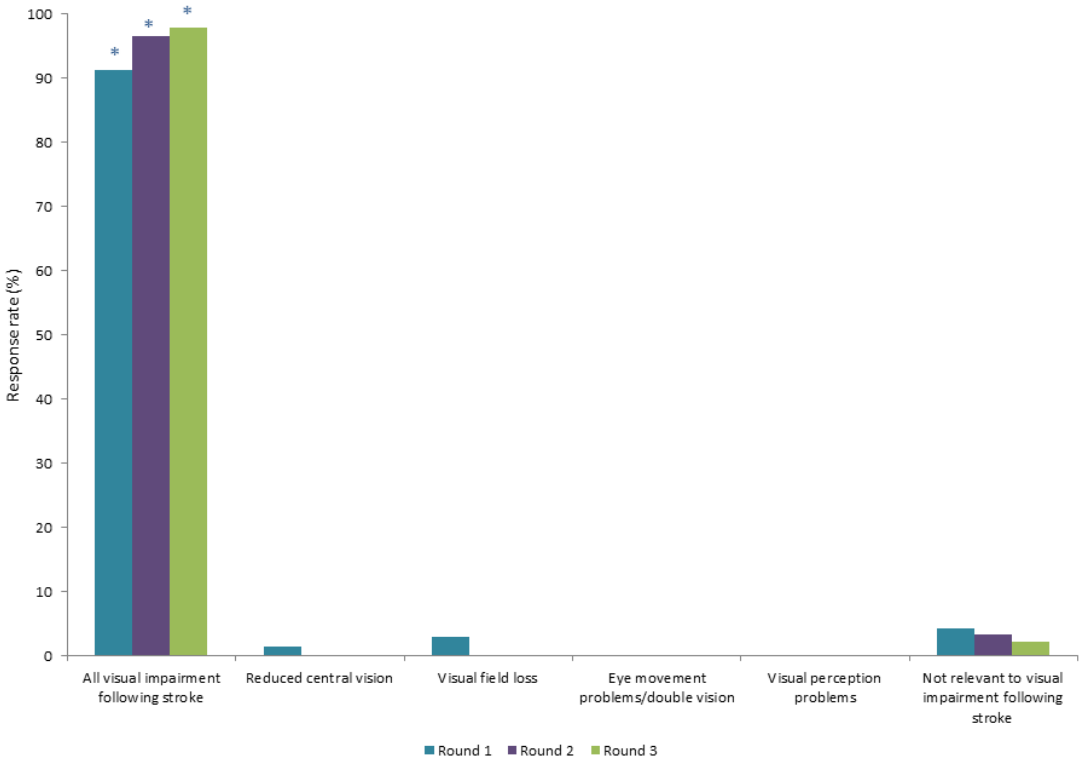


Figure 8.66: Agreement of application of 'vulnerable' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.61: Agreement and importance values for the 'not coping' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	1.3%	2.6%	0.0%	1.6%	0.0%	0.0%
		2	0.0%		1.6%		0.0%	
		3	1.3%		0.0%		0.0%	
	Important but not critical	4	1.3%	10.2%	0.0%	6.5%	0.0%	0.0%
		5	3.8%		1.6%		0.0%	
		6	5.1%		4.9%		0.0%	
	Critical	7	21.8%	87.2%	19.7%	91.9%	12.2%	100%
		8	38.5%		44.3%		65.3%	
		9	26.9%		27.9%		22.5%	
Importance	Median		8.0		8.0		8.0	
	Range		1-9		2-9		7-9	
	Mean		7.6		7.8		8.1	
	SD		1.4		1.2		0.6	
	Mean Rank		2		2		=1	

= Consensus

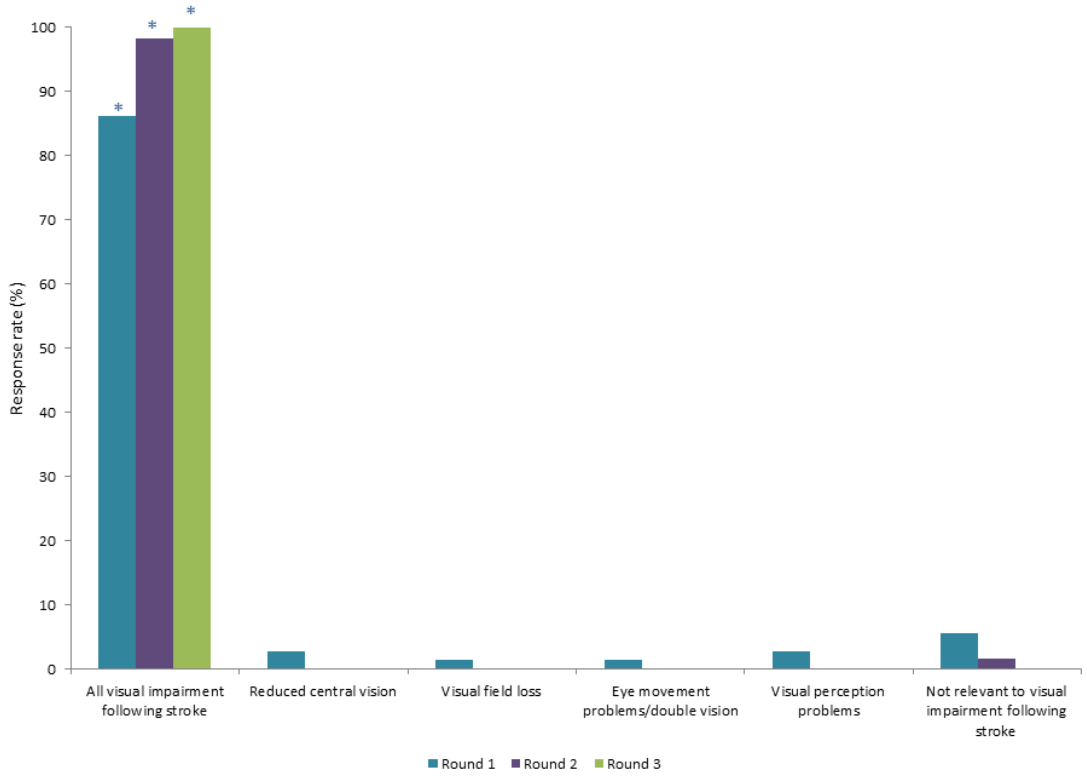


Figure 8.67: Agreement of application of 'not coping' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.62: Agreement and importance values for the 'self-conscious' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	0.0%	2.6%	0.0%	1.6%	0.0%	4.1%
		2	1.3%		0.0%		0.0%	
		3	1.3%		1.6%		4.1%	
	Important but not critical	4	7.7%	52.6%	3.3%	50.9%	4.1%	38.8%
		5	21.8%		27.9%		8.2%	
		6	23.1%		19.7%		26.5%	
	Critical	7	29.5%	44.8%	37.7%	47.5%	40.8%	57.1%
		8	12.8%		9.8%		16.3%	
		9	2.5%		0.0%		0.0%	
Importance	Median		6.0		6.0		7.0	
	Range		2-9		3-8		3-8	
	Mean		6.2		6.2		6.5	
	SD		1.4		1.1		1.2	
	Mean Rank		44		=44		=45	

= Consensus

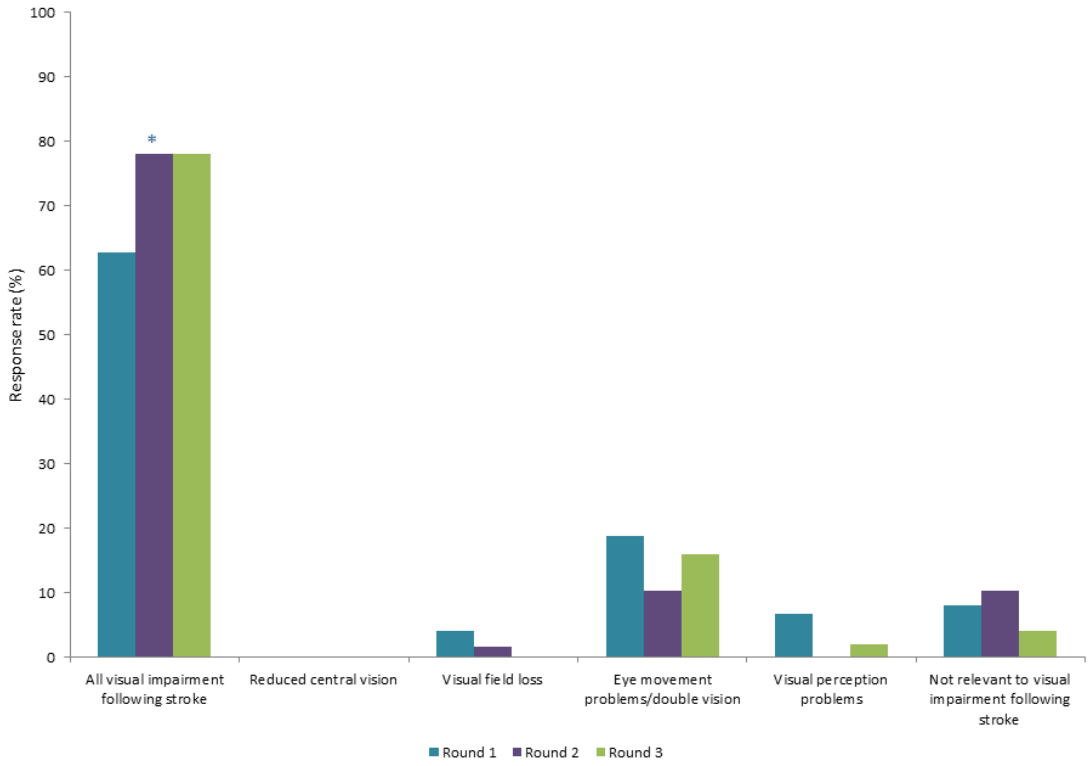


Figure 8.68: Agreement of application of 'self-conscious' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.63: Agreement and importance values for the 'burden to others' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	1.3%	5.2%	0.0%	0.0%	0.0%	0.0%
		2	0.0%		0.0%		0.0%	
		3	3.9%		0.0%		0.0%	
	Important but not critical	4	1.3%	20.5%	0.0%	16.7%	2.0%	12.2%
		5	7.7%		10.0%		4.1%	
		6	11.5%		6.7%		6.1%	
	Critical	7	19.2%	74.3%	23.3%	83.3%	14.3%	87.8%
		8	42.3%		46.7%		59.2%	
		9	12.8%		13.3%		14.3%	
Importance	Median		8.0		8.0		8.0	
	Range		1-9		5-9		4-9	
	Mean		7.1		7.5		7.7	
	SD		1.6		1.1		1.1	
	Mean Rank		9		6		8	

= Consensus

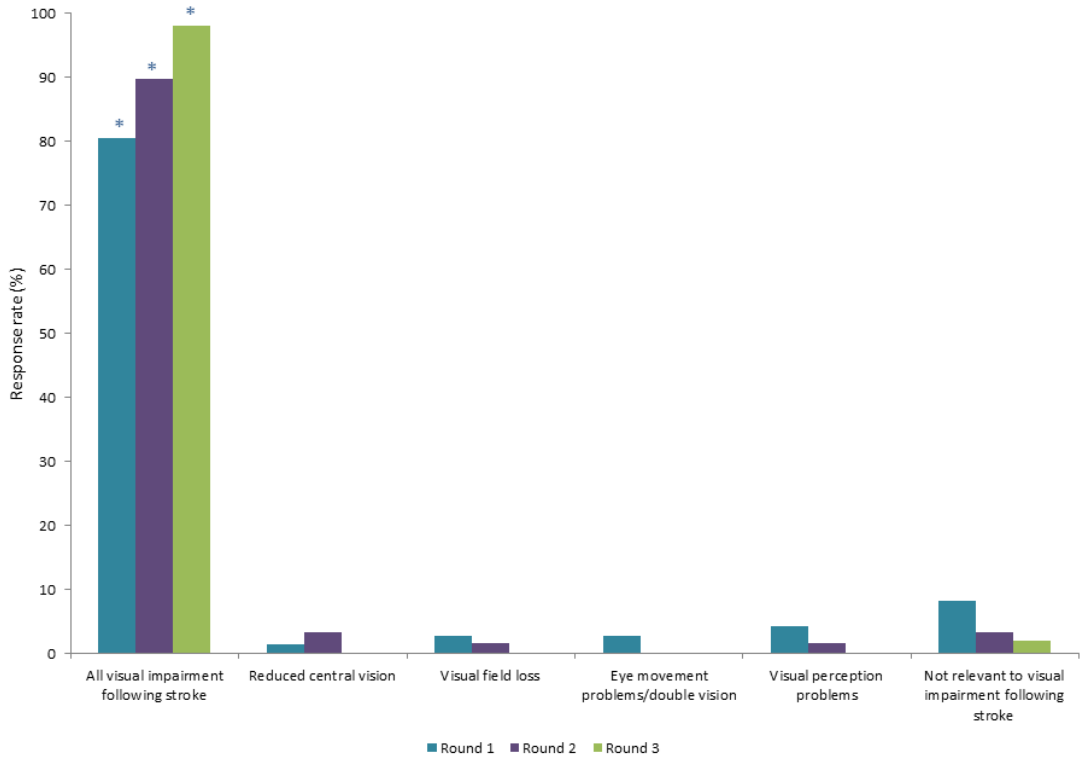


Figure 8.69: Agreement of application of 'burden to others' item to a category of visual impairment. When and where consensus is reached shown by *

Table 8.64: Agreement and importance values for the 'stay at home' item

			Round 1		Round 2		Round 3	
Agreement	Not important	1	6.4%	9.0%	3.3%	3.3%	0.0%	2.0%
		2	1.3%		0.0%		2.0%	
		3	1.3%		0.0%		0.0%	
	Important but not critical	4	0.0%	32.1%	3.3%	27.8%	0.0%	14.3%
		5	15.4%		6.5%		6.1%	
		6	16.7%		18.0%		8.2%	
	Critical	7	28.2%	58.9%	32.8%	68.9%	36.7%	83.7%
		8	26.9%		32.8%		42.9%	
		9	3.8%		3.3%		4.1%	
Importance	Median		7.0		7.0		7.0	
	Range		2-9		1-9		2-9	
	Mean		6.7		6.8		7.2	
	SD		1.4		1.5		1.2	
	Mean Rank		39		28		19	

= Consensus

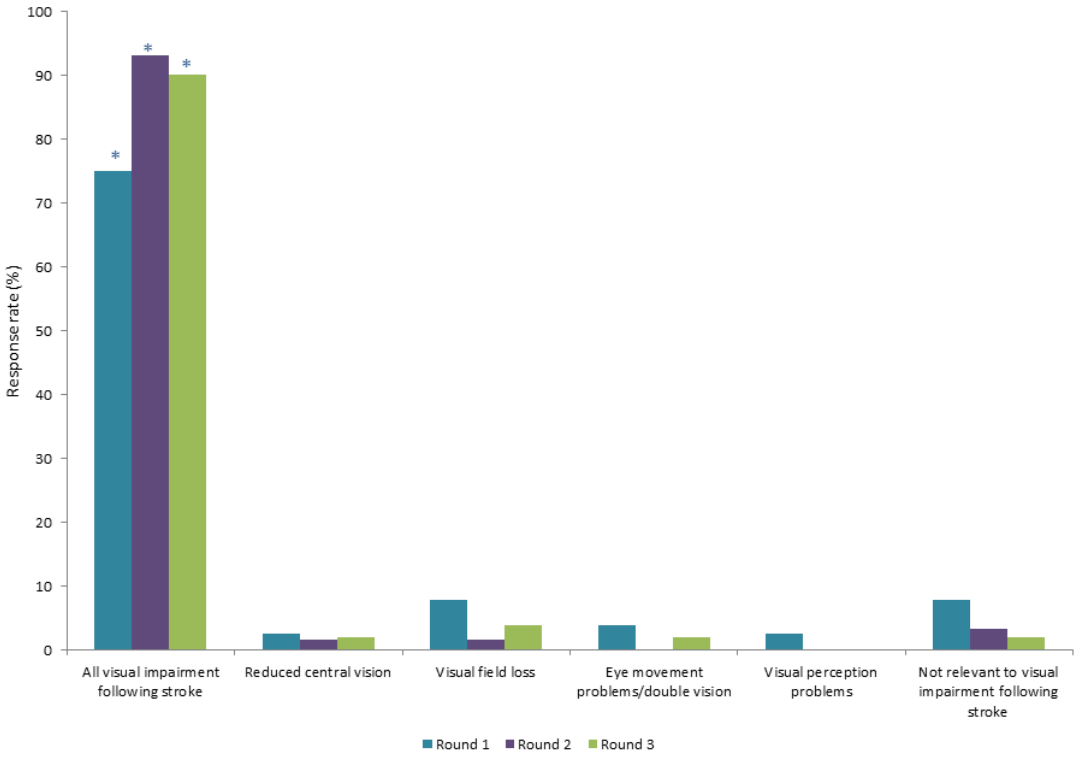


Figure 8.70: Agreement of application of 'stay at home' item to a category of visual impairment. When and where consensus is reached shown by *

8.3.4: Agreement

The level of within-participant agreement has been investigated between the rounds of the survey. The results are outlined in full in Table 8.65.

The greatest amount of agreement was found between the second and third rounds, with 59.7% (n=37) of items having increased agreement from that between the first and second rounds. The majority of items between rounds two and three had either moderate (Kappa 0.41-0.6) or substantial (Kappa 0.61-0.8) agreement; 40.3% (n=25) and 46.8% (n=29) respectively. Three items ('overall vision', 'making eye contact' and 'not coping') had fair (Kappa 0.21-0.4) agreement between rounds two and three. Five items had almost perfect (Kappa 0.81-1.0) agreement between rounds two and three; 'blurred vision', 'fluctuation', 'adjusting to differing lighting', 'negative emotions' and 'vulnerable'. The five items which had almost perfect agreement had a spread of if and when consensus was achieved, from no consensus achieved for two items, to achieved consensus; one in the first round, one in the second round and one in the third round.

The majority of items between rounds one and two also had either moderate 56.5% (n=35) or substantial agreement 33.9% (n=21). The remaining six items had fair agreement; 'overall health', 'overall vision', 'unusual appearance', 'moving around on uneven ground', 'looking after your appearance' and 'bathing or showering'. The items which had fair agreement had a spread of if and when consensus was achieved across all three rounds.

The greatest amount of disagreement was found between the first and third rounds, with 83.9% (n=52) of items showing the lowest levels of agreement compared to the levels of agreement between rounds one and two and rounds two and three. The majority of items between rounds one and three had either fair 48.4% (n=30) or moderate agreement 37.1% (n=23). Three items demonstrated poor agreement (Kappa 0.0-0.2) between the first and third rounds; 'making eye contact', 'toileting' and 'stay at home'. The 'toileting' and 'stay at home' items achieved consensus, in the first and third round respectively, whereas 'making eye contact' did not achieve consensus within the three round process.

Table 8.65: Weighted Kappa values for within-participant agreement in important rankings between rounds of each item

Levels of agreement: Poor (0.0-0.2), Fair (0.21-0.4), Moderate (0.41-0.6), Substantial (0.61-0.8), Almost perfect (0.81-1.0).

Item	Agreement between (Kappa (CI))		
	Round 1 and 2	Round 2 and 3	Round 1 and 3
Overall health	0.393 (0.170 - 0.616)	0.552 (0.230 - 0.873)	0.362 (0.155 - 0.569)
Overall vision	0.408 (0.103 - 0.712)	0.408 (0.115 - 0.702)	0.395 (0.175 - 0.615)
Blurred vision	0.712 (0.559 - 0.866)	0.818 (0.702 - 0.934)	0.638 (0.501 - 0.776)
Objects jumping around	0.499 (0.292 - 0.706)	0.677 (0.430 - 0.924)	0.406 (0.103 - 0.709)
Deterioration of vision	0.504 (0.208 - 0.800)	0.733 (0.540 - 0.926)	0.382 (0.019 - 0.745)
Fluctuation	0.706 0.558 - 0.854)	0.822 (0.699 - 0.945)	0.641 (0.481 - 0.801)
Tired eyes	0.461 (0.229 - 0.693)	0.696 (0.516 - 0.875)	0.463 (0.229 - 0.696)
Eyes seeing differently	0.776 (0.655 - 0.897)	0.777 (0.630 - 0.924)	0.515 (0.260 - 0.769)
Double vision	0.645 (0.396 - 0.894)	0.491 (0.200 - 0.783)	0.506 (0.314 - 0.697)
Judging distances	0.531 (0.273 - 0.789)	0.665 (0.379 - 0.753)	0.429 (0.153 - 0.706)
Unusual appearance	0.333 (-0.047 - 0.713)	0.593 (0.176 - 1.000)	0.554 (0.310 - 0.798)
Seeing far side of a room	0.521 (0.290 - 0.751)	0.645 (0.406 - 0.884)	0.486 (0.188 - 0.784)
Seeing something far away	0.670 (0.528 - 0.812)	0.678 (0.474 - 0.882)	0.515 (0.308 - 0.722)
Seeing faces	0.586 (0.422 - 0.750)	0.518 (0.199 - 0.838)	0.323 (0.094 - 0.552)
Writing	0.622 (0.454 - 0.791)	0.701 (0.549 - 0.852)	0.678 (0.521 - 0.835)
Close-up vision	0.472 (0.219 - 0.725)	0.538 (0.278 - 0.798)	0.421 (0.083 - 0.759)
Finding something	0.584 (0.383 - 0.784)	0.592 (0.418 - 0.766)	0.423 (0.190 - 0.656)
Using a computer	0.754 (0.619 - 0.890)	0.682 (0.481 - 0.883)	0.347 (0.050 - 0.645)
Following a line of print	0.443 (0.184 - 0.702)	0.596 (0.343 - 0.848)	0.333 (0.120 - 0.545)
Reading same print size	0.585 (0.410 - 0.759)	0.524 (0.215 - 0.833)	0.227 (-0.116 - 0.570)
Objects suddenly appearing	0.480 (0.175 - 0.784)	0.681 (0.421 - 0.947)	0.405 (0.122 - 0.688)

Item	Agreement between (Kappa (CI))		
	Round 1 and 2	Round 2 and 3	Round 1 and 3
Missing patches of vision	0.700 (0.496 - 0.904)	0.616 (0.358 - 0.874)	0.385 (0.181 - 0.589)
Noticing objects off to the side	0.706 (0.545 - 0.866)	0.674 (0.487 - 0.861)	0.441 (0.260 - 0.622)
Seeing in poor or dim light	0.540 (0.312 - 0.768)	0.667 (0.465 - 0.870)	0.568 (0.358 - 0.779)
Seeing in bright light	0.476 (0.134 - 0.817)	0.432 (-0.101 - 0.965)	0.556 (0.377 - 0.735)
Adjusting to differing lighting	0.688 (0.546 - 0.830)	0.831 (0.709 - 0.952)	0.691 (0.503 - 0.878)
Change in colour perception	0.742 (0.584 - 0.900)	0.667 (0.502 - 0.832)	0.499 (0.316 - 0.681)
Dry eyes	0.611 (0.369 - 0.853)	0.411 (0.204-0.618)	0.400 (0.088 - 0.712)
Watery eyes	0.745 (0.586 - 0.903)	0.744 (0.586 - 0.902)	0.524 (0.309 - 0.738)
Moving around on uneven ground	0.237 (-0.067 - 0.542)	0.633 (0.418 - 0.848)	0.355 (0.096 - 0.615)
Trips and falls	0.543 (0.231 - 0.552)	0.433 (0.225 - 0.642)	0.227 (0.013 - 0.442)
Crossing the road	0.577 (0.322 - 0.832)	0.761 (0.574 - 0.947)	0.519 (0.136 - 0.902)
Moving around in familiar areas	0.647 (0.403 - 0.892)	0.673 (0.494 - 0.851)	0.470 (0.270 - 0.670)
Moving around in unfamiliar areas	0.532 (0.315 - 0.749)	0.607 (0.385 - 0.829)	0.364 (0.171 - 0.556)
Bumps into or against objects or people in crowded areas	0.517 (0.358 - 0.676)	0.697 (0.557 - 0.837)	0.358 (0.114 - 0.601)
Moving around indoors	0.513 (0.244 - 0.782)	0.485 (0.163 - 0.808)	0.326 (0.065 - 0.587)
Moving around outdoors	0.564 (0.415 - 0.713)	0.657 (0.447 - 0.867)	0.355 (0.013 - 0.697)
Travelling as a passenger	0.670 (0.484 - 0.856)	0.700 (0.504 - 0.895)	0.619 (0.390 - 0.847)
Making eye contact	0.459 (0.131 - 0.787)	0.374 (0.085 - 0.663)	0.066 (-0.297 - 0.428)
Dealing with strangers	0.558 (0.308 - 0.808)	0.493 (0.287 - 0.698)	0.297 (-0.042 - 0.636)
Participating in indoors social activities	0.572 (0.349 - 0.795)	0.415 (0.119 - 0.710)	0.386 (0.181 - 0.526)
Participating in outdoor social activities	0.756 (0.629 - 0.882)	0.640 (0.438 - 0.841)	0.550 (0.340 - 0.760)
Loss of confidence	0.528 (0.306 - 0.750)	0.747 (0.541 - 0.954)	0.243 (-0.041 - 0.528)
Accomplishing as much as would like	0.661 (0.465 - 0.858)	0.654 (0.436 - 0.872)	0.594 (0.343 - 0.845)
Limit of how long activities can be done for	0.556 (0.347 - 0.764)	0.804 (0.698 - 0.910)	0.317 (0.142 - 0.492)

Item	Agreement between (Kappa (CI))		
	Round 1 and 2	Round 2 and 3	Round 1 and 3
Usual standard	0.660 (0.492 - 0.829)	0.579 (0.251 - 0.908)	0.430 (0.158 - 0.702)
Toileting	0.492 (0.251 - 0.732)	0.461 (0.044 - 0.879)	0.200 (-0.038 - 0.438)
Getting dressed	0.499 (0.152 - 0.847)	0.698 (0.571 - 0.826)	0.409 (0.124 - 0.694)
Eating	0.614 (0.416 - 0.811)	0.556 (0.308 - 0.803)	0.261 (0.071 - 0.451)
Taking medication	0.498 (0.240 - 0.757)	0.569 (0.306 - 0.833)	0.387 (0.144 - 0.630)
Pouring a drink	0.512 (0.262 - 0.762)	0.712 (0.549 - 0.875)	0.420 (0.138 - 0.703)
Preparing something to eat	0.495 (0.327 - 0.663)	0.553 (0.310 - 0.795)	0.225 (-0.033 - 0.482)
Looking after appearance	0.407 (0.089 - 0.725)	0.596 (0.303 - 0.869)	0.258 (-0.083 - 0.599)
Household chores	0.601 (0.389 - 0.814)	0.507 (0.266 - 0.747)	0.216 (-0.097 - 0.530)
Shopping	0.449 (0.343 - 0.626)	0.735 (0.502 - 0.969)	0.523 (0.281 - 0.766)
Bathing or showering	0.399 (0.203 - 0.594)	0.566 (0.331 - 0.801)	0.220 (-0.062 - 0.501)
Negative emotions	0.697 (0.523 - 0.871)	0.831 (0.691 - 0.970)	0.618 (0.409 - 0.826)
Vulnerable	0.585 (0.342 - 0.827)	0.823 (0.672 - 0.973)	0.394 (0.085 - 0.703)
Not coping	0.771 (0.562 - 0.980)	0.394 (0.180 - 0.609)	0.258 (0.032 - 0.483)
Self-conscious	0.458 (0.212 - 0.704)	0.794 (0.629 - 0.958)	0.553 (0.267 - 0.838)
Burden to others	0.599 (0.368 - 0.831)	0.579 (0.380 - 0.779)	0.338 (-0.017 - 0.693)
Stay at home	0.606 (0.293 - 0.920)	0.553 (0.207 - 0.899)	0.126 (-0.159 - 0.412)

8.4: Discussion

If this Delphi survey had been the primary method for further development of the new instrument, version two would certainly have been reduced by two items. The decision to remove 'dry eyes' and 'watery eyes' items was based on the consensus decision that these items are not relevant to visual impairment following stroke.

An overview of the item rank order and those which achieved consensus is outlined in Table 8.66. Considering the items that achieved consensus within the three rounds of this Delphi survey and with no further analysis, the next version (three) of the instrument would be constructed of 34 items under eight categories. The eight categories include four categories in each of the two overarching sections – vision/eyes (10 items) and functioning (22 items), with the two general items separate. The categories removed are distance vision, light, discomfort and socialising.

Twenty-eight items required attention at a consensus meeting. It is important to highlight that within this project, the results of the Delphi survey are being used alongside Rasch analysis to achieve item reduction and to compare the two methods of item reduction. The Delphi survey provides clinical and lived experience insight into each item rather than purely relying on the psychometric data provided by Rasch analysis.

The number of items included remained high. A hub and spoke model, therefore, was considered to reduce the number of items based on the visual diagnosis with a core set of items answered by all. However, the set of items which were considered relevant to 'all visual impairment following stroke' based on this analysis would still result in a large number of core items (n=38) with few additional spoke items, shown in Figure 8.71. If this core set was to only include the items which achieved consensus on part one of the survey, it would reduce to 26 items. However, five items which achieved consensus in part one did not attain a categorisation consensus in part two; 'blurred vision', 'judging distances', 'seeing faces', 'following a line of print' and 'bumps into or against objects or people in crowded areas'. This decision would not affect the number of items in the four spokes.

Table 8.66: Items mean rank position after completion of round three

Rank	Item
=1	Toileting
=1	Not coping
3	Trips and falls
4	Overall vision
5	Vulnerable
6	Crossing the road
7	Double vision
8	Burden to others
9	Taking medication
10	Loss of confidence
11	Moving around indoors
12	Negative emotions
13	Moving around on uneven ground
14	Eating
15	Deterioration of vision
16	Moving around in familiar areas
17	Noticing objects off to the side
18	Bumps into or against objects or people in crowded areas
19	Stay at home
20	Preparing something to eat
=21	Moving around in unfamiliar areas
=21	Moving around outdoors
23	Bathing or showering
24	Judging distances
=25	Following a line of print
=25	Missing patches of vision
27	Overall health
=28	Close-up vision
=28	Accomplishing as much as would like
=30	Blurred vision
=30	Objects suddenly appearing

Rank	Item
=32	Objects jumping around
=32	Getting dressed
34	Pouring a drink
35	Seeing faces
=36	Participating in indoor social activities
=36	Participating in outdoor social activities
=36	Looking after appearance
39	Dealing with strangers
40	Usual standard
41	Seeing far side of a room
42	Shopping
=43	Writing
=43	Limit of how long activities can be done for
=45	Eyes seeing differently
=45	Self-conscious
47	Seeing in poor or dim light
48	Finding something
49	Using a computer
50	Making eye contact
51	Seeing in bright light
=52	Fluctuation
=52	Household chores
54	Seeing something far away
55	Adjusting to differing lighting
56	Reading same print size
57	Travelling as a passenger
58	Tired eyes
59	Unusual appearance
60	Change in colour perception
61	Dry eyes
62	Watery eyes

= Consensus

Core items		
'overall health'	'vulnerable'	'stay at home'
'overall vision'	'pouring a drink'	'participating in outdoor social activities'
'toileting'	'eyes seeing differently'	'participating in indoor social activities'
'deterioration'	'finding something'	'dealing with strangers'
'fluctuation'	'using a computer'	'moving around on uneven ground'
'tired eyes'	'loss of confidence'	'moving around in familiar areas'
'writing'	'crossing the road'	'moving around in unfamiliar areas'
'trips and falls'	'usual standard'	'moving around indoors'
'eating'	'getting dressed'	'moving around outdoors'
'shopping'	'taking medication'	'preparing something to eat'
'negative emotions'	'household chores'	'looking after appearance'
'not coping'	'bathing or showering'	'limit of how long activities can be done for'
	'burden to others'	'accomplishing as much as would like'

Consensus in part one

Figure 8.71: Hub and spoke model of questionnaire of items with consensus from the Delphi survey

The overall response rate for the survey (43.4%) was good compared to average figures reported by survey companies (24.8%) (241). Even with the dropout rate in the second (21.8%) and third (23.5%) rounds, the response rate remained good at 62.8% in the final round. A dropout rate of any size carries the risk of non-responder bias. Those who took the decision not to continue participating in the process may have had different views to those completing all three rounds of the survey (228). Various steps were taken within the method of this survey delivery to minimise attrition. These included personalising messages, which has been shown to significantly increase response rate as well as the number completing the task (211, 232, 242). Up to two email reminders were sent with the final reminder including the closing date of the survey. This is within the number (maximum of four emails in total) advised before participants would consider the emails as a nuisance (242). In previous studies it has been shown that the combination of personalisation and reminders creates the largest effect on retention (242). In the third round, a certificate of participation was offered as an incentive. This was only announced to participants after completing two rounds of the survey to reduce the risk of a biased sample (242).

Despite these steps, the survey remained lengthy throughout the three rounds. No items were dropped between rounds when they reached consensus, to enable a measure of agreement (weighted-Kappa) between the rounds. It is known that the time burden of the survey resulted in attrition of participants (206). Within all emails participants were given the opportunity to withdraw and were asked to provide a reason for doing so, to enable a clearer understanding of the final round participants. However, in this survey a large proportion of those that dropped out did so by not responding. A benefit of having level of agreement data is it allows analysis of the quality of the group's decision (228). The items with lower levels of agreement despite achieving consensus, can potentially be considered in future decisions.

A limitation of using a web-based survey was that not all stroke survivors with visual impairment have access to or are able to use a computer. This may have prevented some stroke survivors from participating and may have resulted in a younger group of stroke survivors participating. Initially 15 stroke survivors registered an interest in the study; ten completed the first round which dropped to five by the third round. No demographics are available for those that volunteered but did not participate in the survey. Of the stroke survivors 90% were younger than 64 years of age and 70% younger than 54. In the third round 60% were younger than 54 years of age.

Development involving patients and experts is deemed a key part of creating a high quality instrument (140). Building this collaboration into the development of the new instrument improves the potential quality of the final product. The Delphi survey alone also allows an insight into what stroke survivors and clinicians consider important issues in quality of life following a stroke with an impact on vision. Using the Delphi process and a consensus meeting in conjunction with Rasch analysis will enhance content validity of the new instrument.

The lack of item reduction achieved by the Delphi process alone highlights the need for additional methods of item reduction. Rasch analysis will be performed using data from a pilot of version two of the new instrument. Both the round three Delphi survey and Rasch analysis will be presented to a group of stroke survivors and clinicians at a consensus meeting to enable the finalisation of version three of the new instrument.

Chapter 9
Rasch measurement model analysis

9.1: Introduction

The pilot instrument (version two) was completed by stroke survivors identified as having visual impairment, recruited from NHS hospitals and the voluntary sector. The methodology of the pilot study and the recruited participants are described in Chapter 7.

The instrument being developed in this project uses an ordinal scale (categorical options) like many other patient reported outcome measures (PROMs) (243). These instruments attempt to measure latent traits, dimensions which can be described but not easily quantified or directly measured (e.g. quality of life, depression, fatigue) (188, 244). One aim of these measures is to detect change either between groups or over time, and to enable statistical analysis. It has long been argued that it is difficult to accurately interpret or analyse the scores produced by these instruments due to the arbitrary nature of ordinal scales (245).

Instruments often include numbered scores; the numbers used usually increase with increasing amounts of the trait (e.g. frequency; 'all the time' should have a higher number than 'some of the time'). The description between scores cannot guarantee that the intervals between scores are equal. For example movement from 1 to 2 indicates an increase in frequency, and movement from 1 to 3 indicates a greater increase in frequency, but it is not guaranteed to represent a doubling of increase in frequency (188). Ordinal scales give a false impression; the numbers used within them are merely symbols. Interval scales, however, have known equal intervals with an arbitrary zero point (e.g. time of day on a 12-hour clock; each interval is one hour, the difference between 3pm and 4pm is the same as between 10am and 11am). Any mathematical calculations performed on ordinal scales create misleading outcomes (189). Even simple addition may be false; due to the potential uneven intervals, as adding two scores together does not equal their sum. The only information which is known from this addition is that the total is larger than the parts (188).

Georg Rasch first published the mathematical model which became known as the Rasch measurement model in 1960 (246). The Rasch measurement model allows a conversion to be made from an ordinal scale to a logarithmic interval (linear) scale when data fit to the model is achieved (247). The uses of Rasch analysis include assessing the measurement properties of existing instruments, but its key use is in the development of new instruments (244, 248). The two main factors which influence the outcome when completing a test item within the Rasch model are simply the ability of the individual and the difficulty of the item (249). Rasch analysis was originally widely used in education and has been increasingly used in health care and rehabilitation since the 1980's (250, 251).

The Rasch model applies a probabilistic version of the Guttman pattern to establish the item difficulty and individual ability. A Guttman pattern expects that easier items would be achieved before more difficult items, and a more able individual would be expected to achieve more items than a less able individual (246). Probability is central to the model, with the aim to predict the likelihood of an item being achieved when an individual with a set ability encounters an item of a set difficulty. The statistics of the Rasch measurement model are based on the difference between the observed responses and the expected responses (247). Rasch analysis provides better comprehension of the psychometrics of an instrument. It provides information on the ability of items to differentiate between individuals, the ability of items to measure the target latent trait and suitability of item difficulty targeting for person ability (252).

There are several key assumptions of the Rasch measurement model; unidimensionality (trait dependency), stochastic ordering of items (test fit), local independence (residual correlations), invariance (differential item functioning), and, for polytomous scales, the appropriate ordering of categories. The process of conducting a Rasch analysis involves testing these assumptions to observe how much deviation there is between the instrument and the Rasch model (244).

This chapter discusses the formal assessment of the measurement properties and item reduction of version two of the new instrument using Rasch analysis.

9.2: Methods

The items comprising version two of the instrument are outlined in Table 9.1. Analyses were performed using RUMM 2030 software (253). All fit analyses were documented and monitored using a logbook through the progression of the Rasch analysis (254).

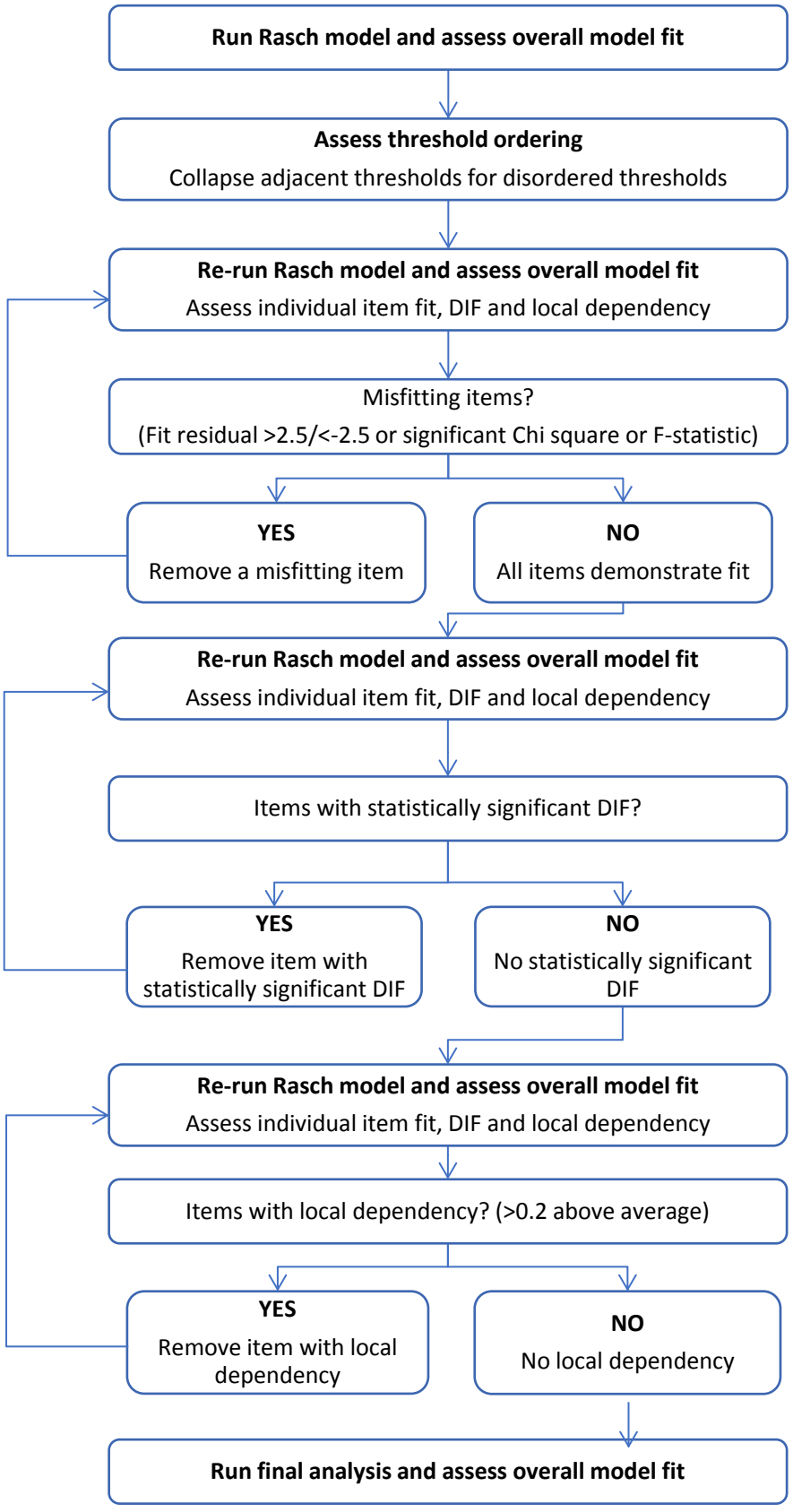
The data were uploaded into the RUMM program in the required format including participant identification number, person factors and the individual item responses. Person factors included: age (<65 or >65 years), gender (male or female), visual impairment diagnosis (reduced central vision, ocular motility defect, visual field defect or visual perception problem), number of visual impairments (isolated or multiple), location (inpatient or outpatient) and time since stroke (hyper-acute, acute, sub-acute or long-term). Checks were made to ensure all items were scored in the same way; items identified as being negatively scored were reverse scored prior to any further analysis.

A flow chart of the Rasch analysis process is outlined in DIF - differential item functioning

Figure 9.1, the following sections describe the process and criteria in detail.

Table 9.1: Abbreviated items comprising version two of the new instrument

i	Overall health	**30**	Crossing the road
ii	Overall vision	**31**	Moving around in familiar areas
1	Blurred vision	**32**	Moving around in unfamiliar areas
2	Objects jumping around	**33**	Bumping into or against objects or people in crowded areas
3	Deterioration of vision	**34**	Moving around indoors
4	Fluctuation	**35**	Moving around outdoors
5	Tired eyes	**36**	Travelling as a passenger
6	Eyes seeing differently	**37**	Making eye contact
7	Double vision	**38**	Dealing with strangers
8	Judging distances	**39**	Participating in indoor social activities
9	Unusual appearance	**40**	Participating in outdoor social activities
10	Seeing far side of a room	**41**	Loss of confidence
11	Seeing something far away	**42**	Accomplishing as much as would like
12	Seeing faces	**43**	Limit of how long activities can be done for
13	Writing	**44**	Usual standard
14	Close-up vision	**45**	Toileting
15	Finding something	**46**	Getting dressed
16	Using a computer	**47**	Eating
17	Following a line of print	**48**	Taking medication
18	Reading same print size	**49**	Pouring a drink
19	Objects suddenly appearing	**50**	Preparing something to eat
20	Missing patches of vision	**51**	Looking after appearance
21	Noticing objects off to the side	**52**	Household chores
22	Seeing in poor or dim light	**53**	Shopping
23	Seeing in bright light	**54**	Bathing or showering
24	Adjusting to differing lighting	**55**	Feeling negative emotions
25	Change in colour perception	**56**	Feeling vulnerable
26	Dry eyes	**57**	Not coping
27	Watery eyes	**58**	Feeling self-conscious
28	Moving around on uneven ground	**59**	Feeling a burden to others
29	Tripping and falling	**60**	Staying at home



DIF - differential item functioning

Figure 9.1: A flow chart of the methodological stages of Rasch analysis. All steps need to be completed and repeated when changes are made, such as item deletion.

9.2.1: Restricted or unrestricted model

There are two versions of the Rasch measurement model when considering polytomous data (more than two response options available): the Rating Scale model (restricted) or the Partial Credit model (unrestricted) (255, 256). The mathematics of the two versions differs slightly. The Rating Scale model constrains the thresholds to being equally spaced for all items (255). The Partial Credit model however, applies no such constraints on the thresholds. It is preferable to use the Rating Scale where possible as this provides a higher degree of specificity (256). However, in reality data rarely fits in the Rating Scale model. The Likelihood-Ratio test can aid the decision of which version of the Rasch Model to use, however it is only valid when the number of response categories is the same across all items (254). The Rasch measurement model equation is outlined in Figure 9.2.

$$ln\left(\frac{P_{nij}}{1-P_{nij-1}}\right) = \theta_{nj} - b_{ij}$$

$\boldsymbol{P_{nij}}$ is the probability that person $\boldsymbol{n}$ will achieve category $\boldsymbol{j}$ of item $\boldsymbol{i}$ [or is impacted to the level specified by the category within the item], $\boldsymbol{\theta}$ is person ability and $\boldsymbol{b}$ is the item difficulty.

Figure 9.2: Rasch measurement model equation (254, 257)

9.2.2: Class intervals

Class intervals are the equivalent of ability groups. All individuals are ranked in terms of ability based on the total score from the instrument and split into groups. Based on the sample size to calculate, RUMM attempts to have equal numbers in each class interval (44, 258). Preferably each class interval would have around 50 individuals (254). The number of class intervals and the distribution should be monitored throughout the analysis (44).

9.2.3: Summary statistics

The Rasch analysis process involves testing the assumptions of the Rasch measurement model. The first assessment is that of the model fit. The model fit for the instrument is calculated by a Chi-square Item-Trait Interaction statistic, produced by the addition of the

chi-square values for each item with statistical significance established using the associated totalled degrees of freedom (259). As the test is run for each item, Bonferroni adjustment is applied to the alpha value (0.05) by dividing it by the number of items in the instrument; initially for this analysis 0.05/62 = 0.0008 (260). If there is initially no substantial deviation from the model, a non-significant ($p > 0.0008$) result will be produced. This figure will change if items are deleted from the instrument. The Bonferroni correction is the most lenient acceptance of model fit; if model fit can be accepted without Bonferroni correction ($p > 0.05$) this indicates a stronger fit.

In the presence of model misfit (a discrepancy between the observed and expected scores), the source should be investigated. The causes of misfit could be a result of misfitting respondents or misfitting items. The Item-Person Interaction statistics present the Fit Residuals as Z-scores for both the persons and the items (254). This is assessing the degree of difference between the observed and expected responses (residuals). For item fit, perfect fit would be indicated with a mean equal to zero and a standard deviation of one (259). A standard deviation >1.4 is suggestive of misfit (254). Individual person fit (Section 9.2.5) and individual item fit (Section 9.2.6) assess respectively how each person and each item fit to the Rasch model. It is these fit statistics which provide the quality control, indicating the instrument represents an interval level measurement.

The Person Separation Index should be noted to provide an indication of the instruments power to discriminate between respondents with different levels of vision-related quality of life (44, 261). It also gives an indication of how much the fit statistics can be relied upon. A higher number indicates less error surrounding the statistics (259). The minimum acceptable level of the Person Separation Index is 0.7, which would allow two distinct groups to be differentiated (261). The Cronbach's Alpha statistic is also available in the absence of missing data, providing another measurement of reliability (262). The minimum acceptable level of the Cronbach's alpha is also 0.7 (range 0 to 1).

9.2.4: Threshold ordering

A threshold refers to the point between two adjacent response categories, where there is an equal likelihood of either response. There is always one less threshold than the number of categories used in the instrument. Disordered thresholds are identified in this section of the analysis. A disordered threshold indicates that the scoring categories are not working

properly (participants are not responding as predicted) which could be a result of too many category options or the semantics of the category labels being confusing (263).

Threshold ordering is viewed graphically using category probability curves. If an item has disordered thresholds, they will require rescoring to allow them to work correctly. Rescoring is achieved by combining response categories together, using the category probability curves and category response frequencies as a guide to which categories should be combined (264). It is also important to consider the nomenclature of the categories being combined, to ensure that they are not conflicting. For example it would not be appropriate to combine 'agree a little' with 'disagree a little' (265). After rescoring, the threshold map should be rechecked to confirm the items now have ordered thresholds. The fit statistics should also be rechecked. All rescoring options should be compared and the one with the best fit to the model chosen.

9.2.5: Individual person fit

The individual person fit is assessed to identify any individual persons that are misfitting, which could skew the analysis (266). Individuals who responded in the expected way would fall within a commonly accepted fit residual range of -2.5 to +2.5 (44, 267, 268). As the fit residuals of individuals increase outside of the acceptable range of -2.5 to +2.5, their observed scores are increasingly divergent from that of the expected score. If an individual person is identified as misfitting, there are a variety of potential areas to investigate for the misfit; demographics, how they scored each item alongside the models expected score and a comparison of the individual persons responses against the whole sample (266). The misfitting persons may need to be removed to complete further analysis. However this should be avoided if possible as the misfit may be clinically relevant (254).

9.2.6: Individual item fit

The individual item fit is assessed to identify any individual items that are misfitting. Misfit could be the result of disordered thresholds, item bias across groups of respondents or multidimensionality. An initial evaluation of fit uses item characteristic curves (ICC), which gives a graphical representation of fit (44, 269). The line curve represents the expected pattern of responses whilst the dots represent the observed responses for each of the class interval (44). A steeper than expected curve indicates over-discrimination, whilst a shallower

curve than expected indicates under-discrimination (44). Individual item fit is assessed formally using three statistics; fit residuals, chi-square probability and F-statistic. Items which are working as expected would have commonly accepted fit residuals within the range of -2.5 to +2.5, a non-significant ($p>0.05$) Chi-square and F-statistic (44, 257, 267). Within this analysis, the following should also be noted: the group size of the class intervals, the mean location (ability level) corresponding to the class interval, the component chi-square and the difference between the observed and expected means.

The item location, which refers to the relative difficulty of the item when compared to the other items of the instrument, can be plotted graphically on a category probability curve.

9.2.7: Differential item functioning

The Rasch Model assumes that the instrument should work in the same way irrespective of which individual or group is completing it. This assessment may reveal bias in the functioning of an instrument between different cultural groups, genders or age groups (244). The lack of differential item functioning (DIF) by diagnosis allows instruments to be used to compare differences between different conditions. It is important to consider the sample size in the person factor groups and the balance of numbers in each group.

There are two different types of DIF; uniform DIF and non-uniform DIF. Uniform DIF is present when groups are systematically different e.g. one group consistently has a greater ability than other groups. This is displayed on an item characteristic curve (ICC), plotting a person factor line for each group. For example for gender two lines would be plotted (one for male and one for female) (44). The person factor lines do not cross in uniform DIF on the ICC (270). Non-uniform DIF presents when the group difference alters across the class intervals, e.g. one group has a higher ability than other groups in the highest class intervals; however the same group has a lower ability than other groups in the lowest class intervals. The person factor lines cross in non-uniform DIF on the ICC (254).

DIF can be assessed statistically using ANOVAs and graphically using ICCs (270). An ANOVA is conducted for each item to compare scores across the different levels of 'person factor' and the class intervals (259). It is important to recheck the class interval distribution for individual person factor groups. The presence of DIF is indicated with a significant result ($p<0.05$). Bonferroni correction is automatically applied by the software at this stage. Using ICCs it is

possible to assess how items are behaving with different person factors and whether this is constant across the class intervals.

9.2.8: Local independence

A potential source of misfit within the scale is local dependency. Local independence is violated when responses to items are interrelated to each other (271). Dependency between items changes the probabilistic structure and can cause an overestimation of construct validity and reliability of the instrument (44, 272). A classic example of local dependency is when measuring walking ability and including the following items; 'can you walk 100 metres' and 'can you walk one mile'. If an individual is able to walk a mile they must also be able to walk 100 metres; therefore one answer predicts the answer of the other item (247).

Local dependence can be identified using residual correlations of the items (44, 271). There is currently no consensus on the level of correlation which indicates the violation of local independence. However, a standardly used cut-off point is a residual correlation of 0.2 above the average of all item residual correlations (271). The local independence analysis uses a combination of RUMM2030 and Microsoft Excel (253, 273).

9.2.9: Unidimensionality

Unidimensionality is a principle of measurement in which only one attribute is measured at any one time. For example, when measuring weather, it has many different attributes (e.g. temperature, precipitation, humidity etc.) but only one of these attributes is focused upon at once. If an attempt is made to measure two or more attributes together, it is not possible to assess if a change is due to one attribute or more. Therefore, the instrument cannot be relied on for any of the included attributes. Within PROMs, no instrument can be truly unidimensional unless each item is isolated (190). The success of this compromise within PROMs is assessed with the Rasch model fit statistics.

Initial unidimensionality testing explores the two subsets which are most different, as these are most likely to reveal any multidimensionality. Principal Component Analysis (PCA) is conducted using fit residuals (the differences between the expected and observed responses) for each person and each item (274). The first factor of the PCA accounts for the largest amount of variance after the 'Rasch factor' (the variance as a result of main scale) is

removed (247). The principal component loadings show how each item contributes to the variance. The primary focus is the first factor of the PCA which can be divided into two subsets; those items which are positively loading and those which are negatively loading. These two subsets are the most divergent within the scale. The instrument being tested has a large set of items (n=62) allowing the items which load most strongly to be selected. The 20 most positive and 20 most negative items make up the two subsets, to create sufficient confidence (275). If the set of items reduces in size below 40 following item deletion, all items are split into two equal groups of the most positive and most negative.

Person estimates (ability) are generated from the aforementioned two subsets of items (negative loading residuals and positive loading residuals) which are compared against each other on an individual person basis using a paired t-test (270, 274). This formally assesses for the presence of multidimensionality. If greater than five percent of t-tests run are statistically significant (<0.05), multidimensionality is indicated (274). If six to seven percent of t-tests run are statistically significant, a binomial test would be performed to calculate the confidence intervals around the t-test results. This takes into account the sample size and allows an assessment of the lower confidence interval. If it is <0.05 the unidimensionality is acceptable (276).

9.2.10: Strategies to improve fit to the model

All stages of analyses (Sections 9.2.3 to 9.2.9) were conducted as part of the initial stage of testing the instrument using the Rasch measurement model, prior to any changes being made.

9.2.10.1*: Dealing with DIF*

There are three options for dealing with DIF. The first option involves splitting items with uniform DIF to allow the item to be scored specifically for the different groups (270). This option allows the data to be corrected in the analysis phase; however the offending item has not been altered within the instrument. The second option is to form a testlet (a group of items), to assess if the DIF is cancelled out (254). If DIF does cancel out this would allow all items to remain within the instrument unchanged without the person estimates being adversely affected. If DIF does not cancel out this would indicate the presence of artificial DIF and the direction of the true DIF. The third option is item deletion. This resolves the issue

of DIF within the instrument, rather than the post-hoc solutions of the first and second options. In view of the aim of the new instrument to be appropriate for all stroke-related visual impairment at all stages post-stroke, during this analysis the method of dealing with DIF was item deletion.

9.2.10.2*: Item removal*

There are numerous reasons to consider the removal of an item; poor item fit, DIF, local dependence and multidimensionality. Removing items changes the relationship between the remaining items and the model. Therefore this process should be conducted in an iterative manner with the removal of only one item at a time (270, 277). Following the removal of any item the analysis should be rerun, monitoring the distribution of class intervals, summary statistics, individual item fit and DIF as outlined in Figure 9.1.

The item map displays the spread of item difficulty and person ability and may aid decisions on item removal. Decisions regarding item removal also took into account, where necessary, the clinical knowledge of the author.

9.2.11: Instrument targeting

Ideal instrument targeting would have items spread along a continuum of ability rather than clustered. This allows person ability to be more accurately pin-pointed (44). When the final scale has been achieved, the person-threshold location distribution should be analysed. The person-threshold location distribution is a graphical representation of targeting, by displaying the ability of the population tested in relation to the item difficulty on the same linear scale (44).

9.2.12: Transformation of raw score to interval scale

This stage is only completed and valid once the instrument fits to the model. A test characteristic curve is created using all items from the final version of the scale. On the y-axis is the raw score (ordinal) and on the x-axis is the logit scale (interval). A conversion table is also created which displays the raw score with the corresponding logit score (254). The logit score can be used in this form for parametric statistics, however, to improve the

interpretability of the figures the logit scores should be transformed into the score range of the raw data scale (254).

9.3: Results

Rasch analysis was undertaken using the Partial Credit model (unrestricted) (256). Due to having different numbers of response categories for items across the instrument (two items with 101 categories and 60 items with five categories), the data therefore does not fit the Rating Scale model (restricted) (255). All 247 cases were deemed valid and accepted by RUMM 2030.

9.3.1: Initial analysis

For the initial analysis, all 62 items were read into RUMM. Items i 'overall health' and ii 'overall vision' were reverse scored as indicated. The summary statistics showed misfit. The fit residual standard deviation was greater than 1.4 for both item fit (8.283) and person fit (3.456) and the Chi-square result was highly significant (<0.0001) (Table 9.2). On inspection of the threshold ordering 61 of the 62 items had disordered thresholds: 'overall vision' was the only exception. Prior to any further analysis, the thresholds were reordered, maintaining as many thresholds as possible.

9.3.1.1*: Threshold re-ordering*

No items retained the original threshold order. Examples of four disordered category probability curves alongside the category probability curves after re-ordering are displayed in Figure 9.3. The two items with visual analogue scales were reduced from 101 options to 11 (10 thresholds), as the majority of participants (89.9%) had selected a round number (Table 9.3). Of the 60 items which originally had a 5-point rating scale (4 thresholds), ten items reduced the number of thresholds to three, 47 items reduced to two and three items reduced to become dichotomous (one threshold) (Table 9.4).

Table 9.2: Summary fit statistics for development process using Rasch analysis

Analysis	Number of items	Item Fit Residual		Person Fit Residual		Item-trait Interaction		Unidimensionality	PSI (with extremes)
		Mean	SD	Mean	SD	Chi square (df)	p	Percent <5% (95% CI)	
Initial	62	1.044	8.283	0.506	3.456	2110.3 (186)	<0.0001	55.9%	0.955
Rescore	62	-0.306	2.407	-0.216	1.681	753.0 (186)	<0.0001	36.0%	0.950
Deletion Item i	61	-0.227	2.002	-0.267	1.743	483.0 (183)	<0.0001	28.7%	0.950
Deletion Item ii	60	-0.196	1.734	-0.276	1.774	401.1 (180)	<0.0001	25.9%	0.945
Deletion Item 26	59	-0.209	1.710	-0.294	1.788	382.1 (177)	<0.0001	24.7%	0.944
Deletion item 27	58	-0.212	1.648	-0.303	1.794	341.0 (174)	<0.0001	25.9%	0.944
Deletion item 7	57	-0.204	1.580	-0.314	1.779	295.3 (171)	<0.0001	24.7%	0.944
Deletion item 3	56	-0.221	1.532	-0.320	1.784	291.1 (168)	<0.0001	25.1%	0.943
Deletion item 6	55	-0.224	1.485	-0.327	1.790	264.4 (165)	<0.0001	22.7%	0.942
Deletion item 30	54	-0.214	1.420	-0.325	1.763	256.0 (162)	<0.0001	24.3%	0.941
Deletion item 32	53	-0.216	1.362	-0.326	1.738	255.6 (159)	<0.0001	23.1%	0.939
Deletion item 43	52	-0.222	1.305	-0.332	1.720	245.9 (156)	<0.0001	21.9%	0.937
Deletion item 41	51	-0.226	1.237	-0.339	1.707	232.9 (153)	<0.0001	20.2%	0.935
Deletion item 39	50	-0.221	1.187	-0.336	1.686	212.9 (150)	<0.0001	20.2%	0.933
Deletion item 52	49	-0.213	1.137	-0.330	1.660	194.4 (147)	0.0005	21.9%	0.932
Deletion item 38	48	-0.201	1.095	-0.325	1.654	180.4 (144)	0.0053	20.7%	0.931
Deletion item 21	47	-0.171	1.107	-0.311	1.630	232.3 (188)	0.0215	19.4%	0.927
Deletion item 20	46	-0.180	1.096	-0.309	1.610	183.6 (138)	0.0155	17.8%	0.925
Deletion item 33	45	-0.185	1.075	-0.310	1.592	159.3 (135)	0.0058	21.1%	0.923
Deletion item 35	44	-0.191	1.033	-0.311	1.568	152.9 (132)	0.0753	19.8%	0.921
Deletion item 16	43	-0.197	1.050	-0.313	1.543	136.9 (129)	0.1029	19.8%	0.919
Deletion item 19	42	-0.205	1.055	-0.314	1.529	145.3 (126)	0.3001	20.7%	0.917
Deletion item 28	41	-0.193	1.054	-0.317	1.522	134.0 (123)	0.1153	17.8%	0.914
Deletion item 23	40	-0.214	1.063	-0.315	1.488	130.8 (120)	0.2342	17.4%	0.912
Deletion item 10	39	-0.221	1.065	-0.318	1.472	133.5 (117)	0.2349	15.4%	0.910

Analysis		Item Fit Residual		Person Fit Residual		Item-trait Interaction		Unidimensionality	PSI (with extremes)
		Mean	SD	Mean	SD	Chi square (df)	p	Percent <5% (95% CI)	
Deletion item 44	38	-0.256	0.998	-0.329	1.470	139.9 (114)	0.1407	12.6%	0.904
Deletion item 54	37	-0.241	0.970	-0.327	1.469	130.8 (111)	0.0512	13.8%	0.903
Deletion item 22	36	-0.254	0.966	-0.330	1.457	127.1 (108)	0.1009	11.7%	0.900
Deletion item 45	35	-0.239	0.962	-0.322	1.452	124.8 (105)	0.0910	12.2%	0.899
Deletion item 47	34	-0.228	0.963	-0.312	1.464	119.7 (102)	0.1116	13.8%	0.898
Deletion item 18	33	-0.253	1.014	-0.315	1.436	125.0 (99)	0.0397	13.0%	0.894
Deletion item 60	32	-0.249	0.992	-0.318	1.430	118.2 (96)	0.0620	11.3%	0.892
Deletion item 4	31	-0.261	1.014	-0.313	1.401	116.4 (93)	0.0505	11.3%	0.890
Deletion item 31	30	-0.25	0.964	-0.305	1.371	114.2 (90)	0.0435	11.3%	0.887
Deletion item 56	29	-0.243	0.988	-0.300	1.338	121.7 (87)	0.0083	10.5%	0.881
Deletion item 50	28	-0.25	0.973	-0.298	1.324	108.9 (84)	0.0354	10.9%	0.878
Deletion item 49	27	-0.242	0.998	-0.297	1.328	108.7 (81)	0.0219	9.3%	0.875
Deletion item 13	26	-0.263	1.027	-0.301	1.307	122.1 (78)	0.0011	9.3%	0.870
Deletion item 37	25	-0.246	0.969	-0.294	1.293	111.1 (75)	0.0043	8.9%	0.866
Deletion item 14	24	-0.274	1.028	-0.299	1.280	106.8 (72)	0.0049	8.1%	0.861
Deletion item 12	23	-0.264	1.059	-0.291	1.254	96.8 (69)	0.0153	6.9% (4.2-9.6%)	0.858
Deletion item 1	22	-0.267	1.035	-0.298	1.238	81.5 (66)	0.0941	6.9% (4.2-9.6%)	0.852
Deletion item 25	21	-0.266	1.087	-0.297	1.239	84.3 (63)	0.0379	4.1%	0.851
Deletion item 48	20	-0.222	1.091	-0.281	1.246	80.5 (60)	0.0398	5.3% (2.5-8.0%)	0.849
Deletion item 57	19	-0.193	0.966	-0.275	1.235	78.1 (57)	0.0332	3.2%	0.841
Deletion misfit n=5	19	-0.232	0.940	-0.247	1.116	80.29 (57)	0.0228	4.1%	0.834

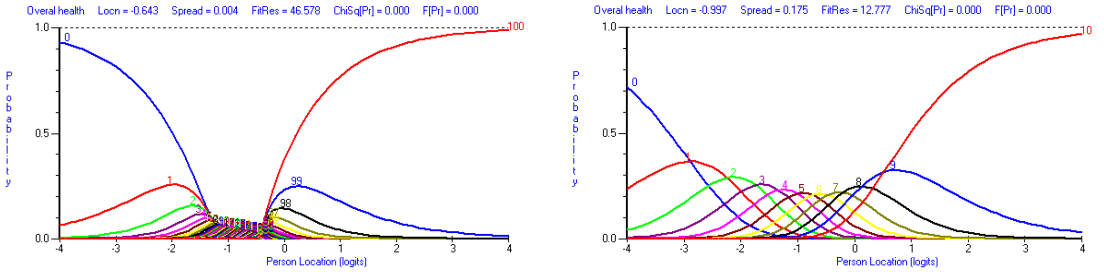
SD = standard deviation, df = degrees of freedom, 95% CI = 95% confidence intervals, PSI = person separation index.

For the data to indicate fit to the Rasch model:

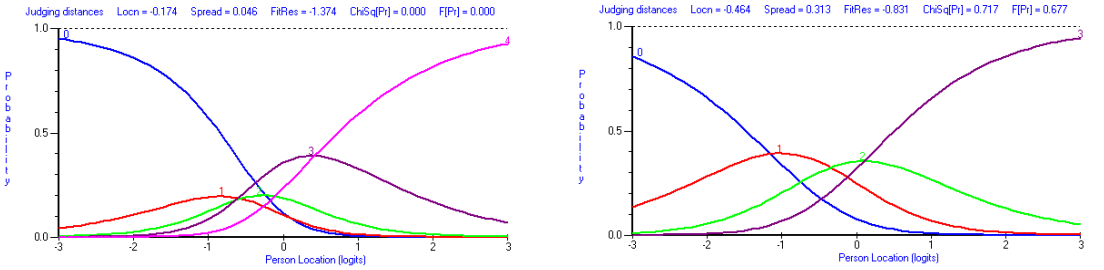
- Perfect fit mean = 1 and SD = 0
- Tolerence range for fit residual mean +2.5 to -2.5
- Chi square value should be low and non-significant
- For indication of unidinmensionality less than 5% of t-tests should be significant (0.05 with Bonferoni correction) or the lower 95% CI should be less than 5%.
- PSI should be ≥0.7 to enable the detect of at least two groups.

Misfit | Fit with adjustment (Bonferoni/95% CI) | Fit without adjustment

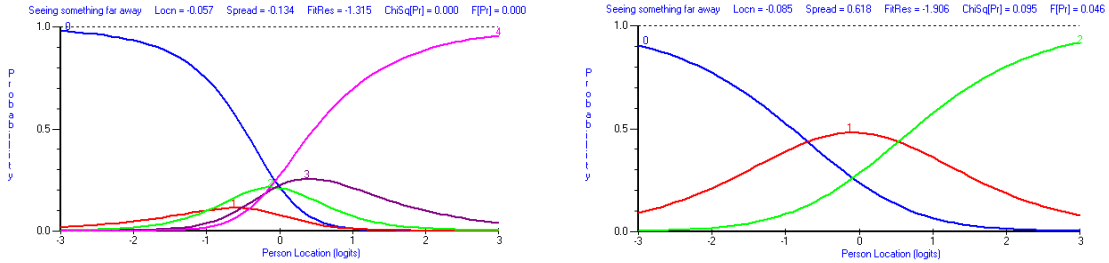
Disordered **Ordered**



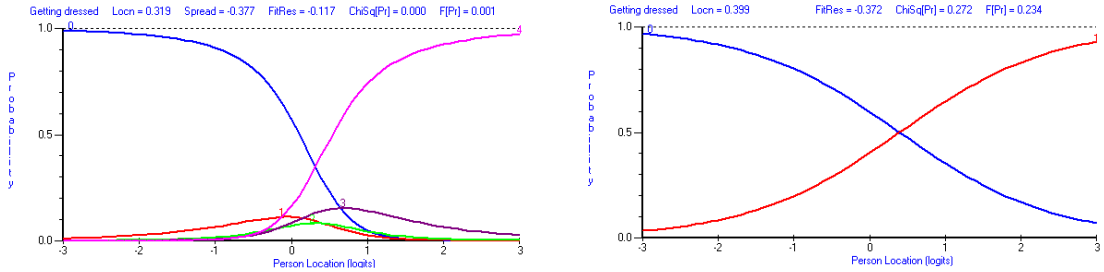
100 thresholds Item i: Overall health **10 thresholds**



4 thresholds Item 8: Judging distances **3 thresholds**



4 thresholds Item 11: Seeing something far away **2 thresholds**



4 thresholds Item 46: Getting dressed **1 thresholds**

Figure 9.3: Examples of category probability curves before and after reordering.

Table 9.3: New threshold ordering for items using visual analogue scale

Item No	Item Name	0-5 Worst	6-15	16-25	26-35	36-45	46-55	56-65	66-75	76-85	86-95	96-100 Best
i	Overall health	0	1	2	3	4	5	6	7	8	9	10
ii	Overall vision	0	1	2	3	4	5	6	7	8	9	10

Table 9.4: New threshold ordering for items originally using 5-point rating scale

	Item Name	**0** None at all	**1** A little bit	**2** A moderate amount	**3** A lot	**4** It limits my activity
1	Blurred vision	0	1	1	1	2
2	Objects jumping around	0	1	1	1	2
3	Deterioration of vision	0	1	1	1	2
4	Fluctuation	0	1	1	1	2
5	Tired eyes	0	1	1	2	3
6	Eyes seeing differently	0	1	1	1	2
7	Double vision	0	1	1	1	2
8	Judging distances	0	1	1	2	3
9	Unusual appearance	0	1	1	1	2
10	Seeing far side of a room	0	1	1	1	2
11	Seeing something far away	0	1	1	1	2
12	Seeing faces	0	1	1	1	2
13	Writing	0	1	1	1	2
14	Close-up vision	0	1	1	1	2
15	Finding something	0	1	1	2	3
16	Using a computer	0	1	1	1	2
17	Following a line of print	0	1	1	1	2
18	Reading same print size	0	1	1	1	2
19	Objects suddenly appearing	0	1	1	1	2
20	Missing patches of vision	0	1	1	1	2
21	Noticing objects off to the side	0	1	1	1	2
22	Seeing in poor or dim light	0	1	1	1	2
23	Seeing in bright light	0	1	1	1	2
24	Adjusting to differing lighting	0	1	1	1	2
25	Change in colour perception	0	1	1	1	2
26	Dry eyes	0	1	1	1	2
27	Watery eyes	0	1	1	1	2
28	Moving around on uneven ground	0	1	1	1	2
29	Trips and falls	0	1	1	1	2
30	Crossing the road	0	1	1	1	2
31	Moving around in familiar areas	0	1	1	1	2

	Item Name	0 None at all	1 A little bit	2 A moderate amount	3 A lot	4 It limits my activity
32	Moving around in unfamiliar areas	0	1	1	1	2
33	Bumps into or against objects or people in crowded areas	0	1	1	2	3
34	Moving around indoors	0	1	1	2	3
35	Moving around outdoors	0	1	1	1	2
36	Travelling as a passenger	0	1	1	1	2
37	Making eye contact	0	1	1	1	2
38	Dealing with strangers	0	1	1	1	2
39	Participating in indoor social activities	0	1	1	1	2
40	Participating in outdoor social activities	0	1	1	1	2
41	Loss of confidence	0	1	1	1	2
42	Accomplishing as much as would like	0	1	1	1	2
43	Limit of how long activities can be done for	0	1	1	1	2
44	Usual standard	0	1	1	2	3
45	Toileting	0	1	1	1	1
46	Getting dressed	0	1	1	1	1
47	Eating	0	1	1	1	2
48	Taking medication	0	1	1	1	2
49	Pouring a drink	0	1	1	1	2
50	Preparing something to eat	0	1	1	1	2
51	Looking after appearance	0	1	1	1	2
52	Household chores	0	1	1	1	2
53	Shopping	0	1	1	1	2
54	Bathing or showering	0	1	1	1	1
55	Negative emotions	0	1	1	2	3
56	Vulnerable	0	1	1	2	3
57	Not coping	0	1	1	2	3
58	Self-conscious	0	1	1	1	2
59	Burden to others	0	1	1	2	3
60	Stay at home	0	1	1	1	2

9.3.2: Rescore analysis

Following threshold re-ordering, the summary statistics improved but remained indicative of significant misfit to the model (Table 9.2). The fit residual standard deviation continued to be greater than 1.4 for both item fit (2.407) and person fit (1.681) and the Chi-square item-trait interaction statistic result remained highly significant (<0.0001).

9.3.2.1*: Threshold ordering*

All items now had functioning thresholds following rescoring (Figure 9.4). Full analysis to investigate the sources of misfit was now possible.

9.3.2.2*: Individual person fit*

Of the 247 participants, one participant (0.4%) had an extreme score. In this case the individual had a score of zero across the entire instrument (the minimum score). This indicated a good quality of life, however due to the limits of the instrument it is not possible to accurately grade how good as the items do not discriminate at this end of the scale. The software gives this individual a location on the logit scale, however, this is only an approximation due to the insufficient information.

Eighteen participants (7.3%) had fit residuals above 2.5 indicating their responses were opposite to the expected responses. Seventeen participants (6.9%) had fit residuals below -2.5 indicating their responses were too predictable (the individual is selecting the same option throughout the instrument, potentially indicating they are not engaging). On analysis of the person factors associated with the misfitting participants no particular patterns could be found.

9.3.2.3*: Individual item fit*

Eleven items were shown to have misfit across the three methods of assessing misfit (Table 9.5). Eight had fit residuals either greater than 2.5 or less than -2.5, six had a significant Chi-square result and ten had a significant F-statistic.

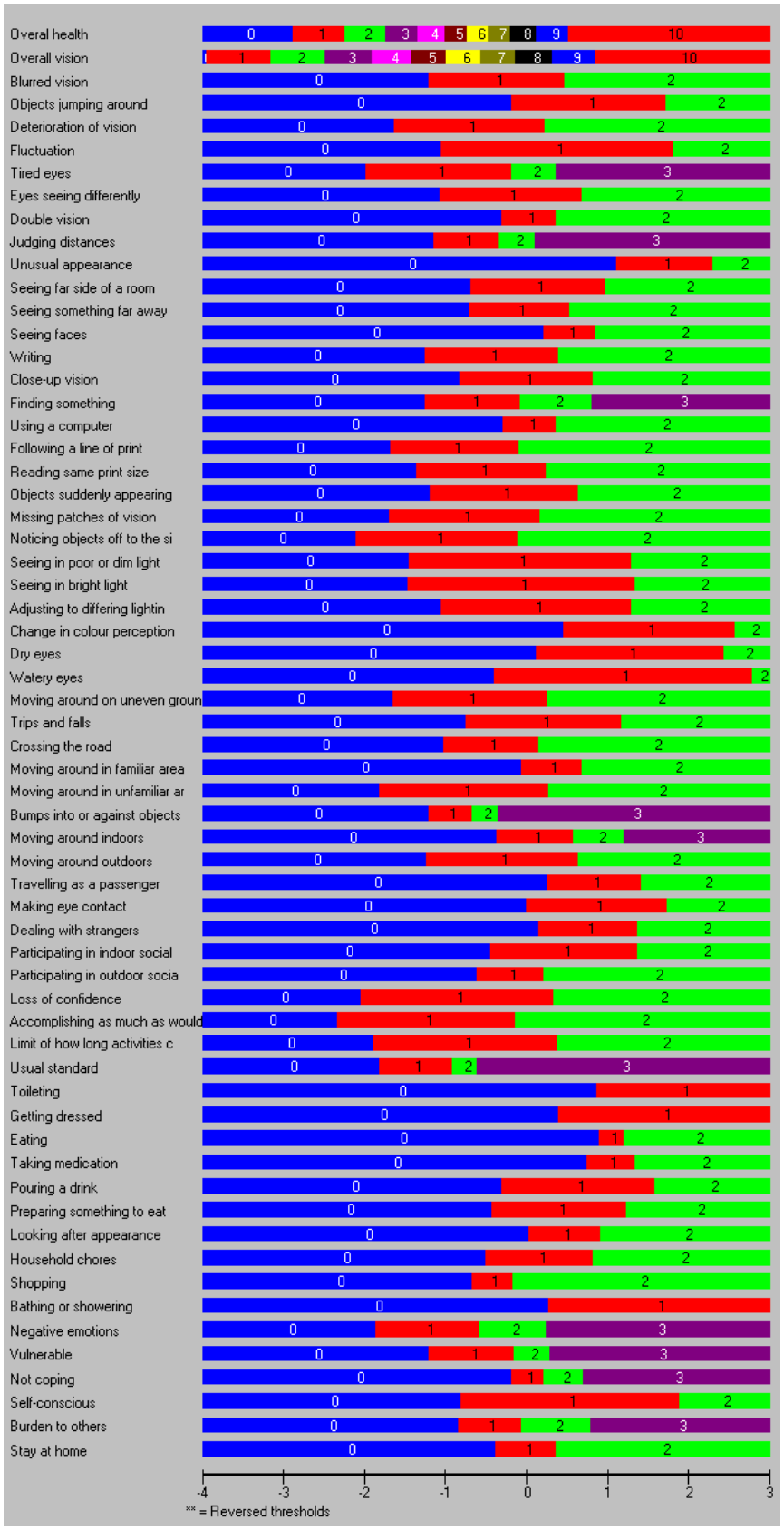


Figure 9.4: Threshold map following threshold rescore, demonstrating all items have ordered thresholds, courtesy of RUMM 2030 (259)

Table 9.5: Individual item fit statistics for the rescore analysis

Misfit

Item No	Item Name	Fit residual	Chi-square		F-statistic		
			Chi-square (df)	*p*	F-stat	df1/df2	*p*
i	Overall health	12.777	299.405 (3)	<0.0001	52.217	3 / 241	<0.0001
ii	Overall vision	6.769	58.041 (3)	<0.0001	13.65	3 / 241	<0.0001
1	Blurred vision	0.539	2.358 (3)	0.5016	0.723	3 / 242	0.5391
2	Objects jumping around	0.004	2.174 (3)	0.5371	0.716	3 / 242	0.5435
3	Deterioration of vision	1.587	3.286 (3)	0.3496	0.958	3 / 242	0.4133
4	Fluctuation	1.120	1.810 (3)	0.6128	0.558	3 / 242	0.6435
5	Tired eyes	0.280	0.868 (3)	0.8332	0.226	3 / 242	0.8783
6	Eyes seeing differently	1.766	10.315 (3)	0.0161	2.911	3 / 242	0.0351
7	Double vision	2.608	15.768 (3)	0.0013	3.848	3 / 242	0.0102
8	Judging distances	-0.831	1.352 (3)	0.7169	0.508	3 / 242	0.6775
9	Unusual appearance	0.716	1.079 (3)	0.7820	0.116	3 / 242	0.9506
10	Seeing far side of a room	-1.765	5.151 (3)	0.1611	2.134	3 / 242	0.0966
11	Seeing something far away	-1.906	6.372 (3)	0.0949	2.700	3 / 242	0.0464
12	Seeing faces	-0.944	2.894 (3)	0.4083	0.824	3 / 242	0.4815
13	Writing	0.247	2.020 (3)	0.5683	0.560	3 / 242	0.6422
14	Close-up vision	-0.732	3.178 (3)	0.3650	1.044	3 / 241	0.3736
15	Finding something	0.038	1.880 (3)	0.5976	0.755	3 / 242	0.5205
16	Using a computer	0.364	0.206 (3)	0.9766	0.195	3 / 242	0.8995
17	Following a line of print	0.940	6.471 (3)	0.0908	1.953	3 / 242	0.1217
18	Reading same print size	-0.516	1.134 (3)	0.7689	0.382	3 / 242	0.7659
19	Objects suddenly appearing	-1.267	3.211 (3)	0.3602	1.295	3 / 242	0.2768
20	Missing patches of vision	0.794	1.244 (3)	0.7424	0.336	3 / 242	0.7996
21	Noticing objects off to the side	1.423	2.360 (3)	0.5011	0.845	3 / 242	0.4706
22	Seeing in poor or dim light	0.773	5.864 (3)	0.1184	1.894	3 / 242	0.1311

Item No	Item Name	Fit residual	Chi-square		F-statistic		
			Chi-square (df)	*p*	F-stat	df1/df2	*p*
23	Seeing in bright light	-0.697	0.749 (3)	0.8615	0.253	3 / 242	0.8591
24	Adjusting to differing lighting	-0.742	0.288 (3)	0.9623	0.121	3 / 242	0.5391
25	Change in colour perception	-0.600	2.763 (3)	0.4297	0.926	3 / 242	0.4287
26	Dry eyes	2.390	14.311 (3)	0.0025	3.679	3 / 242	0.0128
27	Watery eyes	3.376	23.489 (3)	<0.0001	5.646	3 / 242	0.0009
28	Moving around on uneven ground	-1.955	16.687 (3)	0.0008	7.242	3 / 242	0.0001
29	Trips and falls	-1.429	6.361 (3)	0.0953	2.428	3 / 242	0.0661
30	Crossing the road	-3.291	13.111 (3)	0.0044	6.824	3 / 242	0.0002
31	Moving around in familiar areas	-1.996	9.239 (3)	0.0263	4.547	3 / 242	0.0040
32	Moving around in unfamiliar areas	-2.486	11.011 (3)	0.0117	5.044	3 / 242	0.0021
33	Bumps into or against objects or people in crowded areas	-1.249	2.229 (3)	0.5262	0.950	3 / 242	0.4171
34	Moving around indoors	-0.092	6.147 (3)	0.1047	2.021	3 / 242	0.1116
35	Moving around outdoors	-2.271	13.418 (3)	0.0038	5.521	3 / 242	0.0011
36	Travelling as a passenger	-0.443	5.339 (3)	0.1486	1.633	3 / 242	0.1824
37	Making eye contact	-2.026	9.803 (3)	0.0203	4.903	3 / 242	0.0025
38	Dealing with strangers	-2.397	13.348 (3)	0.0039	7.242	3 / 242	0.0001
39	Participating in indoor social activities	-2.648	18.122 (3)	0.0004	9.041	3 / 242	0.0000
40	Participating in outdoor social activities	-2.140	8.187 (3)	0.0423	3.687	3 / 242	0.0126
41	Loss of confidence	-2.852	16.910 (3)	0.0007	7.932	3 / 241	0.0000
42	Accomplishing as much as would like	-1.222	12.410 (3)	0.0061	4.471	3 / 241	0.0045
43	Limit of how long activities can be done for	-3.127	21.525 (3)	0.0001	10.287	3 / 241	0.0000
44	Usual standard	0.702	2.484 (3)	0.4782	0.716	3 / 241	0.5434
45	Toileting	-1.219	2.985 (3)	0.3940	1.210	3 / 242	0.3066
46	Getting dressed	-0.372	3.909 (3)	0.2715	1.432	3 / 242	0.2341
47	Eating	-0.872	3.804 (3)	0.2834	1.470	3 / 242	0.2234
48	Taking medication	-1.763	9.863 (3)	0.0198	4.865	3 / 242	0.0026

Item No	Item Name	Fit residual	Chi-square		F-statistic		
			Chi-square (df)	*p*	F-stat	df1/df2	*p*
49	Pouring a drink	-0.743	2.613 (3)	0.4552	0.725	3 / 241	0.5380
50	Preparing something to eat	-1.346	5.272 (3)	0.1529	2.016	3 / 241	0.1123
51	Looking after appearance	-0.46	1.089 (3)	0.7797	0.397	3 / 242	0.7553
52	Household chores	-2.466	15.778 (3)	0.0013	7.804	3 / 242	0.0001
53	Shopping	-2.168	8.645 (3)	0.0344	4.051	3 / 242	0.0078
54	Bathing or showering	-1.915	5.286 (3)	0.1520	2.301	3 / 242	0.0778
55	Negative emotions	0.451	2.081 (3)	0.5557	0.602	3 / 242	0.6145
56	Vulnerable	0.102	2.038 (3)	0.5645	0.409	3 / 241	0.7465
57	Not coping	-1.394	10.461 (3)	0.0150	4.161	3 / 241	0.0067
58	Self-conscious	-0.525	3.132 (3)	0.3717	0.827	3 / 240	0.4802
59	Burden to others	-0.806	3.520 (3)	0.3182	1.102	3 / 241	0.3491
60	Stay at home	-1.082	6.252 (3)	0.1000	2.389	3 / 241	0.0695

9.3.2.4*: Local independence*

There were 102 incidences of local dependence across the whole instrument (Table 9.6). The majority of local dependence was within sub-category. Eleven of the 12 sub-categories had some degree of local dependence, the exception being the sub-category of discomfort. There were thirteen cross sub-categories incidences of local dependence outlined in Table 9.7.

9.3.2.5*: Unidimensionality*

Comparing the 20 most positive items against the 20 most negative items, 36.0% of the paired t-tests were significant (<0.05) (Table 9.2). This indicates the instrument to be multidimensional.

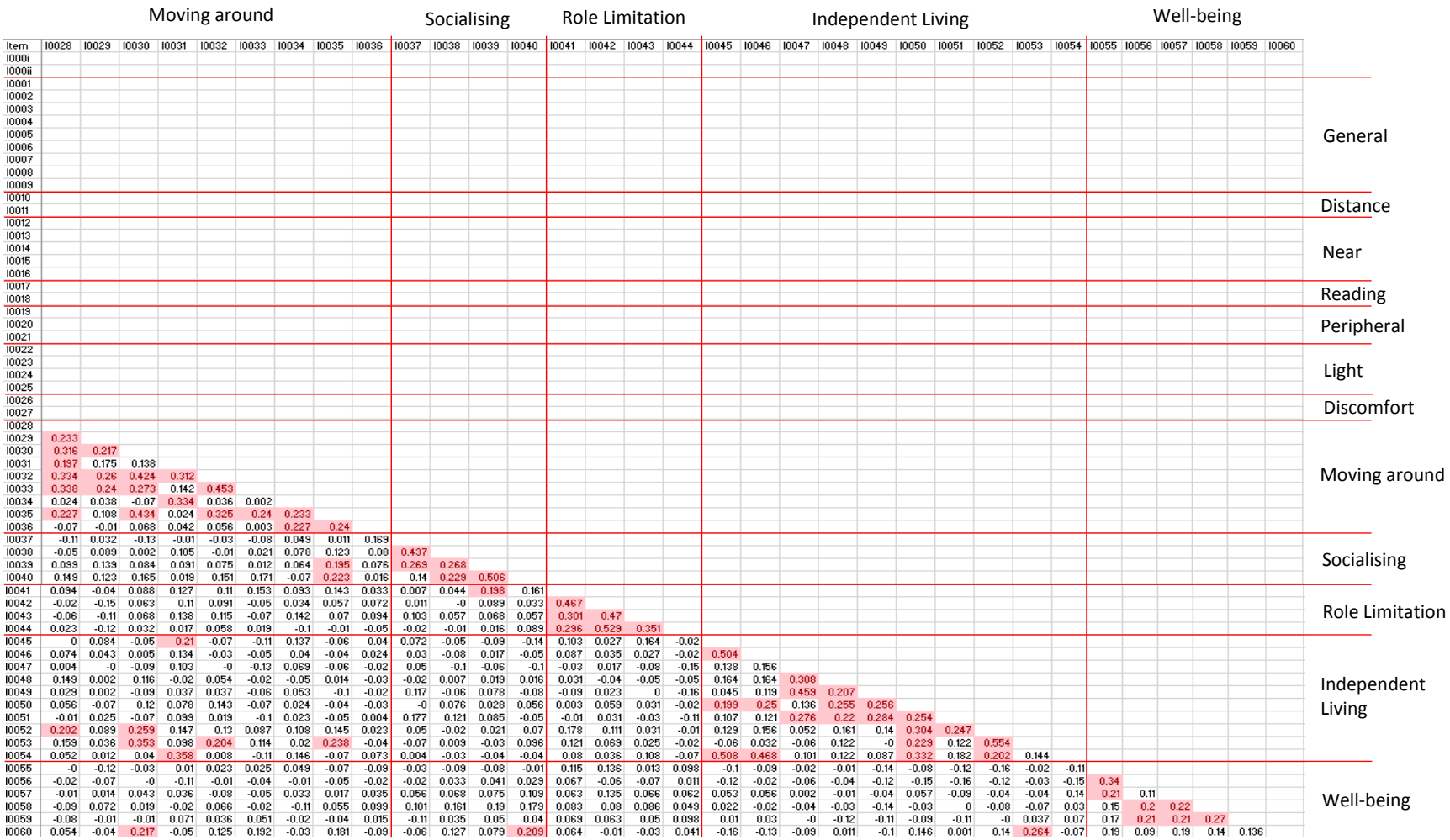
9.3.2.6*: Differential item functioning*

There were roughly equal numbers of each person factor and these were roughly evenly spread across each class interval, with the exception of 'primary visual impairment'. Within 'primary visual impairment', the group of visual field loss was much larger than the other visual impairment groups; each group was split roughly equally over the class interval.

No DIF was present for gender, age or isolated/multiple visual impairment. Three items were identified to have DIF for the time since onset person factor; 'overall health' and 'overall vision' demonstrated uniform DIF and 'using a computer' had non-uniform DIF. Eight items were identified to have uniform DIF for the location person factor; 'overall health', 'overall vision', 'noticing objects off to the side', 'moving around on uneven ground', 'crossing the road', 'moving around in unfamiliar areas', 'bumps into or against objects or people in crowded areas' and 'moving around outdoors'. Four items were identified to have uniform DIF for the primary visual impairment person factor; 'double vision', 'objects suddenly appearing', 'missing patches of vision' and 'noticing objects off to the side'.

Table 9.6: Residual correlations between items, highlighting local dependence. Residual correlations >0.2 above average = 0.1940

		General											Distance		Near				Reading		Peripheral			Light				Discomfort	
	Item	I000i	I000ii	I0001	I0002	I0003	I0004	I0005	I0006	I0007	I0008	I0009	I0010	I0011	I0012	I0013	I0014	I0015	I0016	I0017	I0018	I0019	I0020	I0021	I0022	I0023	I0024	I0025	I0026	I0027
	I000i																												
	I000ii	0.513																											
General	I0001	0.086	0.116																										
	I0002	0.03	-0.01	0.179																									
	I0003	0.159	0.187	0.258	0.079																								
	I0004	-0.01	0.065	0.327	0.222	0.164																							
	I0005	0.069	-0.09	0.003	0.02	0.009	0.055																						
	I0006	0.077	0.047	0.116	0.036	0.107	0.22	0.062																					
	I0007	0.133	0.122	0.129	-0.03	0.016	0.046	0.07	0.214																				
	I0008	-0.08	-0.07	-0.13	0.028	-0.07	0.105	-0.01	0.144	0.196																			
	I0009	0.092	0.028	0.043	0.173	0.093	0.171	0.029	0.1	0.106	0.031																		
Distance	I0010	-0.08	0.015	0.122	0.054	0.184	0.028	0.012	-0.02	0.005	0.063	-0.07																	
	I0011	-0.16	0.005	0.223	-0	0.13	0.063	-0.03	-0.09	-0.02	-0.01	-0.06	0.547																
Near	I0012	-0.13	0.056	0.093	0.072	-0.04	-0.03	-0.14	-0.08	0.046	0.02	0.049	0.305	0.261															
	I0013	-0.04	-0.02	-0	-0.03	-0.02	-0.07	0.035	-0.12	0.025	-0.11	-0.06	0.094	0.044	0.096														
	I0014	-0.16	-0.06	0.027	0	0.041	-0	-0.06	-0.06	0.009	0.033	-0	0.164	0.172	0.27	0.263													
	I0015	-0.23	-0.08	-0.17	-0.02	-0.23	0.026	-0.02	0.028	-0.17	0.043	-0.03	-0.01	0.029	0.144	-0.03	0.19												
	I0016	-0.13	-0.22	-0.04	-0.11	-0.12	0.073	-0.12	-0.07	-0.09	-0.07	-0.05	-0.06	-0.01	-0.01	0.193	0.1	-0.03											
Reading	I0017	-0.09	-0.1	0.009	0.001	-0.04	-0.03	0.036	-0.11	-0.1	-0.02	-0.08	0.031	0.05	0.025	0.297	0.256	0.093	0.22										
	I0018	-0.09	0.003	0.039	-0.01	0.098	-0	0.001	-0.12	-0.14	-0.14	0.004	0.126	0.177	0.111	0.326	0.323	0.023	0.087	0.421									
Peripheral	I0019	-0.19	-0.09	-0.18	0.007	-0.04	-0.06	-0.06	-0.19	-0.3	-0.1	-0.03	-0.13	-0.12	0.027	-0.11	-0.22	0.106	-0.04	0.043	-0.01								
	I0020	-0.17	-0.14	-0.16	-0	0.004	0.058	-0.14	-0.12	-0.32	-0.02	-0.03	-0.2	-0.11	0.015	-0.17	-0.09	0.132	0.042	0.071	-0.07	0.499							
	I0021	-0.09	-0.09	-0.17	-0.17	-0.02	0.09	-0.09	0.029	-0.35	-0.13	-0.03	-0.2	-0.14	-0.15	-0.14	-0.19	0.2	0.064	0.066	-0.04	0.389	0.609						
Light	I0022	-0.09	-0.08	0.051	-0.1	0.01	-0.05	0.06	-0.1	-0.01	-0.04	-0.06	-0	0.053	0.165	-0.04	0.125	0.122	-0.06	0.014	0.127	0.054	0.059	0.026					
	I0023	-0.18	-0.18	0.035	0.066	-0.06	0.087	0.044	-0.09	-0.1	-0.01	-0.03	-0.04	-0.07	0.061	-0.04	0.053	0.173	0.067	-0.06	0.033	0.144	0.022	0.069	0.336				
	I0024	-0.14	-0.16	0.029	0.06	-0.07	0.073	0.082	-0.08	-0.08	-0.07	-0.05	-0.03	0.055	0.02	-0.1	0.011	0.076	0.022	-0.07	0.08	0.114	0.041	0.053	0.451	0.605			
	I0025	-0.08	-0.06	0.015	0.032	0.147	0.101	-0.08	-0.01	0.068	0.102	0.128	0.173	0.14	0.108	0.068	0.046	0.015	0.013	0.056	0.17	0.079	0.041	-0.03	0.161	0.16	0.219		
Discomfort	I0026	0.138	0.008	-0	0.063	0.065	0.102	0.121	0.108	0.146	0.021	0.04	-0.05	-0.04	-0.03	0.027	-0.03	-0.07	-0.06	-0.01	-0.09	-0.06	-0.05	-0.07	-0.03	0.007	0.029	0.012	
	I0027	0.157	0.052	-0.02	0.099	0.074	0.052	0.098	0.032	0.121	0.086	0.076	-0.02	-0.11	-0.05	0.028	0.079	-0.01	-0.02	-0.01	0.036	-0.09	-0.05	-0.05	-0.03	0.037	-0.01	0.036	0.075	
Moving around	I0028	-0.22	-0.18	-0.21	-0.04	-0.12	-0.19	-0.07	-0.1	-0.04	0.056	-0.1	-0.02	-0.06	-0.07	-0.05	-0.04	-0.01	-0.08	-0.15	-0.09	0.073	0.057	0.031	0.003	-0.04	-0.07	-0.09	-0.03	-0.07
	I0029	-0.15	-0.14	-0.19	-0.03	-0.04	-0.14	0.035	0.087	-0.03	-0.04	-0.01	-0.03	-0.01	0.094	-0.04	0.056	0.03	-0.08	-0.06	-0.09	0.005	0.005	-0.07	0.036	-0.04	-0.03	-0.04	-0.06	-0.07
	I0030	-0.39	-0.25	-0.21	-0.14	-0.11	-0.1	-0.1	-0.07	-0.21	-0.05	-0.19	-0.06	0.064	-0.07	0.023	-0.01	0.084	-0.03	-0.04	0.062	0.114	0.096	0.18	-0.04	-0.07	0.033	-0.13	-0.13	-0.1
	I0031	-0.29	-0.25	-0.16	0.079	-0.14	-0.11	-0.03	-0.02	-0.04	0.044	-0.06	-0.04	-0.16	-0.03	-0.04	0.02	0.016	-0.05	-0.02	-0.05	-0.06	0.026	-0.05	-0.1	-0.05	-0.19	-0.13	0.006	0.001
	I0032	-0.42	-0.33	-0.25	-0.04	-0.2	-0.18	-0.08	-0.12	-0.2	-0	-0.09	-0.09	-0.02	-0.12	-0.05	0.026	0.191	0.045	0.017	-0.1	0.076	0.16	0.125	-0.01	-0.03	-0.01	-0.13	-0.15	-0.09
	I0033	-0.23	-0.27	-0.27	-0.08	-0.13	-0.1	-0.01	-0.11	-0.15	0.023	-0.17	-0.08	-0.13	-0.12	-0.17	-0.1	0.1	0.025	-0.02	-0.19	0.256	0.336	0.318	-0.1	0.026	0.007	-0.15	-0.07	-0.15
	I0034	-0.09	-0.1	0.059	-0.02	-0.06	-0.17	0.002	-0.09	0.032	-0.04	0.015	-0.04	-0.06	0.016	0.076	-0.04	-0.08	-0.01	-0	-0.06	-0.01	-0.11	-0.15	-0.07	-0.17	-0.23	0.051	-0.04	-0.07
	I0035	-0.26	-0.23	-0.1	-0.13	-0.17	-0.13	-0.05	-0.09	-0.14	-0.03	-0.14	-0.04	0.137	-0.01	-0.05	-0.02	0.006	-0.04	-0.2	-0.2	0.036	0.094	0.064	0.091	-0.03	0.013	-0.04	-0.11	-0.11
	I0036	-0.09	-0.13	0.011	-0.01	-0.15	-0.13	0.021	-0.15	-0.08	-0.01	-0.02	0.002	0.102	-0.01	-0.13	-0.12	0.062	0.053	-0.08	-0.02	0.08	-0.01	-0.03	-0.03	0.109	0.128	0.086	-0.13	-0.05
Socialising	I0037	-0.12	-0.08	-0.1	-0.01	-0.28	-0.08	-0.06	-0.11	-0.01	0.047	0.157	-0.01	0.05	0.197	-0.01	0.112	0.022	0.033	-0.06	-0.04	0.017	-0.12	-0.19	-0.04	0.126	0.09	0.062	-0.04	-0.1
	I0038	-0.21	-0.21	-0.12	-0.04	-0.21	-0.03	0.026	-0.07	-0.03	-0.08	0.051	-0.11	-0.01	0.079	0.045	0.054	-0.02	0.044	-0.13	0.023	0.07	0.048	-0.04	0.022	0.114	0.076	-0.03	0.06	-0.09
	I0039	-0.29	-0.24	-0.12	-0.13	-0.14	-0.13	-0.03	-0.1	-0.08	-0.09	0.006	-0.03	0.021	-0.01	0.032	-0.03	0.003	0.025	-0.02	-0.02	0.081	-0.01	-0.01	-0.13	0.08	0.043	0.061	-0.04	-0.13
	I0040	-0.29	-0.23	-0.12	-0.06	-0.11	-0.1	-0.05	-0.05	-0.13	-0.1	-0.07	-0.15	-0.11	-0.1	-0.08	-0.06	0.048	0.107	-0.16	-0.17	0.108	0.11	0.19	-0.02	0.075	0.106	-0.07	-0.11	-0.1
Role Limitation	I0041	-0.23	-0.2	-0.1	-0.14	-0.1	-0.25	-0.13	-0.28	-0.13	-0.1	-0.16	0.016	0.038	-0.06	-0.07	-0.13	-0.05	0.018	-0.05	-0.16	0.133	0.044	-0	-0.02	-0.1	-0.07	-0.09	-0.12	-0.24
	I0042	-0.25	-0.15	-0.04	-0.07	-0.11	-0.13	-0.19	-0.09	-0.06	-0.05	-0.12	-0.08	-0	-0.11	0.022	-0.19	-0.05	0.048	-0.01	-0.14	0.011	-0.03	0.012	-0.15	-0.03	-0.08	-0.11	-0.07	-0.08
	I0043	-0.2	-0.23	-0.01	0.04	-0.17	-0.11	0.01	-0.1	-0.05	0.007	-0.13	-0.03	-0.09	-0.12	0.016	-0.07	-0.03	0.046	0.068	-0.07	0.036	-0.1	-0.08	-0.09	0.002	-0.05	-0.03	-0.13	-0.05
	I0044	-0.14	-0.19	-0.03	-0.01	-0.13	-0.11	-0.15	-0.03	-0	-0.05	-0.08	-0.07	-0.04	-0.08	0.015	-0.1	-0.09	0.05	0.007	-0.08	0.084	-0.06	0.056	-0.12	-0.02	-0.08	-0.14	-0.09	0.078
Independent Living	I0045	-0.02	-0.07	-0.01	-0.01	-0.03	-0.08	-0.01	0.041	0.09	0.036	0.012	0.116	0.006	0.023	-0.01	0.037	-0.08	-0.04	-0.08	-0.08	-0.2	-0.25	-0.25	-0.01	-0.16	-0.1	-0.12	-0.03	-0.1
	I0046	-0.04	-0.08	-0.08	-0.09	-0.09	-0.06	-0.02	-0.03	0.036	-0.03	-0.02	-0.01	-0.12	-0.07	-0.01	-0.03	-0.03	-0.01	-0.09	-0.05	-0.06	-0.15	-0.13	0	-0.05	-0.09	-0.13	-0.04	-0.09
	I0047	0.014	0.045	-0.05	-0.02	-0.08	-0.1	-0.03	-0.01	-0.03	0.078	0.023	-0.06	-0.07	0.021	-0.02	0.011	0.02	-0.04	-0.06	-0.06	-0.16	-0.08	-0.15	-0.02	-0.07	-0.07	0.063	-0.06	-0.04
	I0048	-0.15	-0.16	-0.06	-0.05	0.018	-0.06	-0.11	-0.03	-0.03	-0.09	-0.03	-0.08	-0.02	0.031	0.113	0.062	0.019	0.161	-0.03	0.147	-0.09	-0.05	-0.09	-0	-0.09	-0.07	0.049	-0.09	-0.09
	I0049	-0.04	0.004	0.025	-0.06	-0.1	-0.04	-0.14	-0	0.07	0.172	0.034	0	-0.14	0.052	0.085	0.096	0.063	-0.02	-0.07	-0.06	-0.14	-0.09	-0.12	-0.07	0.005	-0.06	0.144	-0.07	-0.02
	I0050	-0.2	-0.1	-0.01	0.045	0.014	0.021	-0.14	-0.05	-0.05	-0.04	0.057	-0.1	-0.11	-0.1	0.024	0.09	-0.05	0.066	-0.14	0.073	-0.14	-0.13	-0.15	-0.03	0.043	-0.02	-0.1	-0.12	-0.03
	I0051	0.003	-0.09	-0.12	-0.04	-0.06	-0.06	0.045	-0.06	0.012	-0.05	0.046	-0.09	-0.13	-0.09	0.089	0.041	-0.07	0.125	-0.09	-0.01	-0.12	-0.21	-0.19	-0.15	-0.08	-0.03	-0.03	-0.04	0.018
	I0052	-0.32	-0.22	-0.05	-0.11	-0.06	-0.08	-0.09	-0.13	-0.03	-0.03	-0	-0.06	-0.08	-0.12	0.052	0.097	-0.12	0.047	-0.02	0.096	-0.08	-0.05	-0.1	-0.07	-0.05	-0.04	0.017	-0.12	-0.11
	I0053	-0.3	-0.17	0.044	-0.1	-0.03	-0.04	-0.07	-0.11	-0.11	-0.02	-0.07	-0.06	-0.01	-0.19	-0.06	-0.04	-0.03	0.071	-0.07	0.031	-0.06	-0.07	0.022	0	-0.05	-0.05	-0.1	-0.19	-0.04
	I0054	-0.12	-0.1	-0.05	-0.05	-0.04	-0.09	-0.01	0.002	-0.01	-0.02	-0.06	-0.03	-0.15	-0.08	-0.09	-0.02	-0.03	-0.08	-0.04	-0.01	-0.12	-0.2	-0.14	-0.01	-0.05	-0.14	-0.12	0.001	-0.02
Well-being	I0055	-0.07	0.014	-0.03	0.035	-0.12	-0.11	-0.07	-0.03	-0.01	-0.04	-0.01	-0.05	-0.05	-0.07	-0.13	-0.18	-0.12	0.129	-0.06	-0.16	0.017	0.027	-0.01	-0.11	-0.14	-0.17	-0.12	-0.06	-0.13
	I0056	-0.06	-0.05	-0.04	-0.02	-0.03	-0.05	-0.08	-0.07	-0.05	0.017	-0.05	0.085	0.049	0.002	-0.07	-0.17	-0.06	-0.04	-0.04	-0.05	0.075	0.086	-0	-0.04	-0.08	0.022	0.014	-0.1	-0.05
	I0057	-0.14	-0.14	-0.06	-0.06	-0.02	-0.13	-0.04	-0.02	-0.04	-0.06	-0.08	-0.07	-0.04	0.012	-0.06	-0.11	-0.08	-0.07	-0.04	-0.18	0.042	-0.02	-0.07	-0.05	0.017	-0.02	-0.08	0.112	-0.16
	I0058	-0.12	-0.25	-0.1	0.009	-0.22	-0.06	-0.02	0.004	0.013	0.02	-0.02	-0.06	0.003	-0.01	-0.1	-0.15	-0	0.01	-0.13	-0.19	-0.03	-0.02	-0.06	-0.02	0.057	0.166	-0.07	0.043	-0.1
	I0059	-0.14	-0.15	-0.08	-0.05	-0.03	-0.05	0.074	0.045	-0	0.023	-0.01	-0.09	-0.08	-0.15	-0.18	-0.17	-0.11	-0.05	-0.06	-0.15	0.07	0.164	0.093	-0.11	-0.07	-0.05	-0.17	-0	-0.15
	I0060	-0.12	-0.11	-0.08	-0.03	-0.1	-0.07	-0.06	-0.03	-0.16	-0.09	-0.09	-0.13	-0.08	-0.12	-0.19	-0.14	-0	-0.08	-0.02	-0.08	0.059	0.115	0.171	-0.09	-0.08	-0.09	-0.15	-0.1	-0.13



Item	I0028	I0029	I0030	I0031	I0032	I0033	I0034	I0035	I0036	I0037	I0038	I0039	I0040	I0041	I0042	I0043	I0044	I0045	I0046	I0047	I0048	I0049	I0050	I0051	I0052	I0053	I0054	I0055	I0056	I0057	I0058	I0059	I0060
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I0028																																	
I0029	0.233																																
I0030	0.316	0.217																															
I0031	0.197	0.175	0.138																														
I0032	0.334	0.26	0.424	0.312																													
I0033	0.338	0.24	0.273	0.142	0.453																												
I0034	0.024	0.038	-0.07	0.334	0.036	0.002																											
I0035	0.227	0.108	0.434	0.024	0.325	0.24	0.233																										
I0036	-0.07	-0.01	0.068	0.042	0.056	0.003	0.227	0.24																									
I0037	-0.11	0.032	-0.13	-0.01	-0.03	-0.08	0.049	0.011	0.169																								
I0038	-0.05	0.089	0.002	0.105	-0.01	0.021	0.078	0.123	0.08	0.437																							
I0039	0.099	0.139	0.084	0.091	0.075	0.012	0.064	0.195	0.076	0.269	0.268																						
I0040	0.149	0.123	0.165	0.019	0.151	0.171	-0.07	0.223	0.016	0.14	0.229	0.506																					
I0041	0.094	-0.04	0.088	0.127	0.11	0.153	0.093	0.143	0.033	0.007	0.044	0.198	0.161																				
I0042	-0.02	-0.15	0.063	0.11	0.091	-0.05	0.034	0.057	0.072	0.011	-0	0.089	0.033	0.467																			
I0043	-0.06	-0.11	0.068	0.138	0.115	-0.07	0.142	0.07	0.094	0.103	0.057	0.068	0.057	0.301	0.47																		
I0044	0.023	-0.12	0.032	0.017	0.058	0.019	-0.1	-0.01	-0.05	-0.02	-0.01	0.016	0.089	0.296	0.529	0.351																	
I0045	0	0.084	-0.05	0.21	-0.07	-0.11	0.137	-0.06	0.04	0.072	-0.05	-0.09	-0.14	0.103	0.027	0.164	-0.02																
I0046	0.074	0.043	0.005	0.134	-0.03	-0.05	0.04	-0.04	0.024	0.03	-0.08	0.017	-0.05	0.087	0.035	0.027	-0.02	0.504															
I0047	0.004	-0	-0.09	0.103	-0	-0.13	0.069	-0.06	-0.02	0.05	-0.1	-0.06	-0.1	-0.03	0.017	-0.08	-0.15	0.138	0.156														
I0048	0.149	0.002	0.116	-0.02	0.054	-0.02	-0.05	0.014	-0.03	-0.02	0.007	0.019	0.016	0.031	-0.04	-0.05	-0.05	0.164	0.164	0.308													
I0049	0.029	0.002	-0.09	0.037	0.037	-0.06	0.053	-0.1	-0.02	0.117	-0.06	0.078	-0.08	-0.09	0.023	0	-0.16	0.045	0.119	0.459	0.207												
I0050	0.056	-0.07	0.12	0.078	0.143	-0.07	0.024	-0.04	-0.03	-0	0.076	0.028	0.056	0.003	0.059	0.031	-0.02	0.199	0.25	0.136	0.255	0.256											
I0051	-0.01	0.025	-0.07	0.099	0.019	-0.1	0.023	-0.05	0.004	0.177	0.121	0.085	-0.05	-0.01	0.031	-0.03	-0.11	0.107	0.121	0.276	0.22	0.284	0.254										
I0052	0.202	0.089	0.259	0.147	0.13	0.087	0.108	0.145	0.023	0.05	-0.02	0.021	0.07	0.178	0.111	0.031	-0.01	0.129	0.156	0.052	0.161	0.14	0.304	0.247									
I0053	0.159	0.036	0.353	0.098	0.204	0.114	0.02	0.238	-0.04	-0.07	0.009	-0.03	0.096	0.121	0.069	0.025	-0.02	-0.06	0.032	-0.06	0.122	-0	0.229	0.122	0.554								
I0054	0.052	0.012	0.04	0.358	0.008	-0.11	0.146	-0.07	0.073	0.004	-0.03	-0.04	-0.04	0.08	0.036	0.108	-0.07	0.508	0.468	0.101	0.122	0.087	0.332	0.182	0.202	0.144							
I0055	-0	-0.12	-0.03	0.01	0.023	0.025	0.049	-0.07	-0.09	-0.03	-0.09	-0.08	-0.01	0.115	0.136	0.013	0.098	-0.1	-0.09	-0.02	-0.01	-0.14	-0.08	-0.12	-0.16	-0.02	-0.11						
I0056	-0.02	-0.07	-0	-0.11	-0.01	-0.04	-0.01	-0.05	-0.02	-0.02	0.033	0.041	0.029	0.067	-0.06	-0.07	0.011	-0.12	-0.02	-0.06	-0.04	-0.12	-0.15	-0.16	-0.12	-0.03	-0.15	0.34					
I0057	-0.01	0.014	0.043	0.036	-0.08	-0.05	0.033	0.017	0.035	0.056	0.068	0.075	0.109	0.063	0.135	0.066	0.062	0.053	0.056	0.002	-0.01	-0.04	0.057	-0.09	-0.04	-0.04	0.14	0.21	0.11				
I0058	-0.09	0.072	0.019	-0.02	0.066	-0.02	-0.11	0.055	0.099	0.101	0.161	0.19	0.179	0.083	0.08	0.086	0.049	0.022	-0.02	-0.04	-0.03	-0.14	-0.03	0	-0.08	-0.07	0.03	0.15	0.2	0.22			
I0059	-0.08	-0.01	-0.01	0.071	0.036	0.051	-0.02	-0.04	0.015	-0.11	0.035	0.05	0.04	0.069	0.063	0.05	0.098	0.01	0.03	-0	-0.12	-0.11	-0.09	-0.11	-0	0.037	0.07	0.17	0.21	0.21	0.27		
I0060	0.054	-0.04	0.217	-0.05	0.125	0.192	-0.03	0.181	-0.09	-0.06	0.127	0.079	0.209	0.064	-0.01	-0.03	0.041	-0.16	-0.13	-0.09	0.011	-0.1	0.146	0.001	0.14	0.264	-0.07	0.19	0.09	0.19	0.14	0.136	

Table 9.7: Local dependence present across sub-categories

Sub-category	Sub-category	Incidences of local dependence (n)
General vision	Distance vision	1
Near vision	Distance vision	2
	Reading	5
	Peripheral vision	1
	Socialising	1
Moving around	Peripheral vision	3
	Socialising	2
	Independent living	7
	Well-being	1
Role limitation	Socialising	1
	Independent living	1
Well-being	Role limitation	1
	Independent living	1

9.3.3: Dealing with misfit to the model

The order of item deletion is listed in Table 9.2, along with the summary statistics of the analysis following each item deletion. The initial analysis highlighted 11 misfitting items; five of these items also demonstrated DIF. Item deletion began with the individual items identified as misfitting, and the order of deletion was led by the degree of misfit. The order and the reason for the deletion decision made is outlined in Table 9.8, which are discussed in more detail in the following sections.

9.3.3.1*: Deletion of item i 'Overall health'*

The 'overall health' item was deleted first as it had the largest fit residual (12.78) distant from the higher limit of 2.5 and significant Chi square (<0.0001) and F statistic (<0.0001) results. Significant uniform DIF for two different person factors was highlighted; time since stroke (<0.0001) and location (<0.0001). It reflected that participants in the hyperacute and acute stages of stroke had more severe scores compared to those in the sub-acute or chronic stages post-stroke. More severe scores were also reported by inpatients than outpatients. It is understandable clinically that participants in the more acute stages of a stroke and still in hospital would report their overall health as being poorer. Local dependence with item ii 'overall vision' (0.513) was also identified. In addition to the misfit, DIF and local dependence, this item is a likely contributor to multidimensionality. The item asks about general health rather than impact of visual impairment and therefore does not fit together with the aim of this instrument.

9.3.3.2*: Deletion of item ii 'Overall vision'*

The 'overall vision' item was deleted due to now having the largest fit residual (8.984) distant from the higher limit of 2.5 and significant Chi square (<0.0001) and F statistic (<0.0001) results. Significant uniform DIF for two different person factors was also highlighted; time since stroke (<0.0001) and location (<0.0001). Participants in the hyperacute stage post-stroke and still inpatients had more severe scores. Local dependence with item 3 'deterioration of vision' (0.239) was also identified.

Table 9.8: Order of item deletion and data influencing decisions for deletion

Item deleted	Misfit	Differential Item Functioning (DIF)	Local dependence (residual correlations)	Clinical
(i) 'Overall health'	Fit residual = 12.78 Chi square $p<0.0001$ F-statistic $p<0.0001$	Uniform Time since stroke $p<0.0001$ Location $p<0.0001$	(ii) 'Overall vision' 0.513	Contribution to multidimensionality as not related to impact of visual impairment
(ii) 'Overall vision'	Fit residual = 8.984 Chi square $p<0.0001$ F-statistic $p<0.0001$	Uniform Time since stroke $p<0.0001$ Location $p<0.0001$	(3) 'Deterioration of vision' 0.239	-
(26) 'Dry eyes'	Fit residual = 3.949 Chi square $p<0.0001$	-	-	-
(27) 'Watery eyes'	Fit residual = 4.100 Chi square $p<0.0001$ F-statistic $p<0.0001$	-	-	-
(7) 'Double vision'	Fit residual = 3.882 Chi square $p<0.0001$ F-statistic $p=0.0002$	Uniform Primary visual impairment $p<0.0001$	(8) 'Judging distances' 0.214	-
(3) 'Deterioration of vision'	Fit residual = 3.707	-	(1) 'Blurred vision' 0.321 (4) 'Fluctuation' 0.212 (10) 'Seeing far side of room' 0.212	No specifics regarding deterioration over what period of time and if this is pre or post-stroke onset
(6) 'Eyes seeing differently'	Fit residual = 3.476 Chi square $p<0.0001$	-	(4) 'Fluctuation' 0.257 (8) 'Judging distances' 0.186	Does not specify if it asking regarding each eye separately at the same time point or both eyes together over different time points

Item deleted	Misfit	Differential Item Functioning (DIF)	Local dependence (residual correlations)	Clinical
(30) 'Crossing the road'	Fit residual = 3.151	Uniform Location p<0.0001	(28) 'Moving around on uneven ground' 0.243 (32) 'Moving around in unfamiliar places' 0.355 (35) 'Moving around outdoors' 0.380	-
(32) 'Moving around in unfamiliar areas'	Fit residual = -2.919	Uniform Location p<0.0001	(28) 'Moving around on uneven ground' 0.264 (29) 'Trips and falls' 0.210 (31) 'Moving around in familiar areas' 0.258 (33) 'Bumps into or against objects or people in crowded areas' 0.384 (35) 'Moving around outdoors' 0.265	-
(43) 'Limit of how long activities can be done for'	Fit residual = -2.961	-	(41) 'Loss of confidence' 0.240 (42) 'Accomplishing as much as would like' 0.436 (44) 'Usual standard' 0.322	-
(41) 'Loss of confidence'	Fit residual = -2.725	-	(42) 'Accomplishing as much as would like' 0.438 (44) 'Usual standard' 0.269	-
(39) 'Participating in indoor social activities'	Fit residual = -2.520 F-statistic p=0.0003	-	(37) 'Making eye contact' 0.218 (38) 'Dealing with strangers' 0.223 (40) 'Participating in outdoor social activities' 0.447	-
(52) 'Household chores'	Chi square p=0.0007 F-statistic p<0.0001	-	(50) 'Preparing something to eat' 0.251 (51) 'Looking after appearance' 0.207 (53) 'Shopping' 0.520	-

Item deleted	Misfit	Differential Item Functioning (DIF)	Local dependence (residual correlations)	Clinical
(38) 'Dealing with strangers'	F-statistic p=0.0006	-	(37) 'Making eye contact' 0.401 (40) 'Participating in outdoor social activities' 0.187	(37) 'Making eye contact' would cover people the person knows as well as strangers
(21) 'Noticing objects off to the side'	-	Uniform Primary visual impairment p<0.0001 Location p<0.0001	(19) 'Objects suddenly appearing' 0.349 (20) 'Missing patches of vision' 0.571 (33) 'Bumps into or against objects or people in crowded areas' 0.268	-
(20) 'Missing patches of vision'	-	Uniform Primary visual impairment p<0.0001	(19) 'Objects suddenly appearing' 0.486 (33) 'Bumps into or against objects or people in crowded areas' 0.306	-
(33) 'Bumps into or against objects or people in crowded areas'	-	Uniform Location p<0.0001	(19) 'Objects suddenly appearing' 0.239 (28) 'Moving around on uneven ground' 0.296 (29) 'Trips and falls' 0.219 (35) 'Moving around outdoors' 0.218	-
(35) 'Moving around outdoors'	-	Uniform Location p<0.0001	(28) 'Moving around on uneven ground' 0.207 (40) 'Participating in outdoor social activities' 0.219 (53) 'Shopping' 0.226 (60) 'Stay at home' (0.183)	-
(16) 'Using a computer'	-	Non-uniform Time since stroke p<0.0001	(17) 'Following a line of print' 0.188	(16) 'Using a computer' involves reading. (17) 'Following a line of print' also covers printed mediums

Item deleted	Misfit	Differential Item Functioning (DIF)	Local dependence (residual correlations)	Clinical
(19) 'Objects suddenly appearing'	-	Uniform Primary visual impairment $p<0.0001$	-	-
(28) 'Moving around on uneven ground'	-	Uniform Location $p<0.0001$	(29) 'Trips and falls' 0.239	-
(23) 'Seeing in bright light'	-	Uniform Location $p=0.0003$	(22) 'Seeing in poor or dim light' 0.302 (24) 'Adjusting to differing lighting' 0.586	(24) 'Adjusting to differing lighting' covers both bright and dim lighting conditions
(10) 'Seeing far side of room'	-	-	(11) 'Seeing something far away' 0.508 (12) 'Seeing faces' 0.253	(11) 'Seeing something far away' more appropriate to cover the difficulty with reduced vision in the distance
(44) 'Usual standard'	-	-	(42) 'Accomplish as much as would like' 0.493	(42) 'Accomplishing as much as would like' more appropriate to cover the difficulty with achieving tasks a person needs to achieve
(54) 'Bathing or showering'	-	-	(31) 'Moving around in familiar areas' 0.296 (45) 'Toileting' 0.492 (46) 'Getting dressed' 0.437 (50) 'Preparing something to eat' 0.320	Of the three ADLs involved with personal hygiene, (46) 'getting dressed' potentially most dependent on vision
(22) 'Seeing in poor or dim light'	-	-	(24) 'Adjusting to differing lighting 0.435	(24) 'Adjusting to differing lighting' covers both bright and dim lighting conditions
(45) 'Toileting'	-	-	(46) 'Getting dressed' 0.496 (52) 'Preparing something to eat' 0.229	(46) 'Getting dressed' potentially most dependent on vision

Item deleted	Misfit	Differential Item Functioning (DIF)	Local dependence (residual correlations)	Clinical
(47) 'Eating'	-	-	(49) 'Pouring a drink' 0.423	-
(18) 'Reading same print size'	-	-	(17) 'Following a line of print' 0.378	(17) 'Following a line of print' more commonly occurs following stroke in both ocular motility defects and visual field loss. Element of (18) 'reading same size print' which relies on memory
(60) 'Stay at home'	-	Non-uniform Time since stroke *p*=0.0003	(40) 'Participating in outdoor social activities' 0.224 (53) 'Shopping' 0.251 (57) 'Not coping' 0.174	-
(4) 'Fluctuation'	-	-	(1) 'Blurred vision' 0.331 (2) 'Objects jumping around' 0.190	No specifics of fluctuation over what period of time and if this is pre- or post-stroke onset
(31) 'Moving around in familiar areas'	-	-	(29) 'Moving around indoors' 0.329	-
(56) 'Vulnerable'	-	-	(55) 'Negative emotions' 0.279 (59) 'Burden to others' 0.172	(55) 'Negative emotions' a more general item about emotional well-being
(50) 'Preparing something to eat'	-	-	(46) 'Getting dressed' 0.245 (48) 'Taking medication' 0.231 (49) 'Pouring a drink' 0.196 (51) 'Looking after appearance' 0.197 (53) 'Shopping' 0.184	(50) 'Preparing something to eat' is commonly not possible in an inpatient setting

Item deleted	Misfit	Differential Item Functioning (DIF)	Local dependence (residual correlations)	Clinical
(49) 'Pouring a drink'	-	-	(48) 'Taking medication' 0.171 (51) 'Looking after appearance' 0.241	-
(13) 'Writing'	-	-	(14) 'Close up vision' 0.222 (17) 'Following a line of print' 0.238	More appropriate to have an item relating to reading (17) 'following a line of print' rather than (18) 'writing'
(37) 'Making eye contact'	F-statistic p=0.0017	-	-	-
(14) 'Close up vision'	-	-	(12) 'Seeing faces' 0.223 (17) 'Following a line of print' 0.231	More appropriate to retain an item related to reading (17) 'following a line of print'
(12) 'Seeing faces'	-	-	(11) 'Seeing something far away' 0.235	(11) 'Seeing something far away' more general item, more appropriate to assess the impact of reduced vision
(1) 'Blurred vision'	-	-	(11) 'Seeing something far away' 0.220	More appropriate (11) 'seeing something far away' to cover the difficulties with reduced vision
(25) 'Change in colour perception'	-	-	(24) 'Adjusting to differing lighting'0.213	More stroke survivors complain of difficulty with lighting than colour
(48) 'Taking medication'	-	-	(51) 'Looking after appearance' 0.190	-
(57) 'Not coping'	-	-	(58) 'Self-conscious' 0.154	-

9.3.3.3*: Deletion of item 26 'Dry eyes'*

The 'dry eyes' item was deleted solely due to having the largest fit residual (3.949) and a significant Chi square result (<0.0001).

9.3.3.4*: Deletion of item 27 'Watery eyes'*

The 'watery eyes' item was deleted due to having the largest fit residual (4.100) which had increased from the previous analysis, and significant Chi square (<0.0001) and F statistic (<0.0001) results.

9.3.3.5*: Deletion of item 7 'Double vision'*

The 'double vision' item was deleted due to having the largest fit residual (3.882) and significant Chi square (<0.0001) and F-statistic (0.0002) results. Significant uniform DIF for the primary visual impairment person factor was demonstrated (<0.0001). Participants with ocular motility defects demonstrated more severe scores than the other types of visual impairment. This is understandable clinically as participants with ocular motility defects are those most likely to experience diplopia (100). Local dependence with item 8 'judging distances' (0.214) was also identified. It was judged more appropriate for the 'judging distances' item to cover the difficulty with loss of binocular vision as this can also be affected by reduced visual acuity, severe visual field loss and visual perception defects.

9.3.3.6*: Deletion of item 3 'Deterioration of vision'*

The 'deterioration' item was deleted due to having the largest fit residual (3.707). Local dependence with item 1 'blurred vision' (0.321), item 4 'fluctuation' (0.212) and item 10 'seeing far side of room' (0.212) was identified. This item had previously also had a local dependence with item ii 'overall vision', which potentially highlights a difficulty with the concept of this item. There are no specifics regarding deterioration over what period of time and if this was pre- or post-stroke onset.

9.3.3.7*: Deletion of item 6 'Eyes seeing differently'*

The 'eyes seeing differently' item was deleted due to having the largest fit residual (3.476) and a significant Chi square result (<0.0001). Local dependence with item 4 'fluctuation'

(0.257) and item 8 ‘judging distances’ (0.186) was identified. There is potentially a difficulty with the concept of this item. The question has two potential meanings, resulting in it being unclear. Firstly, the level of vision in each eye separately but at the same time point, or alternatively the level of vision in with both eyes open over different time points.

9.3.3.8*: Deletion of item 30 ‘Crossing the road’*

The ‘crossing the road’ item was deleted due to having the largest fit residual (3.151). Significant uniform DIF for the location (<0.0001) person factor was demonstrated. Participants who were outpatients at the time of questionnaire completion had more severe scores than inpatients. This is due to inpatients not yet having experienced crossing the road and therefore responding that they do not have difficulty with this activity. Local dependence with item 28 ‘moving around on uneven ground’ (0.243), item 32 ‘moving around in unfamiliar places’ (0.355) and item 35 ‘moving around outdoors’ (0.380) was identified. It is understandable clinically that these items are dependent on each other; crossing the road occurs outdoors and often involves stepping on and off the pavement.

9.3.3.9*: Deletion of item 32 ‘Moving around in unfamiliar areas’*

The ‘moving around in unfamiliar areas’ item was deleted due to having the smallest fit residual (-2.919) beyond the lower limit of -2.5. Significant uniform DIF for the location person factor was demonstrated (<0.0001). Participants who were outpatients at the time of questionnaire completion had more severe scores than inpatients. This was surprising as it could be assumed that being away from your own home in hospital would be considered an unfamiliar area. Local dependence with five other items was identified; item 28 ‘moving around on uneven ground’ (0.264), item 29 ‘trips and falls’ (0.210), item 31 ‘moving around in familiar areas’ (0.258), item 33 ‘bumps into or against objects or people in crowded areas’ (0.384) and item 35 ‘moving around outdoors’ (0.265). The local dependence in this case is clinically understandable; all relate to moving around.

9.3.3.10*: Deletion of item 43 ‘Limit of how long activities can be done for’*

The ‘limit of how long activities can be done for’ item was deleted due to having the smallest fit residual (-2.961). Local dependence with item 41 ‘loss of confidence’ (0.240), item 42 ‘accomplishing as much as would like’ (0.436) and item 44 ‘usual standard’ (0.322) was

identified. It is understandable clinically that these items are dependent on each other; all relate to being able to perform activities.

9.3.3.11*: Deletion of item 41 'Loss of confidence'*

The 'loss of confidence' item was deleted due to having the smallest fit residual (-2.725). Local dependence with item 42 'accomplishing as much as would like' (0.438) and item 44 'usual standard' (0.269) was identified.

9.3.3.12*: Deletion of item 39 'Participating in indoor social activities'*

The 'participating in indoor social activities' item was deleted due to having the smallest fit residual (-2.520) and a significant F-statistic result (0.0003). Local dependence with item 37 'making eye contact' (0.218), item 38 'dealing with strangers' (0.223) and item 40 'participating in outdoor social activities' (0.447) was identified. All these items make up the 'socialising' sub-category and it is understandable clinically that these items are dependent on each other.

9.3.3.13*: Deletion of item 52 'Household chores'*

The 'household chores' item was deleted due to having significant Chi-square (0.0007) and significant F statistic (<0.0001) results. The fit residual was within the accepted boundaries at -2.375. Local dependency with item 50 'preparing something to eat' (0.251), item 51 'looking after appearance' (0.207) and item 53 'shopping' (0.520) was identified. All these items are from the 'independent living' sub-category and it is understandable clinically that these items are dependent on each other.

9.3.3.14*: Deletion of item 38 'Dealing with strangers'*

The 'dealing with strangers' item was deleted due to having a significant F-statistic result (0.0006). The fit residual was within the accepted boundaries at -2.312. Local dependence with item 37 'making eye contact' (0.401) and item 40 'participating in outdoor social activities' (0.187) was identified. Clinically it is more appropriate for 'making eye contact' to cover the difficulty with social interaction. This would cover people the person knows as well as strangers.

9.3.3.15*: Deletion of item 21 'Noticing objects off to the side'*

The 'noticing objects off to the side' item was deleted due to significant uniform DIF for the primary visual impairment person factor (<0.0001). Participants with visual field loss and visual inattention demonstrated more severe scores than the other types of visual impairment. This is understandable clinically as individuals with visual field loss are those most likely to have peripheral vision problems (100). The items fit residual (2.139) was within the accepted boundaries, but in comparison to other items it was relatively high. Local dependence with item 19 'objects suddenly appearing' (0.349), item 20 'missing patches of vision' (0.571) and item 33 'bumps into or against objects or people in crowded areas' (0.268) was identified. It is understandable clinically that these items are dependent on each other, as all relate to loss of peripheral vision.

9.3.3.16*: Deletion of item 22 'Missing patches of vision'*

The 'missing patches of vision' item was deleted due to significant uniform DIF for the primary visual impairment person factor (<0.0001). Participants with visual field loss and visual inattention demonstrated more severe scores than the other types of visual impairment. Local dependence with item 19 'objects suddenly appearing' (0.486) and item 33 'bumps into or against objects or people in crowded areas' (0.306) was identified. Clinically this is understandable for the same reasons as for the 'noticing objects off to the side' item.

9.3.3.17*: Deletion of item 33 'Bumps into or against objects or people in crowded areas'*

The 'bumps into or against objects or people in crowded areas' was deleted due to significant uniform DIF for the location person factor (<0.0001). Participants who were outpatients at the time of completion had more severe scores than inpatients. This is due to inpatients not yet having to navigate crowded areas and therefore responding that they do not have difficulty with this activity (score of zero). Local dependence with item 19 'objects suddenly appearing' (0.239), item 28 'moving around on uneven ground' (0.296), item 29 'trips and falls' (0.219) and item 35 'moving around outdoors' (0.218) was identified. It is understandable clinically that these items are dependent on each other, either because they are related to peripheral vision loss or describe areas that may increase the risk of bumping into things.

9.3.3.18*: Deletion of item 35 'Moving around outdoors'*

The 'moving around outdoors' item was deleted due to significant uniform DIF for the location person factor (<0.0001). Participants who were outpatients at the time of completion had more severe scores than inpatients. This is due to inpatients not yet having to navigate outdoors and therefore responding that they do not have difficulty with this activity. Local dependence with item 28 'moving around on uneven ground' (0.207), item 40 'participating in outdoor social activities' (0.219), item 53 'shopping' (0.226) and item 60 'stay at home' (0.183) was identified. It is understandable clinically that these items are dependent on each other, either because they are activities which require outside movement or reversely, with the 'stay at home' item, going outside maybe being avoided.

9.3.3.19*: Deletion of item 16 'Using a computer'*

The 'using a computer' item was deleted due to significant non-uniform DIF for the time since stroke person factor (<0.0001). Participants in the hyperacute stage post-stroke had more severe scores in the higher ability class interval. Local dependence with item 17 'following a line of print' (0.188) was identified. Clinically this is understandable as using a computer involves reading. It would therefore be more appropriate for 'following a line of print' to cover these difficulties as it also covers printed mediums, despite having the larger fit residual of the two items.

9.3.3.20*: Deletion of item 19 'Objects suddenly appearing'*

The 'objects suddenly appearing' item was deleted due to significant uniform DIF for the primary visual impairment person factor (<0.0001). Participants with visual field loss and visual inattention demonstrated more severe scores than the other types of visual impairment. This is understandable clinically as individuals with visual field loss and visual inattention are those most likely to have peripheral vision problems (100).

9.3.3.21*: Deletion of item 28 'Moving around on uneven ground'*

The 'moving around on uneven ground' item was deleted due to significant uniform DIF for the location person factor (<0.0001). Participants who were outpatients at the time of completing had more severe scores than inpatients. This is due to inpatients not yet having to attempt this activity and therefore responding that they do not have difficulty. Local

dependence with item 29 'trips and falls' (0.239) was identified. It is understandable clinically that these items are dependent as trips and falls are more likely on uneven ground.

9.3.3.22 *Deletion of item 23 'Seeing in bright light'*

The 'seeing in bright light' item was deleted due to significant uniform DIF for the location (0.0003) person factor. Participants who were outpatients at the time of completing had more severe scores than inpatients. Local dependence with item 22 'seeing in poor or dim light' (0.302) and item 24 'adjusting to differing lighting' (0.586) was identified. All three items are from the lighting subsection. It would be more appropriate for 'adjusting to differing lighting' to cover the difficulty with lighting as this would address both bright and dim lighting conditions.

9.3.3.23*: Deletion of item 10 'Seeing far side of a room'*

The 'seeing the far side of a room' item was deleted due to consistent and highest degree of local dependence with item 11 'seeing something far away' (0.508). Clinically it would be more appropriate for 'seeing something far away' to cover the difficulty associated with reduced vision in the distance. Local dependence with item 12 'seeing faces' (0.253) was also identified.

9.3.3.24*: Deletion of item 44 'Usual standard'*

The 'usual standard' item was deleted due to now having the highest degree of local dependence with item 42 'accomplishing as much as would like' (0.493). Clinically it would be more appropriate for item 42 to cover the difficulty associated with achieving tasks a person needs to achieve.

9.3.3.25*: Deletion of item 54 'Bathing or showering'*

The 'bathing or showering' item was deleted due to local dependence with four items; item 31 'moving around in familiar areas' (0.296), item 45 'toileting' (0.492), item 46 'getting dressed' (0.437) and item 50 'preparing something to eat' (0.320). Of these, three activities of daily living (ADLs) are involved with personal hygiene, of which 'getting dressed' is the item which is potentially most dependent on vision. Between items 45 'toileting' and 54

'bathing and showering' which had the largest degree of local dependence, item 54 had the fit residual furthest from zero (perfect fit) at -1.501.

9.3.3.26*: Deletion of item 22 'Seeing in poor or dim light'*

The 'seeing in poor or dim light' was deleted due to having the highest degree of local dependence with item 24 'adjusting to differing lighting' (0.435). The item 22 'seeing in poor or dim light' fit residual was furthest from zero at 0.923. It had already been proposed that it would be more appropriate for 'adjusting to differing lighting' to cover the difficulty with lighting as this would cover both bright (already deleted) and dim lighting conditions (Section 9.3.3.22).

9.3.3.27*: Deletion of item 45 'Toileting'*

The 'toileting' item was deleted due to having the highest degree local dependency with item 46 'getting dressed' (0.496). Of these items 'getting dressed' is the activity which is potentially most dependent on vision and therefore would be most appropriate to remain in the instrument. Local dependency with item 50 'preparing something to eat' (0.229) was also identified.

9.3.3.28*: Deletion of item 47 'Eating'*

The 'eating' item was deleted due to having the highest degree of local dependence with item 49 'pouring a drink' (0.423). Of the two items, 'eating' fit residual furthest from zero (-0.927).

9.3.3.29*: Deletion of item 18 'Reading same print size'*

The 'reading same print size' item was deleted due to having the highest degree of local dependence with item 17 'following a line of print' (0.378). Clinically it would be more appropriate for item 17 'following a line of print' to cover the difficulty with reading, as this is a problem commonly occurring in both ocular motility defects and visual field loss (48). There is an element of item 18 'read same print size' which relies on memory of their vision prior to stroke, making it potentially difficult to answer for stroke survivors with cognitive impairment or those whose stroke onset was many months since.

9.3.3.30*: Deletion of item 60 'Stay at home'*

The 'stay at home' item was deleted due to significant non-uniform DIF for the location person factor (0.0003), which appeared in the last analysis run following the deletion of item 18. Participants who were outpatients at the time of completion had more severe scores than inpatient except in the less able class interval where the inpatient group had more severe scores. Local dependency, with item 40 'participating in outdoor social activities' (0.224), item 53 'shopping' (0.251) and item 57 'not coping' (0.174) was also identified.

9.3.3.31*: Deletion of item 4 'Fluctuation'*

The 'fluctuation' item was deleted due to having the highest degree of local dependence with item 1 'blurred vision' (0.331). Of the two items, item 4 'fluctuation' had the largest fit residual at 1.438. There is potentially a difficulty with the concept of this item. The question has at least two potential meanings, resulting in it being unclear. Firstly, fluctuation of vision over a short period of time (i.e. within the same day) or alternatively fluctuation of vision from prior to stroke to post-stroke onset. Local dependence with item 2 'objects jumping around' (0.190) was also identified.

9.3.3.32*: Deletion of item 31 'Moving around in familiar areas'*

The 'moving around in familiar areas' item was deleted due to having the highest degree of local dependence with item 29 'moving around indoors' (0.329). Of the two items, item 31 had a fit residual furthest from zero (-1.971).

9.3.3.33*: Deletion of item 56 'Vulnerable'*

The 'vulnerable' item was deleted due to having the highest degree of local dependence with item 55 'negative emotions' (0.279). Clinically it would be more appropriate to have a more general item about emotional well-being than one more specific. Local dependence with item 59 'burden to others' (0.172) was also identified.

9.3.3.34*: Deletion of item 50 'Preparing something to eat'*

The 'preparing something to eat' item was deleted due to the large amount of local dependency with five items identified within the independent living sub-section; item 46 'getting dressed' (0.245), item 48 'taking medication' (0.231), item 49 'pouring a drink' (0.196), item 51 'looking after appearance' (0.197) and item 53 'shopping' (0.184). With the aim of developing an instrument suitable for inpatients as well as outpatients to complete, the activity 'preparing something to eat' would not be possible in the former setting.

9.3.3.35*: Deleting of item 49 'Pouring a drink'*

The 'pouring a drink' item was deleted due to having the highest degree of local dependence with item 51 'looking after your appearance' (0.241). Of the two items, 'pouring a drink' had a fit residual furthest from zero at -0.264. Local dependence with item 48 'taking medication' (0.171), was also identified.

9.3.3.36*: Deleting of item 13 'Writing'*

The 'writing' item was deleted due to having the highest degree of local dependence with item 14 'close up vision' (0.222) and item 17 'following a line of print' (0.238). Clinically it would be more appropriate to have an item relating to reading rather than writing, as writing involves more skills of dexterity in addition to vision.

9.3.3.37*: Deletion of item 37 'Making eye contact'*

The 'making eye contact' item was deleted due to a significant F statistic (0.0017), which appeared in the last analysis run following the deletion of item 13.

9.3.3.38 *Deletion of item 14 'Close-up vision'*

The 'close-up vision' item was deleted due to having the highest degree of local dependency with item 12 'seeing faces' (0.223), and item 17 'following a line of print' (0.231). These two items are examples of close-up vision. It would potentially be clinically more appropriate to retain an item related to reading.

9.3.3.39 *Deletion of item 12 'Seeing faces'*

The 'seeing faces' item was deleted due to having the highest degree of local dependence with item 11 'seeing something far away' (0.235). The latter item is a more general item which is more appropriate to assess the impact of reduced vision. In addition, the 'seeing faces' item could be confused by prosopagnosia.

9.3.3.40*: Deletion of item 1 'Blurred vision'*

The 'blurred vision' item was deleted due to having the highest degree of local dependence with item 11 'seeing something far away' (0.220). Of the two items, the 'blurred vision' fit residual was furthest from zero at 1.335. Clinically it would be more appropriate for item 11 'seeing something far away' to cover the difficulties with reduced vision.

9.3.3.41*: Deletion of item 25 'Change in colour perception'*

The 'change in colour perception' item was deleted due to having the highest degree of local dependence with item 24 'adjusting to differing lighting' (0.213). Clinically, more stroke survivors complain of difficulty with lighting than changes in colour perception, and it would therefore be more appropriate for the latter to be removed from the instrument.

9.3.3.42*: Deletion of item 48 'Taking medication'*

The 'taking medication' item was deleted due to having the highest degree of local dependency with item 51 'looking after your appearance' (0.190). Of the two items, the 'taking medication' fit residual was furthest from zero at -1.274.

9.3.3.43*: Deletion of item 57 'Not coping'*

The 'not coping' item was deleted due to having the last incident of local dependency with item 58 'self-conscious' (0.154). Of the two items, the 'not coping' fit residual was furthest from zero at -2.135.

9.3.3.44*: Deleting misfitting persons*

Following item deletion to remove local dependency, after deletion of item 59 'not coping', model fit was achieved. Of the 247 participants, a total of 12 demonstrated misfit. The largest degree of misfit was a fit residual of -5.301. It was therefore decided to remove all participants with fit residuals greater than 3.0 and less than -3.0 from the analysis (n=5). This action did not improve the fit to the model further; the Chi-square result remained non-significant with Bonferroni correction (p=0.0228). The result moved further away from achieving non-significance without Bonferroni correction which would demonstrate a stronger fit. The analysis was reverted to using the full cohort of participants (n=247), so as not to impact on external construct validity. This analysis was therefore greyed out in Table 9.2 where the full summary statistics are outlined (247).

9.3.4: Fit to model achieved

Following deletion of 43 items the summary statistics improved to indicate the instrument had achieved fit with the Rasch model (Table 9.2). The fit residual means were close to zero and the standard deviation close to one for item fit (mean -0.193, SD 0.966) and person fit (mean -0.275, SD 1.235). The Chi-square item-trait interaction statistic result was non-significant with Bonferroni correction (p=0.0332).

9.3.4.1*: Individual person fit*

Of the 247 participants, eight participants (3.2%) had an extreme score, all of which had a score of zero for the whole instrument (minimum). This figure increased with the reduction of items from one individual at the outset of analysis, but not to an unreasonable level. Five participants (2.0%) had fit residuals above 2.5 (2.602 to 2.831), indicating their responses were opposite to those expected. Eight participants (3.2%) had fit residuals below -2.5 (-2.544 to -5.301), indicating their responses were too predictable, suggesting the individual was potentially not engaged. The figures of misfitting participants decreased with the reduction of items without removing any participants in the process. This may be the result of removing items whose ambiguity caused participants to guess a response. On analysis of the person factors associated with the misfitting participants no particular patterns could be found. The cognitive screen scores available for this group were also scrutinised but no pattern found.

9.3.4.2*: Individual item fit*

No items indicated misfit across the three methods of assessment; fit residuals (range 1.848 to -1.699) were all within the accepted boundaries of +2.5 to -2.5, and Chi-square tests and F-statistics were all non-significant. There were no incidences of local dependence or DIF.

9.3.4.3*: Unidimensionality*

The instrument now has only 19 items. The nine most positive items were compared against the nine most negative items. The instrument is indicated to be unidimensional by only 3.24% of the paired t-tests being significant (<0.05).

9.3.4.4*: Instrument targeting*

Targeting for the current 19-item instrument is represented in Figure 9.5. The person locations are shown above the *x*-axis representing the level of quality of life (moving left to right on the *x*-axis represents a worsening of quality of life). The item locations are shown below the *x*-axis representing the level of vision-related quality of life measured by the items (difficulty of items increasing right to left). The item locations are always centred around the figure of zero logits (247). The negative logit value of the person location (mean -1.545, SD 1.284) indicates the sample population have experienced a higher vision-related quality of life than the average of the scale, presenting evidence of a ceiling effect. Despite this apparent mistargeting, less than 5% of the sample population had extreme scores.

9.3.4.5*: Reliability*

The person separation index of the current 19-item instrument was 0.84 (Cronbach's alpha 0.90) exhibiting good interval validity.

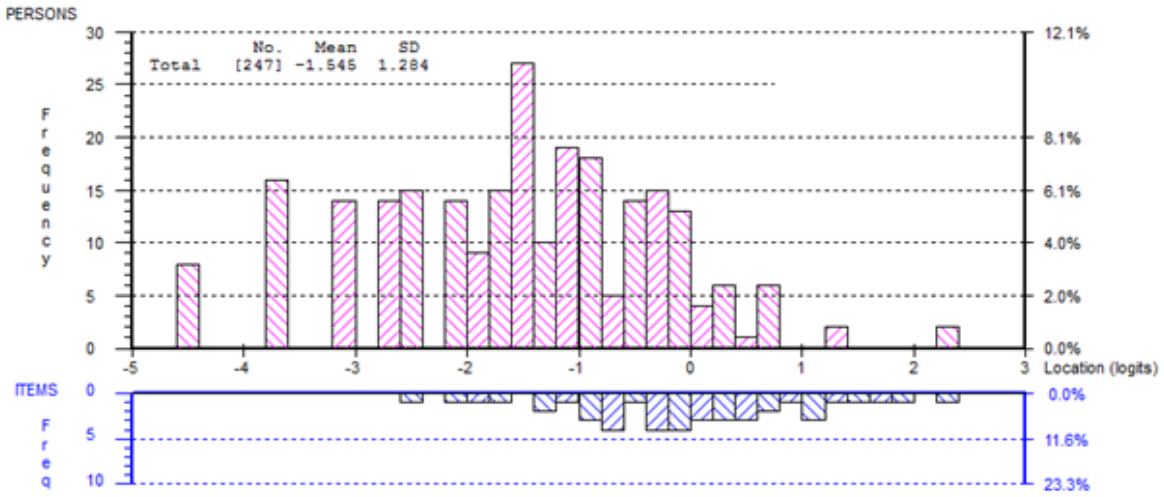


Figure 9.5: Person-item threshold distribution of the 19-item instrument following item deletion achieving fit to the model and unidimensionality; a graphical representation of targeting.

9.4: Discussion

The final analysis which achieved fit to the Rasch measurement model and unidimensionality, comprised of 19 items. The 19 items span ten of the original 12 categories. The item split between the two original overarching sections includes eight items from the vision/eyes section and 11 items from the functioning section. The two categories no longer represented are 'peripheral vision' and 'discomfort'. It is arguable that using Rasch analysis has resulted in an instrument that is a more appropriate length for a population of stroke survivors and suitable for conversion to an interval scale allowing for statistical analysis.

The analysis revealed mistargeting of the instrument. There were insufficient items to differentiate between participants with a better vision-related quality of life. This could be the result of participants with asymptomatic mild visual impairment (e.g. partial superior homonymous quadrantanopia) or a visual impairment for which the symptoms had been eliminated by treatment (e.g. diplopia joined with a prism). In these types of cases, the visual impairment may not have any impact on the individuals' vision-related quality of life.

During the analysis, the thresholds of all 62 original items were changed due to disordering. Of the 19 items remaining in the final analysis, six items had three thresholds (four categories), 12 items had two thresholds (three categories) and one item had one threshold

(dichotomous). It is clear from this analysis that the category options within version three will have to be altered.

During the process of Rasch analysis the psychometrics have led the majority of decisions on which items to remove and in which order. However, on occasion, clinical judgements were made by the author when deciding which items to delete, especially when picking between items with local dependence, resulting in some item selection being subjective. Rasch analysis selects the items with the best statistics, but this does not necessarily translate to the best items to measure vision-related quality of life of stroke survivors (278). Comparing the remaining 19 items with the results of the Delphi survey (Chapter 8), eight items did not achieve consensus and potentially are deemed less important when measuring quality of life by stroke survivors and clinicians. In order to combine the two methods of Rasch analysis (psychometrics) and the Delphi process (stroke survivor and clinician opinions), the next stage of development was to conduct a nominal group meeting.

Chapter 10

Nominal Group – Consensus Development

10.1: Introduction

The prior stages of development of the new patient reported outcome measure (PROM) for visual impairment following stroke included a Delphi process and Rasch analysis of version two of the new instrument. Rasch analysis provided detailed psychometric data of the instrument, highlighting misfitting items and items which had local dependency. Although this gave an indication of which items should be removed, clinical and lived experience was required to make decisions which are practicable in terms of the condition, the specific items and the target population.

Within the Delphi process, consensus was achieved for 34 items for inclusion within the instrument. The ideal aim for the new instrument was to have fewer than 20 items to minimise the task burden for stroke survivors completing it.

The nominal group technique was originally developed in the 1960s as a method for generating ideas (198). It has more recently been used as a vehicle for consensus development (229). The aim of this nominal group meeting, involving both stroke survivors and clinicians, was to make decisions regarding the items to include and those which could be removed. The meeting brought together the data from the Delphi process (Chapter 8), Rasch analysis (Chapter 9) and the expert group's personal knowledge and experience to inform these decisions.

10.2: Methods

Ethical approval was granted by the University of Liverpool Institute of Psychology, Health and Society Research Ethics Committee (Reference: IPHS-14145-040).

10.2.1: Participants

The participants who completed the third round of the Delphi survey were invited by email to participate in the nominal group meeting. A date on which sufficient individuals ($n \geq 5$) could attend was agreed for the meeting. The aim was to have a mixed group of stroke survivors and clinicians, with the clinicians comprising of orthoptists and occupational therapists (OTs).

10.2.2: Nominal group meeting process

The meeting began with introductions and a short study overview to set the context of the session. This included the current version of the instrument (version two), the plan of what the new instrument aims to measure and who it is aimed at, the two data analyses (Delphi survey and Rasch analysis) and the ground rules of the meeting process. The following steps were used for each task (229):

1. Verbal and written presentation of the data set with questions to consider
2. Generation of ideas and opinions in silence
3. Feedback from each participant in turn to the group, listed by the facilitator on a flip-chart for reference during the discussion
4. Group discussion regarding the feedback
5. Voting and decision agreement regarding inclusion or exclusion of items

The consensus definition used for the session when voting was “an acceptable resolution, one that can be supported, even if not the ‘favourite’ of each individual” (279).

The facilitator (the author) had expert knowledge of the subject; thereby adopting the Delbecq technique (229). The full session was audio recorded and transcribed to allow any in depth discussions to be analysed in detail.

The session was organised into ten tasks, which are outlined in Table 10.1. Each participant was given a pack which included the data sets relevant for tasks one to eight and the template for task nine. The data sets included response histograms from the final round of the Delphi survey (part one), where appropriate categorisation responses (part two) were presented, and explanations relating to Rasch analysis findings given. In addition to this, participants were given a list of all 62 abbreviated items included in version two of the instrument for reference and a copy of the full instrument (version two) was available.

Table 10.1: Overview of tasks for the nominal group process

Task One – Misfitting items	
'Deterioration'	'Dealing with strangers'
'Eyes seeing differently'	'Participating in indoor social activities'
'Dry eyes'	'Loss of confidence'
'Watery eyes'	'Limit of how long activities can be done for'
'Making eye contact'	'Household chores'
Task Two – Items with DIF for location and time since stroke person factors	
'Overall health'	'Crossing the road'
'Overall vision'	'Moving around in unfamiliar areas'
'Using a computer'	'Bumps into or against objects or people in crowded areas'
'Seeing in bright light'	
'Moving around on uneven ground'	'Moving around outdoors'
	'Stay at home'
Task Three – Items with DIF for primary visual impairment person factor	
'Double vision'	'Missing patches of vision'
'Objects suddenly appearing'	'Noticing objects off to the side'
Task Four – Items with local dependency in the general and distance vision categories	
'Blurred vision' OR 'Objects jumping around' OR 'Fluctuation'	
'Blurred vision' OR 'Seeing something far away'	
'Seeing far side of a room' OR 'Seeing something far away' OR 'Seeing faces'	
Task Five – Items with local dependency in the near vision and reading categories	
'Following a line of print' OR 'Reading same print size'	
'Writing' OR 'Close-up vision' OR 'Following a line of print'	
'Seeing faces' OR 'Close-up vision' OR 'Following a line of print'	
Task Six – Items with local dependency in the lighting, moving around and role limitation categories	
'Seeing in poor or dim lighting' OR 'Adjusting to differing lighting' OR 'Change in colour perception' (Delete 2)	
'Accomplishing as much as you would like' OR 'Usual standard'	
'Moving around in familiar areas' OR 'Moving around indoors'	
Task Seven – Items with local dependency in the independent living and moving around categories	
'Moving around in familiar areas' OR 'Toileting' OR 'Getting dressed' OR 'Preparing something to eat' OR 'Bathing or showering' (Delete 2)	
'Getting dressed' OR 'Preparing something to eat' OR 'Taking medication' OR 'Looking after your appearance' OR 'Pouring a drink' OR 'Shopping' (Delete 3)	
'Eating' OR 'Pouring a drink'	
Task Eight – Items with local dependency in the well-being category	
'Negative emotions' OR 'Vulnerable' OR 'Burden to others'	
'Not coping' OR 'Self-conscious'	
Task Nine – Rating scale labelling (See Figure 10.1)	
Task Ten – Overview of remaining items	
Any further exclusions required	

Tasks one to three dealt with items which required exclusion during Rasch analysis due to either individual item misfit or differential item functioning (DIF). The participants were asked to consider three questions for each of the items within these first three sets:

a) Are these items important to measuring vision-related quality of life?
b) If an item is important, is the topic covered by another item?
c) Can this item be excluded?

Tasks four to eight dealt with items for which local dependence had been detected. The participants were given the items in groups which had been found to have local dependence and asked to choose which item could be excluded.

During task nine the participants used the template shown in Figure 10.1, and were asked to suggest new appropriate nomenclature for the combined response options. The top row of the template showed the 5-point rating scale used in version two of the instrument, followed by with the response options that were combined during Rasch analysis (Chapter 9: Section 9.3.1.1) with blank spaces to complete.

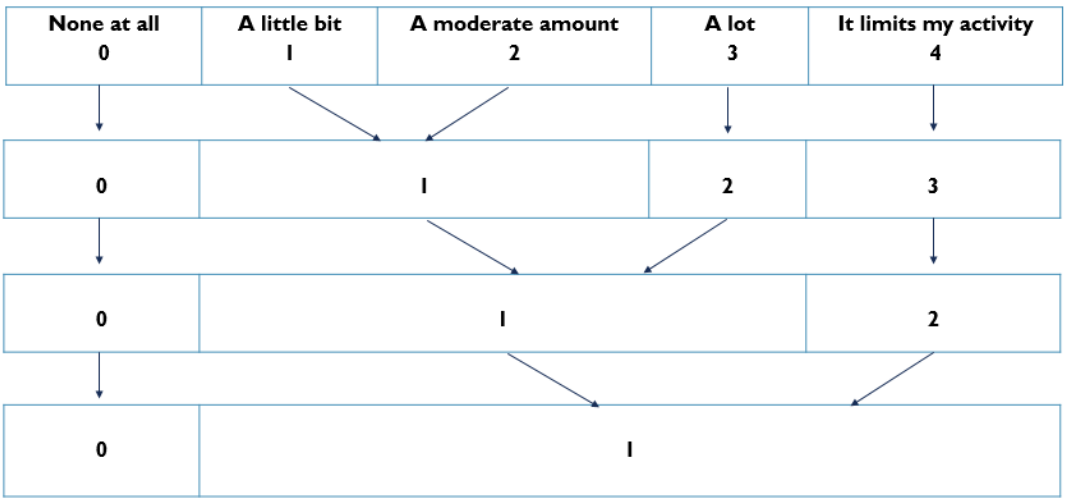


Figure 10.1: Task nine – rating scale nomenclature template

10.3: Results

The presentation of results follows the organisation of the meeting, as set out in Table 10.1.

10.3.1: Participants

Of the 47 participants who completed the third round of the Delphi survey, 14 expressed an interest in participating in the nominal group meeting (two stroke survivors, six orthoptists and six OTs). Five participants were able to attend on the day of the session (two stroke survivors, two orthoptists and one OT) to form the expert panel.

10.3.2: Task one

This task focused on ten items which were found to be misfitting during Rasch analysis and were therefore deleted. Three of the items ('deterioration', 'eyes see differently' and 'loss of confidence') had achieved consensus for inclusion during the Delphi survey.

10.3.2.1*: 'Deterioration'*

During the initial individual feedback, each participant commented on 'deterioration' as being an important question. However, the group also highlighted some flaws with the item; that is it not specific enough and that this question could be covered by other items which focus on function or specifics of how vision has deteriorated. This thread developed during the discussion with the conclusion that it could be better captured by other items.

One interpretation of the item linked it to deterioration due to a natural ageing process, rather than as a result of stroke. Later during the discussion it was put forward that if this question is unclear, *"I'm just wondering if people have just guessed"* - stroke survivor. This could be a potential cause for the items misfit.

A unanimous decision was taken by the group to discard the 'deterioration' item, despite it previously achieving consensus with the Delphi process, in view of issues with the question and potential for coverage of the issue elsewhere within the instrument.

10.3.2.2*: 'Eyes seeing differently'*

There was very little expression that this item was important. The feedback and discussion focused around the relevance of the question and that it could be covered better elsewhere in the instrument with function related items:

> *"In everyday life we have both eyes open, does it matter that the right eye and the left eye see differently, what's important really is how we function in terms of quality of life"* - orthoptist.

> *"I wonder if it could be picked up more from the functional point of view"* - OT

It was highlighted that stroke survivors may have difficulty interpreting that their eyes see differently as a problem for a number of reasons:

> *"Another aspect of stroke is you don't necessarily recognise erm, the difference in the quality of paired erm … senses, so I think it is quite hard to interpret"* - stroke survivor.

> *"Some people, most people in fact who have a visual field loss, so they have lost their vision to the left side, will say I've lost the vision in my left eye and they would answer that question to say my eyes see differently because they think their left eye has a problem"* - orthoptist.

Other items which could potentially cover the difficulties experienced if an individual has different levels of vision in each eye were identified. These included 'judging distances' and 'double vision'.

> *"Someone whose eyes see differently would more likely report that actually, I'm struggling to judge distances"* - orthoptist.

A unanimous decision was taken by the group to discard the 'deterioration' item, despite it previously achieving consensus with the Delphi process, in view of issues with the question; and more relevant items elsewhere within the instrument which would cover the issues caused by this problem.

10.3.2.3*: 'Dry eyes' and 'Watery eyes'*

These two items were talked about together by all participants, so therefore were analysed together. The independent feedback highlighted two details relating to the Delphi survey

outcomes. First that consensus to include these items had not been achieved and second that consensus was achieved to categorise that both were 'not relevant to stroke related visual impairment'. One participant disagreed with the categorisation, qualifying that if innervation of the lacrimal gland was affected this would affect eye lubrication. The majority of participants agreed that it was a more general ophthalmic issue and perhaps another item could cover eye comfort.

A unanimous decision was taken by the group to discard both the 'dry eyes' and 'watery eyes' items with the caveat that there should be an item that covers issues relating to these problems in the final selection.

10.3.2.4*: 'Making eye contact', 'Dealing with strangers', 'Participating in indoor social activities' and 'Loss of confidence'*

These four items were analysed together because they were discussed as a group during the independent feedback by several participants. It was even suggested that these items could potentially be linked together, with the overarching theme of socialising.

> *"'Making eye contact', 'dealing with strangers', 'loss of confidence' and the social interaction, I didn't know if there was a way of making those four questions into one"* - stroke survivor.

> *"There is something around communication, social, eye contact might be important"* - OT.

Whilst all of these items were considered important during the independent feedback, 'dealing with strangers' had the least support at this stage. It was highlighted that dealing with strangers did not have to be a face to face event; this interaction could occur through other mediums, for example on the phone, and would not require a vision element.

The initial feedback also revealed a personal experience relating to eye contact from one of the stroke survivors:

> *"Mainly my … family who couldn't understand why I had this inability to maintain eye contact and they found it very disturbing"* - stroke survivor.

There was an extensive discussion regarding this group of items. The discussion developed from the initial independent feedback to questioning how difficult it would be to answer

'making eye contact' and whether it has an effect on the stroke survivor's quality of life or the people surrounding them:

> *"Does everybody know if they make eye contact or not, I wonder if that's quite a difficult question to answer?"* - OT.

> *"Is it your quality of life or others quality of life? So I suppose it can affect the way people talk to you"* - OT.

Discussions also moved into the aspect of importance of non-verbal communications, with the conclusion there was more to this than solely eye contact.

A unanimous decision was taken by the group to discard the 'dealing with strangers' item in view of it not being vision specific. It was also decided that the remaining three items in this discussion would be put aside for further discussion in task ten (Section 10.3.11).

10.3.2.5*: 'Limit of how long activities can be done for'*

There was no indication that anyone thought this was an important item. Comments were made regarding it not being vision specific and trying to cover too much:

> *"I think it is important what activities the person wants to be involved in, but how long they can do them for, well how long I can get dressed for might be quite different to how long I go bowling for"* - OT.

It could be that this lack of clarity was the cause for the misfit found in Rasch analysis.

Little was said about this item in discussion. All participants were in agreement that this was a weak item and a unanimous decision was taken to discard it.

10.3.2.6*: 'Household chores'*

Participants agreed in their independent feedback that this item could be covered better in other ways. Therefore, a unanimous decision was taken to discard the item.

10.3.3: Task two

This task focused on ten items which had been found to have issues with DIF during Rasch analysis and had therefore been deleted. For the items which had DIF for more than one

person factor, only one was used for the purpose of clarity of explanation to the group. With the exception of two items 'using a computer' and 'seeing in bright light' all items achieved consensus for inclusion during the Delphi survey.

10.3.3.1*: 'Overall health'*

All participants reported in their independent feedback that this item was not relevant to vision-related quality of life and could be easily confused by multiple co-morbidities. Therefore, a unanimous decision was taken by the group to discard the item.

10.3.3.2*: 'Overall vision'*

Very little comment was provided in the independent feedback. However, it was apparent that this item was viewed as being too generic and that other more specific items were better placed to assess vision-related quality of life. These comments were the focus of a short discussion. A unanimous decision was taken by the group to discard the item.

10.3.3.3*: 'Using a computer'*

Two different opinions emerged during the independent feedback. There was a view that considered it as important, and that there was an element within this item that was not covered elsewhere in the instrument.

> *"That's really important that question and that's going to relate to the effect of their vision on the real world"* - stroke survivor.

The other view considered that it could be important but there was nothing specific about this activity that wasn't covered elsewhere. It was highlighted that the issue shown in the Rasch analysis related primarily to stroke survivors in the hyperacute stage and the group questioned how relevant this stage was to the instrument. The terminology of computer was also raised; the question already included examples of laptop and tablet. It was suggested that smart phones should also be included:

> *"I wonder whether we should be more generic, in that, in terms of a mobile device because people are going to be using … when you think of people's mobile phones now which are so smart, most people are going to be using a mobile phone no matter what their demographic"* - stroke survivor.

An important point raised was that clinicians are now prescribing rehabilitation using computers or mobile devices:

> *"I was thinking it could be a relevant question even on wards, some places do have computer training"* - orthoptist.

During the discussion which followed, the two views continued to be debated:

> *"I'm not convinced that there is anything specific about using a computer that isn't covered within other questions"* - orthoptist.

> *"I think it's so important as we all use them all the time"* - OT.

> *"When someone loses use of their computer or mobile device and they go to pieces"* - stroke survivor.

The topic of age and use of computers also arose. The debate focused around whether this item was relevant to enough of the population:

> *"The age that we're dealing with, the majority of them actually never used a computer to start with"* - orthoptist.

> *"As generations come through I think it's just going to be vital"* - stroke survivor.

> *"To make the questionnaire robust sort of for long-term … more people are going to be suffering stroke that are going to be younger"* - orthoptist.

The vote was split but the majority wanted to include the 'using a computer' item, and the remaining participant agreed that this was acceptable.

10.3.3.4*: 'Seeing in bright light'*

The report from all participants in their independent feedback was that this item could be covered better in other ways, primarily by 'adjusting to differing lighting'. This developed during the discussion as a confirmation that the group was in agreement:

> *"If you had problems adjusting, you would have a problem seeing in bright light because you wouldn't have adjusted in time and you would have problems seeing in dim light because you wouldn't have adjusted in time"* - orthoptist.

A unanimous decision was taken by the group to discard this item on the basis of duplication.

10.3.3.5: *'Moving around on uneven ground', 'Crossing the road', 'Moving around in unfamiliar areas', 'Bumps into or against objects or people in crowded areas', 'Moving around outdoors' and 'Stay at home'*

These items were all grouped together by participants as the same issue was detected for all six by Rasch analysis. There was a strong focus through the independent feedback that these items were important with the acceptance that there was some overlap and perhaps not all the items were required. A couple of participants made a link between the 'stay at home' item and loss of confidence.

> *"Stay at home, I feel we could cover that better in terms of the loss of confidence rather than specifically does someone stay at home"* - orthoptist.

The whole group accepted that most of the items within this group were not suitable for inpatients with the exception of 'bumps into or against objects or people in crowded areas' and 'moving around in unfamiliar areas'. The reason for these exceptions was the thought that the hospital ward would be an unfamiliar environment.

> *"I don't think you can really ask that question of inpatients because they have got to be able to answer that in the context of their stroke once they have had the chance to experience it and live it"* - stroke survivor.

The first point at the start of the discussion was the aim of the new instrument being relevant to both inpatients and outpatients:

> *"If you're going to try to standardise it these ones where there's a difference between outpatients and inpatients I don't think you can use"* - OT.

> *"They've got no experience have they"* - orthoptist.

> *"I mean they can answer the question but it would be meaningless"* - stroke survivor.

The level of importance of these items was further discussed with some trepidation at the thought of excluding them:

> *"I think they're really important and that's my nervousness about getting rid of them"* - OT.

> *"I wouldn't like to just completely get rid of them"* - stroke survivor.

Discussion turned to the consideration that not all the items in this group were required due to some degree of overlap, and therefore which items could be excluded. The focus was on

keeping 'moving around in unfamiliar areas', although a suggestion was made as to why inpatients reacted differently to this item:

> *"You wonder how much of that is swayed by people who haven't actually tried to get out of bed yet"* - orthoptist.

Alternatives were suggested which could potentially be applicable for inpatients, including navigation and alternative wording to the existing items.

> *"Navigation has to take far more account of cognition*" - stroke survivor.

> *"Would you feel vulnerable moving around in unfamiliar areas and then, you are then tapping into a cognition bit because you're asking the person to think about what it would feel like"* - OT.

The discussion did turn back to how the instrument would work if these items were included:

> *"You wouldn't be able to repeat that measure after someone has gone home to compare and that wouldn't work"* - orthoptist.

> *"Where you can compare, can't keep them then, I don't think you can keep them"* - OT.

> *"It's really difficult isn't it because these are really important aspects, but obviously the measure has got to work hasn't it"* - orthoptist.

A unanimous decision was taken by the group to discard these items on the basis of providing the ability to compare results between when a stroke survivor is an inpatient and following their discharge from hospital.

10.3.4: Task three

This task focused on four items which had been found to have issues with DIF during Rasch analysis for the primary visual impairment person factor and had therefore been deleted. All of these items had achieved consensus for inclusion during the Delphi survey. Both the importance and categorisation Delphi responses were available for this task.

10.3.4.1*: 'Double vision', 'Objects suddenly appearing', 'Missing patches of vision' and 'Noticing objects of to one side'*

All participants grouped these four items together due to the issue being the same. An explanation was required as to why the instrument could not have items reacting differently depending on an individual's type of visual impairment. Following the explanation that the instrument should be relevant to generalised stroke related visual impairment, discussion was very brief. A unanimous decision was taken by the group to discard these items on this basis.

10.3.5: Task four

This task focused on the items for which local dependence had been detected from the general vision and distance vision sub-categories. A decision of which item or items should be excluded was required with the aim of eradicating local dependency.

10.3.5.1*: 'Blurred vision' versus 'Objects jumping around' versus 'Fluctuation'*

The group was asked to select one item for exclusion from these three items. During the independent feedback, all participants chose the 'fluctuation' item for exclusion. This was following the results of the Delphi survey in which the other two items, 'blurred vision' and 'objects jumping around' achieved consensus for inclusion. No further discussion was required and a unanimous decision was taken by the group to discard the 'fluctuation' item.

10.3.5.2*: 'Blurred vision' versus 'Seeing something far away'*

The group was asked to select between these two items and exclude one, having previously kept 'blurred vision' in the previous decision (Section 10.3.5.1). A difference of opinion emerged during the independent feedback. Some of the group preferred the exclusion of the 'seeing something far away', while others preferred to keep this item:

> *"I got rid of 'seeing something far away' … because the importance of it is lower down and I thought it was a less clear question"* - OT.

> *"I think 'seeing something far away' to me strikes me of erm, driving and safety outdoors or indoors for that matter"* - stroke survivor.

During the discussion those who preferred the 'blurred vision' item did so as it could encompass near and distance vision, whereas 'seeing something far away' was limited to distance vision. The group discussed the other items currently available within the instrument which covered near vision.

> *"If we are going to ask about close-up and far away we also don't need to ask about blurred because that probably covers both"* - orthoptist.

The other area of discussion compared the differences between the two items and how they each fit into the instrument currently following the earlier exclusions:

> *"I just think now looking at the list a lot of what's on here is quite functional and 'seeing things far away', seeing something close to, fits into that and for me as an OT, 'blurred vision' is an element of that rather than actual activity itself"* - OT.

The participants who previously wanted to exclude 'seeing something far away' then divulged they no longer agreed with their previous decision.

> *"It's a bit more specific actually seeing it, when you think about it can you 'see something far away' because 'blurred vision' could mean anything couldn't it"* - orthoptist.

A unanimous decision was taken by the group to discard the 'blurred vision' item.

10.3.5.3*: 'Seeing far side of a room' versus 'Seeing something far away' versus 'Seeing faces'*

The group was asked to exclude two of these three items, having kept 'seeing something far away' in the previous decision (Section 10.3.5.2). A difference of opinion emerged in the independent feedback with the group split between 'seeing something far away' and 'seeing faces'. None of the group expressed a preference for 'seeing far side of a room'. For those that wished to keep 'seeing faces' their argument focused on the importance they place on being able to see people's faces during conversations. The argument against keeping 'seeing faces' involved this issue potentially being complicated by cognitive issues of not being able to recognise faces (prosopagnosia).

"Someone with prosopagnosia they might struggle to see faces but it might not be a visual concern and actually 'seeing something far away' was a bit more specific" - orthoptist.

During the discussion, this latter point was picked up by the group. The importance of 'seeing something far away' which had also featured in the prior decision resurfaced (Section 10.3.5.2). A unanimous decision was taken by the group to discard the 'seeing far side of a room' item and agreement was also reached to discard the 'seeing faces' item.

10.3.6: Task five

This task focused on the items for which local dependence had been detected from the near vision and reading sub-categories. A decision of which item or items should be excluded was required with the aim of eradicating local dependency.

10.3.6.1*: 'Following a line of print' versus 'Reading same size print'*

The group was asked to select one item for exclusion from these two items. Two lines of reasoning were put forward through the independent feedback.

"Implicit within 'reading same size print' is also, can be following print" - stroke survivor.

"Can you actually read, can you actually follow a line of print, regardless, you could make it bigger so it doesn't matter so much" - orthoptist.

These opposing lines of reason were discussed and clarified:

"Often you can read the print in terms of you can see the words but then not actually able to follow the line and then find the next line which impacts on the reading ability" - orthoptist.

A unanimous decision was taken by the group to discard the 'reading same size print' item.

10.3.6.2*: 'Writing' versus 'Close-up vision' versus 'Following a line of print'*

The group was asked to exclude one of these three items, having kept 'following a line of print' in the previous decision (Section 10.3.6.1). A difference of opinion emerged during the independent feedback. Some of the group preferred the exclusion of the 'writing' item, while others preferred to exclude 'close-up vision':

> *"'Writing' … I think it is involving so many other skills, it's not just vision, so I don't think that's relevant in that case"* - stroke survivor.

> *"Kept 'writing' because it is a clearly defined activity"* - OT.

> *"Get rid of 'close-up vision' because if you can follow a line of print hopefully you can see"* - stroke survivor.

The discussion focused on the relevance of a question regarding the act of writing in a time when technology is so prevalent:

> *"Writing is actually becoming quite old school isn't it"* - stroke survivor.

> *"It's a dying skill isn't it"* - orthoptist.

> *"Try to future proof this questionnaire for as long as possible"* - stroke survivor.

A unanimous decision was taken by the group to discard the 'writing' item.

10.3.6.3*: 'Seeing faces' versus 'Close-up vision' versus 'Following a line of print'*

The group were asked to exclude one of these three items. However, discussion was not required as 'seeing faces' had already been excluded in a previous decision (Section 10.3.5.3).

10.3.7: Task six

This task focused on the items for which local dependence had been detected within a mixture of different sub-categories; lighting, role limitation and moving around. A decision of which item or items should be excluded was required with the aim of eradicating local dependency.

10.3.7.1*: 'Seeing in poor or dim lighting' versus 'Adjusting to differing lighting' versus 'Change in colour perception'*

The group was asked to select two of these three items for exclusion. During the independent feedback, all participants chose to keep the 'adjusting to differing lighting' item. This related back to previous discussion involving the 'seeing in bright light' item (Section 10.3.3.4). No discussion was required and a unanimous decision was taken by the group to discard the 'seeing in poor or dim light' and 'change in colour perception' items.

10.3.7.2*: 'Accomplishing as much as would like' versus 'Usual standard'*

The group was asked to select between these two items and to exclude one. During the independent feedback, all participants chose the 'accomplishing as much as would like' item for exclusion. The reasons given to keep 'usual standard' included:

> *"closely linked to vision"* - stroke survivor.

> *"something they could measure"* - stroke survivor.

No discussion was required and a unanimous decision was taken by the group to discard the 'accomplishing as much as would like' item.

10.3.7.3*: 'Moving around in familiar areas' versus 'Moving around indoors'*

The group was asked to select one item for exclusion from these two items. A difference of opinion emerged during the independent feedback. Some of the group preferred the exclusion of the 'moving around in familiar areas', while others preferred to exclude 'moving around indoors':

> *"I thought 'moving around in familiar areas' could be the work place, could be at home, could be going to their local shops, it could cover a lot of different areas'* - stroke survivor.

> *"I had 'moving around indoors' because I thought … it didn't matter if you've got familiarity if you can't see things then you are more likely to make mistakes"* - stroke survivor.

During the discussion it was agreed that there is significant overlap between these two items. There was also a return to the previous issue of relevance to inpatients and outpatients:

"'Moving around indoors' is more relevant to people who are inpatients and outpatients" - stroke survivor.

"Indoors seems more relevant than if it's familiar or unfamiliar" - orthoptist.

The participants who previously wanted to exclude 'moving around indoors' then divulged they had changed their minds, resulting in a unanimous decision by the group to discard the 'moving around in unfamiliar areas' item.

10.3.8: Task seven

This task focused on the items for which local dependence had been detected, mainly within the independent living sub-category. A decision of which item or items should be excluded was required with the aim of eradicating local dependency.

10.3.8.1*: 'Moving around in familiar areas' versus 'Toileting' versus 'Preparing something to eat' versus 'Getting dressed' versus 'Bathing and showering'*

The group was asked to exclude two of these five items. However, 'moving around in familiar areas' had previously been excluded in a previous decision which therefore accounts for one exclusion (Section 10.3.7.3). All of these items achieved consensus for inclusion during the Delphi survey. During the independent feedback 'toileting', 'preparing something to eat' and 'getting dressed' were suggested for exclusion:

"If you are bathing and showering yourself, hopefully you can get yourself undressed and dressed and hopefully get yourself to the toilet" - stroke survivor.

"'Preparing something to eat' because I didn't feel it was as relevant for inpatients because they don't necessarily get the opportunity to prepare something to eat" - orthoptist.

The discussion focused on the activities which were more reliant on vision:

"I'm minus 12 short-sighted and I wouldn't ever get dressed without my glasses on because you wouldn't even know what I would end up in but you obviously would shower without glasses on and if you get up in the night to go to the toilet you wouldn't put your glasses on to do it" - orthoptist.

It was also discussed that 'toileting' in the Delphi survey had been ranked very highly and a potential reason for this may have been impact on general quality of life, and relation to loss of dignity rather than specifically vision-related quality of life. A unanimous decision was taken by the group to discard the 'toileting' item.

10.3.8.2*: 'Getting dressed' versus 'Preparing something to eat' versus 'Taking medication' versus 'Looking after appearance' versus 'Pouring a drink' versus 'Shopping'*

The group was asked to exclude three of these six items. Four of these items achieved consensus for inclusion during the Delphi survey with the exception of 'pouring a drink' and 'shopping'. During the independent feedback all items were suggested for exclusion. The most common item suggested for exclusion in the independent feedback was the 'taking medication' item, as participants considered this to be covered by other items relating to close-up vision and reading.

At the start of the discussion the focus turned to prior arguments regarding the relevance to inpatients and outpatients:

> *"You don't get much opportunity to shop in the hospital do you?"* - stroke survivor.

> *"One of the most powerful arguments to remove it"* - stroke survivor.

This discussion had occurred in relation to the 'preparing something to eat' item in the previous step (Section 10.3.8.1). The group agreed very quickly that 'shopping' and 'preparing something to eat' were strong candidates for exclusion. The discussion then focused on the remaining four items to identify the third item suitable for exclusion. Points raised during the independent feedback relating to 'taking medication' were revisited.

A unanimous decision was taken by the group to discard the 'preparing something to eat', 'shopping' and 'taking medication' items.

10.3.8.3*: 'Eating' versus 'Pouring a drink'*

The group was asked to select between these two items and exclude one. The 'eating' item achieved consensus within the Delphi survey. During the independent feedback, all participants put 'pouring a drink' forward for exclusion, primarily because it is covered

elsewhere within the instrument. The discussion highlighted the importance of 'eating' to quality of life and vision within that activity:

> *"You can taste food better when you can see it can't you"* - stroke survivor.

A unanimous decision was taken by the group to discard the 'pouring a drink' item.

10.3.9: Task eight

This task focused on the items for which local dependence had been detected within the well-being sub-category. A decision of which item or items should be excluded was required with the aim of eradicating local dependency.

10.3.9.1*: 'Negative emotions' versus 'Vulnerable' versus 'Burden to others'*

The group was asked to select between these three items and exclude one. All items within this group achieved consensus within the Delphi survey. Both 'negative emotions' and 'vulnerable' were suggested for exclusion during the independent feedback:

> *"I deleted 'vulnerable' just because I felt it ['negative emotions'] was quite nice that it gives examples of how people might be feeling"* - orthoptist.

> *"Many people who we have contact with say how vulnerable they feel and how they hate having to ask people to help them so they hate being a burden to others"* - stroke survivor.

A common thread of discussion was the large degree of overlap between these items. Further discussion specifically involved the 'burden to others' item, being a difficult question to ask:

> *"You almost feel like it puts the idea into their head"* - orthoptist.

> *"It's a loaded question"* - stroke survivor.

There was a suggestion within the discussion that the examples list within the 'negative emotions' item could be added to:

> *"So could you add the 'vulnerable' and 'burden to others' in with that 'negative emotions' as in with the example"* - orthoptist.

A unanimous decision was taken by the group to amalgamate 'vulnerable' into the example list of the 'negative emotions' item, leaving 'burden to others' as a separate item.

10.3.9.2*: 'Not coping' versus 'Self-conscious'*

The group was asked to select between these two items and exclude one. The 'not coping' item achieved consensus within the Delphi survey. During the independent feedback, all participants chose the 'self-conscious' item for exclusion. No discussion was required and a unanimous decision was taken by the group to discard the 'self-conscious' item.

10.3.10: Task nine

The group was asked to make suggestions for the nomenclature associated with the 5-point rating scales following the combining of response options during Rasch analysis. The suggestions put forward in independent feedback are outlined in Figure 10.2. These suggestions fell into two different categories. Some followed the original nomenclature relating to amount of difficulty, and others followed a nomenclature relating to frequency (181). No discussion was requested for this task. These suggestions will be taken into account when building version three of the instrument.

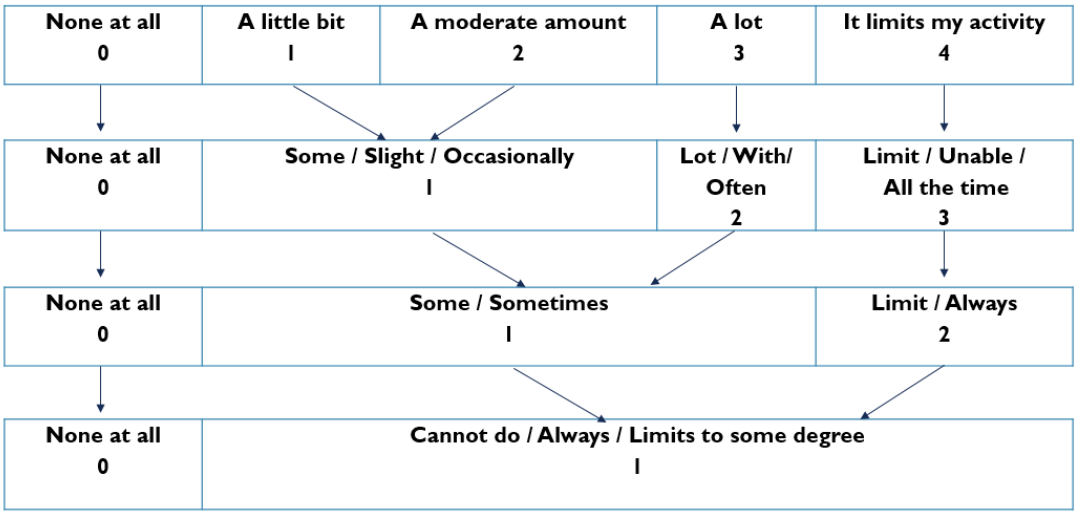


Figure 10.2: Rating scale nomenclature suggestions

10.3.11: Task ten

The group was presented with the remaining items following the exclusions which were agreed in tasks one to eight. In total 23 items remained, which are outlined in Table 10.2. These items included three items which had been found to misfit as part of the Rasch analysis and no decision had been made in task one; 'making eye contact', 'participating in indoor social activities' and 'loss of confidence'.

The majority of the items had been discussed during tasks one to eight. The items were discussed by the group in order, either individually or on occasion bringing together items which overlapped to discuss as a collection.

Table 10.2: Remaining items to consider in task ten following exclusions in tasks one to eight

4. Objects jumping around	39. Making eye contact
7. Tired eyes	41. Participating in indoor social activities
10. Judging distances	42. Participating in outdoor social activities
11. Unusual appearance	43. Loss of confidence
13. Seeing something far away	46. Usual standard
16. Close-up vision	48. Getting dressed
17. Finding something	49. Eating
18. Using a computer	53. Looking after appearance
19. Following a line of print	56. Bathing and showering
26. Adjusting to differing lighting	57. Negative emotions
31.Trips and falls	59. Not coping
36. Moving around indoor	61. Feeling a burden
38. Travelling as a passenger	

10.3.11.1*: 'Objects jumping around'*

A short discussion took place which reflected previous conversation relating to items that asked about symptoms not effect, and items which were specific to certain conditions:

> *"If we are applying the same rules to what we have applied all the way along and we're being consistent we need to get rid of that don't we"* - orthoptist.

Items were identified which cover the potential effects of 'objects jumping around', such as 'following a line of print' and 'trips and falls'. A unanimous decision was taken by the group to discard the 'objects jumping around' item.

10.3.11.2*: 'Tired eyes'*

The discussion in relation to this item focused on the meaning of the question and what it covered; whether this related to eye strain, or at the other end of the spectrum, neurological fatigue. The discussion also related back to two previously excluded items 'dry eyes' and 'watery eyes', and whether this item was suitable to cover the *"uncomfortable"* - OT or *"eyes feeling prickly"* - stroke survivor, caused by those conditions. It was agreed that this question is separate to one about tiredness or sleepiness. A unanimous decision was taken by the group to keep the 'tired eyes' item within the instrument in its current form.

10.3.11.3*: 'Judging distances'*

Following a very short discussion about the importance of this item to vision-related quality of life, a unanimous decision was taken by the group to keep the 'judging distances' item within the instrument in its current form.

10.3.11.4*: 'Unusual appearances'*

The discussion revolved around the relevance of this item. It was also raised if this question had the potential to be specific to a particular type of visual impairment, such as ocular motility problems. A unanimous decision was taken by the group to exclude the 'unusual appearance' item.

10.3.11.5*: 'Seeing something far away' and 'Close-up vision'*

Although these two items were not linked by the group, they quickly agreed that there had been a lot of discussion for both 'seeing something far away' (Section 10.3.5) and 'close-up vision' (Section 10.3.6) and this did not need to be repeated. A unanimous decision was taken by the group to keep both the 'seeing something far away' and 'close-up vision' items within the instrument in their current form.

10.3.11.6*: 'Finding something'*

A short discussion occurred focusing on the importance of this item and the lack of coverage for this problem elsewhere within the instrument.

> *"If we take that out we lose that ability for someone to actually be able to pick out something from other objects, yeah, when other things are around, that whole crowding effect, so I don't think we can cover that in anything else"*
> - orthoptist.

A unanimous decision was taken by the group to keep the 'finding something' item within the instrument with a simplification of the wording.

10.3.11.7*: 'Using a computer', 'Following a line of print' and 'Adjusting to differing lighting'*

Although these three items were not linked by the group, they quickly agreed that there had been a lot of discussion for the 'using a computer' (Section 10.3.3.3), 'following a line of print' (Section 10.3.6) and 'adjusting to differing lighting' (Sections 10.3.3.4 and 10.3.7.1) items and this did not need to be repeated. However, the number of young stroke survivors was highlighted again in relation to the 'using a computer' item. A unanimous decision was taken by the group to keep the 'using a computer', 'following a line of print' and 'adjusting to differing lighting' items within the instrument in their current form.

10.3.11.8*: 'Trips and falls'*

The facilitator highlighted the poor wording and lack of clarity of this item in its current form. The group expressed that it is an important issue to ask about in relation to vision-related quality of life, especially with the exclusion of items such as 'moving around on uneven

ground'. In view of this importance a discussion regarding new focus and clarity of the question followed:

> *"Do you think it should cover the fear of tripping and falling or do you think it should be … have you had trips and falls"* - facilitator.

The group reflected that the fear of trips and falls could potentially target both inpatients and outpatients.

> *"It's still an impact if you don't get out of bed because you're scared of tripping and falling. Just because you haven't fallen yet doesn't mean it's not having an impact"* - orthoptist.

A unanimous decision was taken by the group to keep the 'trips and falls' item within the instrument with an alteration of the item wording.

10.3.11.9*: 'Moving around indoors'*

The discussion began with an assessment of other items in the remaining list which related to moving around. The only other remaining item relating to moving in the instrument was the reworded 'trips and falls' item (Section 10.3.11.8). It was suggested that the wording of this item should be changed to become more generic:

> *"How people navigate, not necessarily indoors, outdoors, familiar, unfamiliar, it doesn't really matter, it's just how do people actually get from A to B wherever that might be"* - orthoptist.

The wording *"getting around"* - orthoptist, was put forward. With this change of wording a unanimous decision was taken by the group to keep the 'moving around indoors' item in a new format of 'getting around'.

10.3.11.10*: 'Travelling as a passenger'*

A short discussion reflected previous conversation relating to items that were not suitable for inpatients:

> *"In the context of what we've been discussing we can't ask inpatients about travelling as a passenger in a car"* - orthoptist.

A unanimous decision was taken by the group to discard the 'travelling as a passenger' item.

10.3.11.11*: 'Making eye contact'*

The discussion returned to earlier points of whether it would be the quality of life of the person completing the question that is affected by difficulty with eye contact (Section 10.3.2.4). A unanimous decision was taken by the group to discard the 'making eye contact' item on the grounds it did not fit within the purpose of the current instrument.

10.3.11.12*: 'Participating in indoor social activities' and 'Participating in outdoor social activities'*

The initial discussion linked these two items with a suggestion for merging the two items together, removing the specifics of indoors and outdoors:

> *"Could it not just be participating in social activities?"* - stroke survivor.

This was supported by further discussion of the 'participating in outdoor social activities' not being relevant to inpatients. There was also discussion around whether inpatients participate in social activities, and it was agreed that hospital visiting and group sessions could be considered as social activities. A unanimous decision was taken by the group to technically exclude the 'participating in indoor social activities' and 'participating in outdoor social activities' items, with a wording change to create a new item 'participating in social activities'.

10.3.11.13*: 'Loss of confidence', 'Not coping' and 'Burden to others'*

The initial discussion quickly linked these three items as potentially overlapping:

> *"There's a few here that overlap isn't there, there's the 'not coping', the 'feeling a burden', there's the 'loss of confidence' it just feels like we've got a lot of questions on a very similar theme"* - orthoptist.

The importance of the 'loss of confidence' item was expressed. Another link was made between 'loss of confidence' and the newly formed item 'fear of tripping and falling'. A suggestion was made that the concept of loss of independence could encompass two of the items originally grouped together:

> *"Is 'feeling a burden' and 'not coping' all about loss of independence"* - stroke survivor.

The group liked the term independence and took this forward into further discussion with potential of forming a new item.

> *"If we got rid of 'feeling a burden' and 'not coping' and had something about accepting help or loss of independence"* - orthoptist.

The discussion then reverted back to the 'loss of confidence' item and whether this needed to be a separate item or could be covered by the new item. A unanimous decision was taken by the group to technically exclude the 'loss of confidence', 'not coping' and 'burden to others' items and creating a new item 'doing things for yourself'.

10.3.11.14*: 'Usual standard'*

At the start of the discussion, the opinion among the group was that this item did not fit with the rest of the items in the instrument. It was not relevant to ask about 'usual standard' because the way in which activities are done may have changed post-stroke. The wording of the question was also described as *"negatively loaded"* - orthoptist. The group returned to the discussions in task six, when they were asked to select one item from two; the group at the time excluded 'accomplishing as much as would like' (Section 10.3.7.2). The discussion then switched to the positives for the 'accomplishing as much as would like' item:

> *"At no point are we really asking people are you doing everything that you want to do, is this getting in the way, of actually, what you want to be achieving"* - orthoptist.

There was some debate if the 'accomplishing as much as would like' would be a suitable question for inpatients. It was agreed that one of these questions was required within the instrument. Rewording of 'accomplishing as much as would like' was discussed, and it was agreed that if reference to usual activities was avoided, it could be relevant to an inpatient population.

> *"I think there's a question there somewhere about how vision affects what you want to do"* - stroke survivor.

A unanimous decision was taken by the group to technically exclude the 'usual standard' and 'accomplishing as much as would like' items with a wording change, creating a new item 'doing what you want to do'.

10.3.11.15*: 'Getting dressed', 'Eating', 'Looking after appearance' and 'Bathing and showering'*

The group discussed these four items relating to ADLs together. The start of the discussion reverted back to previous conversations relating to 'bathing and showering' not being vision-specific and that 'getting dressed' is more appropriate to cover these activities (Section 10.3.8.1):

> *"You don't really need your vision to bath and shower"* - orthoptist.

There was short discussion as to whether 'eating' was covered by the 'close-up vision' item.

A unanimous decision was taken by the group to exclude the 'bathing and showering' item and to keep the 'getting dressed' and 'looking after appearance' items. The decision was taken to leave the 'eating' item until further analysis was conducted.

10.3.11.16*: 'Negative emotions'*

The group quickly agreed that there had been a lot of discussion for this item, and that this did not need to be repeated (Section 10.3.9.1). A unanimous decision was taken by the group to keep the 'negative emotions' item within the instrument with vulnerable added to the examples list.

10.3.12: Check for local dependence

Following the nominal group meeting, the items that were excluded unanimously were deleted from the instrument using the RUMM 2030 software (253). The wording of some of the items was altered during the nominal group process. For the purpose of checking for any residual local dependence the origin of the new item was used. An example of this would be, 'participating in outdoor social activities' which was the origin for the new 'participating in social activities' item. The 17 items which were included in this analysis are outlined in Table 10.3.

No items indicated misfit and the instrument was unidimensional. However, there were two residual incidences of local dependence. One incidence was between 'eating' and 'looking after appearance'. The other incidence was between 'close-up vision' and 'following a line of print'.

Table 10.3: Items used to check for any residual local dependence following exclusions in the nominal group process

7. Tired eyes	36. Moving around indoors
10. Judging distances	42. Participating in outdoor social activities
13. Seeing something far away	44. Accomplishing as much as would like
16. Close-up vision	48. Getting dressed
17. Finding something	49. Eating
18. Using a computer	53. Looking after appearance
19. Following a line of print	57. Negative emotions
26. Adjusting to differing lighting	61. Feeling a burden
31. Trips and falls	

10.3.13: Electronic nominal group

Further item exclusion was required with the detection of two incidences of residual local dependence within the 17 items remaining after the nominal group process. The participants of the nominal group were emailed with the items requiring discussion, along with the relevant round three Delphi survey responses. The participants were asked to reply to the whole group with their thoughts replicating the independent feedback at the meeting. Following discussion another email requested a vote of which items were to be excluded, replying only to the facilitator.

10.3.13.1*: 'Eating' versus 'Looking after appearance'*

The group quickly agreed that there had been discussion towards the end of task ten which put the presence of the 'eating' item into question (Section 10.3.11.15). A unanimous decision was taken by the group to discard the 'eating' item.

10.3.13.2*: 'Close up vision' versus 'Following a line of print'*

During the independent feedback, the participants all expressed that this was a difficult choice. The participants also expressed views on how the two items interacted with each other:

"Close-up vision was only a component of reading a line of print" - stroke survivor.

"You need to have the ability to see up close to be able to see a line of print" - stroke survivor.

The discussion via email moved onto discussing the ability of the 'close-up vision' item to cover a multitude of activities. This was countered by concern of including too many generic items and that there are several specific activities which require near vision already included within the instrument. The group then returned to the importance and specificity of the 'following a line of print' item:

"'Following a line of print' is so important, and one of the things many people do complain about. 'Following a line of print' involves so much more than vision itself, eye movements for following as well as visual field to see what's coming next" - orthoptist.

A majority decision was taken by the group to discard the 'close-up vision' item.

10.4: Discussion

This nominal group process brought together two different methodologies in order to create version three of the new instrument. Whilst taking account of the Delphi survey results, the expert panel were presented with more information about the items, especially in relation to DIF and local dependence.

The expert panel was at the smaller end of what is recommended for a nominal group (280). The panel did have representation from the three key stakeholders (stroke survivors, OTs and orthoptists). Within the group there was a mix of more vocal and less vocal individuals. Due to the nature of the methods of nominal group each person was able to express their opinion and partake in the discussion and decision making (281).

Through the nominal group process, the expert panel created a set of rules which aided them with decision making. One of these rules came from the aims for the instrument which were outlined in the introduction; i.e. the application to both inpatient and outpatient populations. Another rule was self-created to shape the instrument using items which were important when measuring vision-related quality of life. This included the exclusion of symptom related items. The group considered that difficulty with a symptom did not

necessarily correspond to an impact on quality of life. The group favoured items which focused on specific activities which individuals either need to perform, or do for enjoyment.

The instrument has been reduced to 15 items, which are listed in Table 10.4. The 15 items span ten of the original 12 categories. The two categories which are no longer represented are 'peripheral vision' and 'discomfort'.

In addition to reducing the number of items within the instrument, the expert panel also refined the wording of five items. This was for mixture of reasons: 1) to clarify what the question was asking, as was the case with the 'trips and falls' item, 2) to dispense with the specifics of indoors and outdoors, as with the socialising items, and 3) to enable a new item to be created from the combination of two or more items, which was the case in the creation of 'doing things for yourself'.

The next step of development involved bringing together the decisions and suggestions made during this nominal group process to create version three of the new instrument. A comparison of the three methods used in this development process (Delphi survey, Rasch analysis and nominal group) will also be conducted.

Table 10.4: Items to be included in the final version of the new instrument

How much difficulty do you have, due to your eyes or eyesight with…..?
1. Tired eyes
2. Judging distances
3. Seeing something far away
4. Finding something
5. Using a computer
6. Following a line of print
7. Adjusting to differing lighting
8. Fear of tripping and falling
9. Getting about
10. Socialising
11. Doing what you want to do
12. Getting dressed
13. Looking after your appearance
14. Feeling negative emotion
15. Doing things for yourself

Chapter 11

Development of the final version of the new instrument

11.1: Overview

The aim of this project was to evaluate the impact of stroke related visual impairment on quality of life. The literature reviews (Chapter 3 and 4) identified that a wide range of instruments were currently being used to assess the impact of visual impairment following stroke, but that there were no existing instruments which specifically targeted this population group.

Due to the lack of a 'gold standard' development method for patient reported outcome measures (PROMs), two common methods of instrument development were used. Rasch modelling was chosen for the psychometric analysis, in view of the current move away from Classical Test Theory (44). The use of a Delphi process allowed the incorporation of stroke survivor and frontline clinician experiences and viewpoints. These two methods were united using a nominal group process; involving a group of experts comprising stroke survivors and clinicians. The final product of the instrument would have been constructed very differently if each method had been used in isolation. The outcomes from each method are compared within this chapter, along with formation of version three, comparison of the new instrument to pre-existing tools and plans for future work with the new instrument.

Stroke survivors and clinicians have been involved at every stage of the process in order to create an instrument suitable for measuring the impact on quality of life caused by the visual impairments associated with stroke.

11.2: Comparison of methods

If the three round Delphi process had been used in isolation, the instrument would have had the largest number of items; if the items which reached consensus during this process had been used to formulate version three it would have comprised of 34 items. If Rasch analysis with minimal clinical input had been used in isolation the instrument would have comprised of 19 items. The result of drawing these two methods together with an expert group of individuals in a nominal group meeting led to the final version of the instrument comprising 15 items.

The individual items selected by each method are outlined in Table 11.1. Nine of the final 15 items were selected by all three methods. Of the remaining six items, five were selected within Rasch analysis but did not achieve consensus in the Delphi survey. One item, 'using a computer', was selected only during the nominal group process. Another item, 'objects

jumping around', was selected by both the Delphi survey and Rasch analysis which was not then selected during the nominal group.

Whilst the Delphi survey selected a much larger number of items than the other methods, it would still have been possible to include them all in a final version. However, it is important to consider the task burden to patients in terms of both length of the instrument and relevance of items (282). Within the items selected for inclusion by the Delphi survey there were items which were not relevant to all types of visual impairment following stroke as highlighted by the potential hub and spoke model (Chapter 8, Figure 8.71). Rather than considering the instruments specific items, it is possible to consider the broader categories considered important by the Delphi participants, and compare to the outcomes of the other two methods. The Delphi survey achieved consensus for over half of the items within the following categories: general vision, reading, peripheral vision, moving around, role limitation, independent living and well-being. Within version three of the instrument all these categories had good representation, with the exception of peripheral vision. If the category originally contained a large number of items (≥5 items), version three included two items from that category. The peripheral vision category was completely removed from version three, as all items within it had been found to be specific to stroke survivors with visual field loss during Rasch analysis. The participants of the Delphi survey did not consider the following categories critical, with fewer than half the items achieving consensus: distance vision, near vision, lighting, discomfort and socialising. These categories were all represented in version three, with the exception of discomfort. Of the five items included in the final version from these categories, all were considered 'important but not critical', and a maximum of 4.1% of the group responded using the 'not important' category.

The benefit of using the three methods was that it enabled the robustness of the psychometrics provided by Rasch analysis to be informed by the experiences, values and perspectives of stroke survivors and frontline clinicians (19). Although item deletion in Rasch analysis can be informed subjectively using theory or clinical knowledge, there is often very little detail in the literature about how these decisions are made or who has informed them. Involving stroke survivors and frontline clinicians in the decision process has allowed the creation of an instrument which is able to measure vision-related quality of life using items which are considered important by these stakeholders. The relevance to individuals created by using a bottom-up methodology has the potential to improve content validity and the instruments usage (283).

Table 11.1: Items included within each method of development

Items		Delphi	Rasch	Nominal Group / Version 3
i	Overall health	√		
ii	Overall vision	√		
1	Blurred vision	√		
2	Objects jumping around	√	√	
3	Deterioration of vision	√		
4	Fluctuation			
5	Tired eyes		√	√
6	Eyes seeing differently			
7	Double vision	√		
8	Judging distances	√	√	√
9	Unusual appearance		√	
10	Seeing far side of a room			
11	Seeing something far away		√	√
12	Seeing faces	√		
13	Writing			
14	Close-up vision			
15	Finding something		√	√
16	Using a computer			√
17	Following a line of print	√	√	√
18	Reading same print size			
19	Objects suddenly appearing	√		
20	Missing patches of vision	√		
21	Noticing objects off to the side	√		
22	Seeing in poor or dim light			
23	Seeing in bright light			
24	Adjusting to differing lighting		√	√
25	Change in colour perception			
26	Dry eyes			
27	Watery eyes			
28	Moving around on uneven ground	√		
29	Tripping and falling	√	√	√ *
30	Crossing the road	√		
31	Moving around in familiar areas	√		
32	Moving around in unfamiliar areas	√		
33	Bumping into or against objects or people in	√		
34	Moving around indoors	√	√	√ *
35	Moving around outdoors	√		
36	Travelling as a passenger		√	
37	Making eye contact			
38	Dealing with strangers			
39	Participating in indoor social activities			
40	Participating in outdoor social activities		√	√ *
41	Loss of confidence	√		
42	Accomplishing as much as would like	√	√	√ *
43	Limit of how long activities can be done for			
44	Usual standard			
45	Toileting	√		
46	Getting dressed	√	√	√
47	Eating	√		

48	Taking medication	√		
49	Pouring a drink			
50	Preparing something to eat	√		
51	Looking after appearance	√	√	√
52	Household chores			
53	Shopping		√	
54	Bathing or showering	√		
55	Feeling negative emotions	√	√	√
56	Feeling vulnerable	√		
57	Not coping	√		
58	Feeling self-conscious		√	
59	Feeling a burden to others	√	√	√ *
60	Staying at home	√		

√ Single selection √ Double selection √ Triple selection * Reword /new

11.3: Limitations within the project

11.3.1: Literature reviews

The searches for the three literature reviews were conducted at the beginning of the project and updated prior to publication. The literature reviews (Chapters 2 - 4) have not been updated with the findings of a more recent search as they heavily influenced the project going forward, in that it was these reviews which indicated the need for a new instrument. The literature was re-explored in March 2017. New relevant articles were found, eight for the prevalence and recovery review (Chapter 2) (7, 284-290), two for the quality of life review (Chapter 3) (290, 291) and four for the PROMs review (Chapter 4) (292-295). However, the conclusions of the three reviews would not have been altered by this new evidence.

11.3.2: Stroke survivor input

Although stroke survivor input was sought at every stage of the development process, it was not possible to achieve sufficient numbers of stroke survivors with visual impairment required for them to have the majority voice or vote. This was especially true at the nominal group session for item reduction of version one, where only one of the three stroke survivors was able to attend. There was no contingency for late involvement of other stroke survivors and the meeting went ahead with one stroke survivor present. An attempt was made to seek the input from those unable to attend by sending them material after the meeting to comment on. The number of stroke survivors with visual impairment involved with the Delphi survey was also less than anticipated.

11.4: Version three

11.4.1: Rating scale

During Rasch analysis the number of response options on the rating scale was reduced for all items (Chapter 9, Section 9.3.1.1). This was done to achieve threshold ordering; the maximum number of response options possible was maintained during this process. Of the 15 items remaining following the nominal group process, the majority of items allowed three response options (n=8), six items allowed four response options and one item required two response options (dichotomous). Rasch analysis was used to assess which best suited the model; a 3-point or a 4-point rating scale. For the purpose of this analysis the origin of the

new item was used, as was done for the post-nominal group analysis (Chapter 10, Section 10.3.12). The model fit and unidimensionality were stronger using the 4-point rating scale (three thresholds) across all the items. The project team therefore decided to reduce the number of response options for all items from five in version two to four in version three. Keeping the maximum number of response options improves the potential sensitivity of the instrument to detect change (248). As the instrument requires further validation, it is consequently best to have four categories, which later can be collapsed further using Rasch analysis. However, if three categories were to be used, the data related to a fourth would not be collected.

An aim in the development of this instrument was to apply the same rating scale with the same number of options for each item. The reason for standardising the rating scale in this way was in view of the target population. Cognitive impairment is a potential consequence of stroke (4). It was important that version three was developed to be as simple a task as possible to reduce cognitive load and increase the likelihood of accurate and meaningful responses.

The additional benefit of the rating scale being consistent across the whole instrument allows for future development into a preference based measure for use in economic evaluation (296). The resulting rating scale scores each item from 0 'none' to 3 'limits activity' or 'unable to do', with the no response scored as 0 (perceived as no difficulty experienced). The maximum possible score on the 15-item scale would be 45, indicating the highest impact.

11.4.2: Formatting

The order and layout of the version three of the new instrument has been carried forward from version two. This decision was based on the minimal amount of missing data in the version two pilot study (0.1%). The formatting was commented on by three stroke survivors, who suggested small adjustments with regard to column widths.

11.5: Comparison to literature

To assess how the content of version three compares to existing vision-specific instruments, the systematic narrative review of the impact of visual impairment following stroke on quality of life was used to identify sub-categories which displayed reduced scores (Chapter

3, Section 3.3.3.2). The NEI VFQ-25 used by five studies had six common subscales with reduced scores for stroke survivors with visual field loss compared to healthy individuals: general health, general vision, near activities, vision-specific mental health, driving and peripheral vision (130, 133-136). Of these six subscales, version three of the new instrument included items related to three. The sub-categories not included in version three, general health, driving and peripheral vision, had all been included in either version one or two of the instrument, and subsequently removed for a variety of reasons; not relevant to the majority of the target population or not relevant to measuring vision-related quality of life. One study included in the review had a study population with reduced visual acuity in addition to visual field loss. As a consequence, the list of sub-categories with reduced scores was extended: general vision, near vision, distance vision, social functioning, vision-specific mental health, role difficulties and dependency (130). Version three contains items covering all these sub-categories. This demonstrates that version three has incorporated items relevant to the sub-categories which potentially reveal the impact of visual impairment following stroke. It must be highlighted that the samples of these studies used as comparison were predominantly stroke survivors with visual field loss. There were no studies found in the review which investigated the impact of ocular motility defects using a vision-specific PROM. One study has used the NEI VFQ-25 to assess vision-related quality of life in a small sample with spinocerebellar ataxia of which 63.2% of participants had at least one ocular motor defect (297). They found reduced scores when compared to a normal reference population in the following sub-categories: general vision, near vision, distance vision, driving, peripheral vision, vision-specific role difficulties, dependency, social functioning and mental health. These subcategories are similar to those raised with co-existing visual field loss and reduced central vision (130). Version three has items which would be grouped into seven of these nine sub-categories. The two exceptions are driving and peripheral vision; the reasons for these disparities were explained above. This comparison has exhibited that version three has face validity, as it contains items in sub-categories which have previously demonstrated an impact of visual impairment associated with a neurological cause.

In terms of size and the number of items, version three of the new instrument is the smallest of the vision-related PROMs previously used with stroke survivors. Using the quality assessment modified from Pesudovs *et al.* and Hamzah *et al.*, which was completed on all relevant existing PROMs as part of the review process (Chapter 4) (45, 142). Version three of the new instrument scored 13 out of 14, equivalent to the Activity Inventory (AI), the Daily Tasks Dependent on Vision (DLTV) questionnaire and the Veterans Affairs Low Vision Visual

Functioning (VA LV VFQ) questionnaire (176). In the review of existing instruments (Chapter 4), both the AI and DLTV were found to have a serious flaw in the question wording when using the instrument with individuals with co-existing non-ocular deficits, in that there was no reference to vision or eyesight (156, 175). The VA LV VFQ had a potential high task burden with up to 192 items. Three alternative instruments which had not previously been validated with stroke survivors were identified in the review; the Impact of Vision Impairment (IVI), the Vision-related Quality of Life (VQoL) questionnaire and Visual Symptom and Quality of Life (VSQ) questionnaire (162, 164, 165). Both the IVI and VQoL measure frequency, i.e. "In the past month, how much has your eyesight interfered with …" (164, 165). These questionnaires would not be appropriate for use close to onset of the condition. An element of memory is also required to answer these items, which may cause difficulties in the presence of cognitive impairment. The VSQ does contain some items measuring frequency but this is not standardised throughout the whole instrument. During the development of the new instrument these elements were avoided, with all questions specifying "difficulty due to your eyes or eyesight" and the rating scale measuring the amount of difficulty experienced at the time of completion.

On the unmodified development section of the quality assessment tool, version three of the new instrument scored well, with a total of 14 out of 16. The area of development identified as being weaker was the failure to remove all items with floor and ceiling effects (45). Items with floor or ceiling effects were not removed at this stage due to the risk of removing the 'easier' or 'harder' items from the instrument. The quality assessment tool for PROMs only advocates for consultation with patients during the item identification stage of development (45). The development of the new instrument employed consultation with stroke survivors throughout the development process including item identification, item selection and scoring.

This study has been able to demonstrate the new instrument fulfils some of the criteria considered to be important when selecting a PROM (23, 36). Unidimensionality has been demonstrated using Rasch analysis indicating internal consistency (23). Face and content validity can be argued due to the employment of stroke survivors and clinicians at every stage of development (298). This involvement also aids with creating an acceptable instrument. However, version three has not yet been assessed in its current form. Other criteria are yet to be satisfied and require testing in a further validation study specifically; precision, reproducibility, construct validity and responsiveness (23).

11.6: Future validation project

Further validation is now required following the amendments made to items during the nominal group process, and for potential broadening of the target population. An overview of the planned validation process is outlined in Figure 11.1.

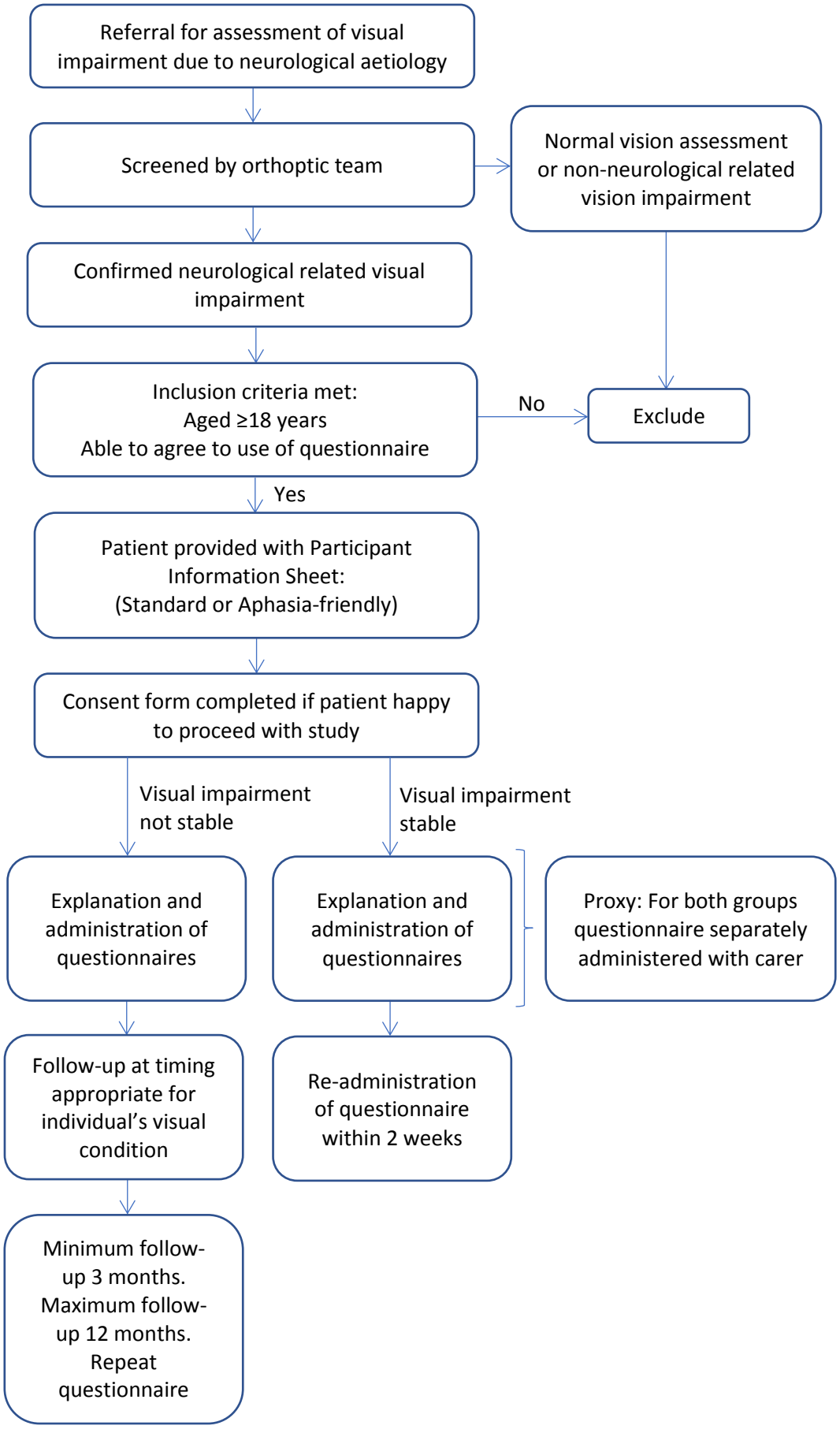
11.6.1: Target population

The decision was taken by the project team to broaden the target population of the new instrument to include brain injury and other neurological conditions. This had always been a potential for the new instrument. It was initially developed using stroke survivors, as the visual sequelae of stroke is broad and can include visual field loss, ocular motility defects, reduced central vision and visual perception problems (9-12). Stroke can also result in numerous other sequelae occurring simultaneously, such as physical disability, communication problems and cognitive impairments (4). The visual impairments associated with a stroke can also result from other neurological aetiologies, such as traumatic brain injury (TBI), space occupying lesions, vascular, inflammation, e.g. multiple sclerosis (MS), infection, e.g. meningitis and degeneration, e.g. Parkinson's disease. These conditions can also be associated with other global signs and symptoms affecting mobility, communication and cognition.

The questionnaire was developed to be suitable for any of the four main categories of visual impairment. The population sample completing the version two pilot had a range of dependency as measured by the Barthel Index, indicating it is suitable to measure vision-related quality of life in the presence of other impairments.

A future validation study is required to evaluate if this instrument is suitable to be used with a population with broader neurological conditions. This is particularly important as the individuals involved in the development of the instrument were all stroke survivors. It is also essential due to the alterations made to the wording of four items from version two, it is yet unknown how these 'new' items will work with either a stroke survivor or a broader neurology population.

Figure 11.1: Overview of validation study process



11.6.2: Other instruments for the extended target population

There are currently other vision-specific instruments available for this wider population. These include the Impact of Vision Impairment Scale (IVIS), the Neuro 10 supplement to the NEI VFQ-25 (Neuro 10) and Brain Injury Vision Symptom Survey Questionnaire (BIVSS) (144, 299, 300).

The IVIS comprises five items within the Multiple Sclerosis Quality of Life Inventory (MSQLI) with a total of between 81 and 138 items. Of the five items, three relate to near vision and reading and the remaining two relate to distance vision. It is advised that the MSQLI be used in its entirety rather than separate instruments, limiting the isolation of the vision-related impact on quality of life (299).

The Neuro 10 supplement has previously been discussed in the systematic narrative review of existing PROMs (Chapter 4). This supplemental instrument was originally developed to target individuals with MS, with particular focus on those with ocular motility defects (144). This targeting resulted in four of the ten items being specific to impairments linked to ocular motility defects. The implication of this is a lack of relevant items for other visual impairments which occur as a result of neurological disease or brain injury, such as visual field loss, reduced central vision and visual perception problems.

The BIVSS is a 28-item instrument aimed at assessing the presence and frequency of visual symptoms following brain injury, rather than the impact these have on quality of life (300).

There is a lack of instruments available for this wider target population for measuring the impact of the variety of visual impairments resulting from neurological disease or brain injury. In view of plans to extend the target population in a future validation study, a suggested name for the instrument going forward is the Brain Injury related Visual Impairment Quality of Life questionnaire (BIVI-QoL). Version three, the BIVI-QoL can be seen in Appendix 4. The BIVI-QoL fills this gap in the tool box, but needs validation to evaluate its use with these wider neurological populations, including TBI, space occupying lesions, stroke, MS and Parkinson's disease.

11.6.3: Validation options

Alongside the validation of the BIVI-QoL administered either by self-completion or in interview format, other formats and administration methods are also planned. This includes the development of an aphasia friendly version of the 15-item BIVI-QoL, preventing the

exclusion of individuals within the target population due to communication difficulties. Participants would be given the format which was best-suited to their individual circumstances.

Included in the validation process would be an assessment of test-retest reliability and sensitivity to change. Participants known to have a stable visual impairment would be asked to complete the questionnaire again at a minimum interval of two weeks (14 days) and a maximum interval of four weeks (28 days) of the original completion to assess test-retest reliability. These time intervals were chosen as a balance between allowing for memory decay and minimize likelihood of actual clinical change (301, 302). Participants with a visual impairment with unknown stability i.e. acute stage would be asked to complete the questionnaire again at their next clinical visit. No restriction would be placed on the interval to the next completion. For this group of participants, clinical anchors of improvement or deterioration in their visual impairment would be required as a comparison, to assess the responsiveness of the instrument (303). These clinical measures will be different depending on the type of visual impairment diagnosed. These could include; perimetry for visual field loss, cancellation task for visual inattention, visual acuity for reduced central vision and ocular motility measurements for ocular motility defects. Reading assessment (acuity, speed and accuracy) could potentially be relevant to the majority of visual impairment. Objective measurements are not possible for some visual impairments, for example visual hallucinations, and may have to rely on subjective reports of change since their last visit.

In addition to making the instrument accessible for individuals with communication difficulties, a proxy administration method would also be tested. This would involve asking a carer to complete the questionnaire on the patients' behalf. The definition of a carer could include a nurse that knows the patient well, in addition to spouses and other family members. This opens the potential for the assessment of impact on quality of life in individuals who are not able to complete a standard questionnaire for themselves. However, the subjective nature of quality of life using a proxy potentially introduces the risk of bias of carer opinion including the effect of the condition on the carers own quality of life (304-306). The administration using a proxy requires good inter-rater reliability. This could be assessed by asking a participant who is able to answer themselves and their carer to complete the questionnaire independently and comparing the responses.

The BIVI-QoL would need to be validated against what is perceived as the current 'gold standard' for measuring the quality of life of stroke survivors with visual impairment. This

process requires referral back to the completed systematic narrative reviews, which informed the initial development of version one. The systematic narrative review investigating what was known about quality of life with visual impairment post-stroke (Chapter 3), highlighted that the instrument most commonly used by past studies was the NEI VFQ-25 (Neuro 10) (139). The NEI VFQ-25 (Neuro 10) scored highly in the quality appraisal of existing instruments in the systematic narrative review of PROMs and was found to have been used in a wide variety of visual conditions allowing for comparisons (Chapter 4) (176). Another instrument would be required to measure general health-related quality of life. The European Quality of Life Score (EQ-5D) is the 'gold standard' for this purpose. The EQ-5D is used to measure quality of life in long-term conditions within the NHS as outlined in the NHS outcomes framework since 2011 (307).

Rasch analysis would be performed on the completed questionnaire data to reassess fit to the model, presence of misfitting items, unidimensionality and local dependence with the aim of converting the raw data to an interval scale (45, 254). The sample size required to achieve this would be the same as the pilot study of version two; 243 completed questionnaires. A sub-sample would also be randomly selected from the non-stable and stable groups for qualitative one-to-one interviews. Due to the targeting of the new instrument, it is an important part of a future study to assess if the instrument can capture impact on quality of life when it is present, but subtle.

11.7: Conclusion

Prior to this body of work, there were no PROMs specifically designed to measure the impact of visual impairment following stroke on quality of life. In conclusion, the BIVI-QoL questionnaire is presented; a 15-item instrument reporting quality of life for individuals with visual impairment related to stroke. A validation study is now required to confirm that the BIVI-QoL is an effective tool in an extended target population of neurological disease or brain injury, that it is unidimensional, and through using Rasch analysis creates an interval measurement for use in both clinical and research settings.

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Appendices

Appendix 1

Descriptive analysis of patient-reported outcome measures

Activities of Daily Vision Scale (ADVS)	
Aim	To assess visual function in patients with cataracts to assess timing for surgery for use in research and clinical settings. Intended population: patients with cataracts
Item identification	Item identification *Literature review/other instruments:* No *Lay focus group:* 15 cataract patients *Expert focus group:* No *Expert opinion:* 6 Ophthalmologists (308) *Views of stroke patients considered:* No
Item selection	A pilot instrument was developed and questions were eliminated from the draft questionnaire on the basis of factor analysis (308, 309). Rasch analysis reduced to 15 items with a compromise between good item fit and precision (310). Further Rasch analysis reduced to 8-items predominantly from the near vision scale (ADVS-Near Vision Scale) (311).
Population with which instrument was validated	Patients scheduled for cataract extraction (308, 310, 311) Elderly community (309)
Actual content area	Distance vision activities Near vision activities Glare disability Night and daytime driving
Scale	Ordinal 5-point scale: 1 ‘do not do the activity because of vision problems’ to 5 ‘not difficult at all’ Reduced to a 4-point scale. Combining points 2 and 3 to create ‘a lot of difficulty’ (311, 312).
Method of administration	Interview (309, 312) Self-administration (311)

Activity Inventory (AI)	
Aim	Assess functional history and visual ability Intended population: patients with visual impairment
Item identification	*Literature review/other instruments:* Yes *Lay focus group:* No, 30-45 minute interviews conducted with 3200 patients *Expert focus group:* No *Expert opinion:* Yes, 17 American Academy of Optometry diplomats in low vision were surveyed (313) *Views of stroke patients considered:* No
Item selection	A pilot questionnaire (3 objectives, 24 goals and >200 activities) was developed using the Activity Breakdown Structure (313). During testing patients were able to suggest additional activities relevant to them which were not included. Modification following pilot study resulted in the tool containing 41 goals and 337 activities (314). Further Rasch analysis made no changes to included items (315).
Population with which instrument was validated	Patients attending the low vision service (ARMD, glaucoma, diabetic retinopathy, refractive disorders, cataract, corneal disorders and other conditions causing visual impairment) (314). In addition to the above listed conditions; stroke, brain injury and developmental disorders (156), ocular injuries and retinal detachments (150).
Actual content area	Daily living Social interaction Recreational activities (313) Alternative subcategories: Visual information Mobility Reading Visual motor (156)
Scale	Ordinal 6-point scale: 0 ‘not important’ to 5 ‘extremely important’ and ordinal 6-point scale: 0 ‘not difficult’ to 5 ‘extremely difficult or impossible’ (313) Following Rasch analysis categories 1 and 2, and 3 and 4 were collapsed to create a 4 point scale: 0 ‘not difficult’ to 3 ‘impossible’ (156, 314)
Method of administration	Interview (150, 156, 314)

Adaptation to Age-related Vision Loss scale (AVL)	
Aim	To assess the psychological adaptation of older people to visual impairment Intended population: older patients with visual impairment
Item identification	*Literature review/other instruments:* Yes *Lay focus group:* No *Expert focus group:* No *Expert opinion:* No *Views of stroke patients considered:* Unclear
Item selection	A pilot 33-item questionnaire was developed, through initial testing the number of items reduced to 24 (316). The number of items was reduced again to develop a short-form of the questionnaire. The decisions to remove 10 items were based on skewness, interviewer feedback, missing data and low correlations. A further 2 items were removed through factor analysis resulting in the AVL-12 (317). Rasch analysis was performed on the original AVL-24, in order to achieve unidimensionality 5 items were deleted and a further 3 misfitting items were removed (318).
Population with which instrument was validated	Patients older than 65 years with visual impairment (316). Older patients with visual impairment (glaucoma, cataract, ARMD and diabetic retinopathy) (317). Patients with cataracts (318)
Actual content area	Acceptance of the vision loss Attitudes towards rehabilitative training Attitudes towards relationships with family members and friends
Scale	'Agree' or 'disagree' (316) Ordinal 4-point scale: 3 'strongly agree' to 0 'disagree' (317)
Method of administration	Interview (316)

Adult Strabismus Quality of Life questionnaire (AS-20)	
Aim	Evaluate health-related quality of life in adults with strabismus Intended population: adults with strabismus
Item identification	*Literature review/other instruments:* No *Lay focus group:* No – 30 individual interview with patients *Expert focus group:* No *Expert opinion:* No *Views of stroke patients considered:* Unclear
Item selection	The draft questionnaire developed contained 181 items from unique statements from the patient interviews. This was reduced to 20 items using factor analysis (159). Rasch analysis reduced the questionnaire by two items (hobbies and depth perception) to 18 items (161).
Population with which instrument was validated	Patients with childhood and acquired strabismus (159).
Actual content area	Psychosocial Function Subscales were divided following Rasch analysis: Self-perception Interactions Reading function General function (161)
Scale	Ordinal 5-point scale: 100 'never' to 0 'always' plus a 'not applicable' option. Rasch analysis indicated to collapse 'never' and 'rarely' in the function subscale (161)
Method of administration	Self-administration (159, 161)

Amblyopia and Strabismus Questionnaire (ASQE)	
Aim	Evaluate health-related quality of life in patients with amblyopia and strabismus Intended population: adults with strabismus
Item identification	*Literature review/other instruments:* Existing questionnaires *Lay focus group:* Yes *Expert focus group:* No *Expert opinion:* No *Views of stroke patients considered:* No
Item selection	A pilot questionnaire was developed using themes from the patient focus group (319). Translation of Dutch version (26 items) to English (320). Rasch analysis highlighted problems with testing non-strabismic amblyopes, a reduction of 3 items was required to improve fit (321).
Population with which instrument was validated	Patients with strabismus with or without amblyopia (319-321)
Actual content area	Fear of losing the better eye Distance estimation Visual disorientation Double vision Social contact and appearance
Scale	Ordinal 5-point scale: 1 ‘none of the time’ to 5 ‘all of the time’ (319) Rasch analysis suggested the collapse of categories 4 ‘some of the time’ and 5 ‘all of the time’ (321)
Method of administration	Self-administration (320, 321)

Catquest	
Aim	Assess benefits of cataract surgery Intended population: patients before and after cataract surgery
Item identification	*Literature review/other instruments:* Yes *Lay focus group:* No, 139 patients were interviewed *Expert focus group:* No *Expert opinion:* No *Views of stroke patients considered:* No
Item selection	The questionnaire started with 37 items, this was reduced using results from patient interviews to 6 activities which were deemed to be important plus a question about the persons preferred activity, creating an 18 item questionnaire (322). Rasch analysis suggested the removal of frequency and symptom items. The remaining disability and global items were combined to create a 9-item short form measure (Catquest-9SF) (323). Another Rasch analysis agreed with the removal of the frequency items, however, kept two symptom items and one driving item – creating a 12-item questionnaire (324).
Population with which instrument was validated	Patients awaiting cataract surgery (323, 325)
Actual content area	Frequency of performing activities Perceived difficulty in performing activities Difficulties in general and satisfaction with vision Cataract symptoms
Scale	Ordinal 5-point scale: 1 'no difficulty' to 5 'cannot perform the activity because of bad vision' plus a 'cannot say' option (325) Following Rasch analysis, categories 3 and 4 in the frequency scale were collapsed (323).
Method of administration	Interview (325)

Daily Living Tasks Dependent on Vision (DLTV)	
Aim	Evaluate an individual's visual status Intended population: patients with age-related macular degeneration (ARMD)
Item identification	*Literature review/other instruments:* No *Lay focus group:* Yes – list activities which cause difficulties *Expert focus group:* No *Expert opinion:* Yes – asked for comment on patients lists *Views of stroke patients considered:* No
Item selection	A pilot question was developed using the activities suggested by patients and health care professionals, it consisted of 22 items plus 2 overall visual function rating scales (154). Item response theory analysis found two redundant items (reading correspondence and identifying money), therefore these were removed (175). Rasch analysis was performed on the original 22 item questionnaire, resulted in the removal of 5 items (adjusting to dark, objects off to one side, seeing and using steps and pouring a drink) reducing the overall questionnaire to 17 items (326).
Population with which instrument was validated	Patients with ARMD or awaiting cataract surgery with a control group from an elderly population (154). Patients with ARMD (175, 327). Patients with visual impairment following stroke (51).
Actual content area	The domains are not named (175)
Scale	Ordinal 4-point scale: 1 = 'cannot see to do' to 4 = 'no difficulty' (154) Rasch adjusted 4-point scale was found to be optimal (326)
Method of administration	Interview (175) Self-administration (327)

Diplopia questionnaire	
Aim	To assess the frequency of diplopia Intended population: patients with diplopia
Item identification	*Literature review/other instruments:* No *Lay focus group:* No *Expert focus group:* No *Expert opinion:* Yes *Views of stroke patients considered:* Unclear
Item selection	A short questionnaire was developed with 8 items, one for each position of gaze (160). The questionnaire was revised, which resulted in the removal of one item (328).
Population with which instrument was validated	Patients with acquired diplopia (160)
Actual content area	-
Scale	Ordinal 3-point scale: 'always' to 'never', weighted scores to primary and reading position (160) 'Rarely' and 'often' were added creating a 5-point scale (328)
Method of administration	Interview (160)

Glaucoma Quality of Life -15 questionnaire (GQL-15)	
Aim	Assess the impact of common disabilities suffered by patients with glaucoma Intended population: patients with glaucoma
Item identification	*Literature review/other instruments:* Yes – existing questionnaires for glaucoma and other visual conditions *Lay focus group:* No *Expert focus group:* No *Expert opinion:* No *Views of stroke patients considered:* No
Item selection	A pilot questionnaire underwent item reduction to 15 items using factor analysis (329). The GQL-15 was assessed using Rasch analysis. Items were removed to eliminate multidimensionality (reading newspaper, tripping, crossing the road, bumping into objects, recognising faces and adjusting to bright lights). The re-engineered instrument was named the Glaucoma Activity Limitation-9 (GAL-9) (330). A second Rasch analysis of the GQL-15 was completed and items were reduced to 10 and renamed Glaucoma Activity Limitation-10 (GAL-10) (331). A more recent Rasch analysis found 2 misfit items, however, removal did not improve fit statistics and concluded the original GQL-15 is valid (332).
Population with which instrument was validated	Patients with glaucoma
Actual content area	Outdoor mobility and navigation Lighting and glare Activities demanding functional peripheral vision Household tasks and personal care
Scale	Ordinal 5 point scale: 1 ‘no difficulty’ to 5 ‘severe difficulty’ plus a ‘not relevant’ option (330)
Method of administration	Self-administration (329) Combination of self-administration and interview (331) Interview (332)

Houston Vision Assessment Test (HVAT)	
Aim	Aid the decision making process when considering cataract surgery Intended population: patients with cataracts
Item identification	*Literature review/other instruments:* No *Lay focus group:* Yes *Expert focus group:* No *Expert opinion:* No *Views of stroke patients considered:* No
Item selection	A pilot questionnaire was developed containing 11 items. For each item both physical and visual impairment is estimated (180). Rasch analysis was not conducted as the rating scale could not be fixed (333).
Population with which instrument was validated	Patients awaiting cataract surgery (180)
Actual content area	Cooking Night driving Day driving Housework Leisure activities Outdoor activities Reading Taking medication Watching television Writing
Scale	Part A - ordinal 5-point scale: 0 'not at all limited' to 4 'severely limited' plus a 'not relevant' option. Part B - ordinal 6-point scale: 0 'I have no visual or other physical limitations' to 5 'all due to eyesight' (180). Rasch analysis of scales: Part B - reduced to a 4-point scale: 0 'none due to eyesight' to 3 'all due to eyesight', categories 2 and 3 were collapsed. Reanalysis indicated more adjustment to the scales was required but it could not be isolated which categories needed to be collapsed (333).
Method of administration	Self-administration (333)

Impact of Vision Impairment (IVI)	
Aim	To assess the impact of vision impairment on a visually impaired patient's ability to participate in daily life activities Intended population: patients with various visual impairments
Item identification	*Literature review/other instruments:* Existing quality of life instruments, VF-14, NEI-VFQ, VQOL and VCM1. *Lay focus group:* 53 patients with visual impairment (diabetic retinopathy, glaucoma, ARMD, cataracts, retinitis pigmentosa and congenital visual impairments) (163) *Expert focus group:* No *Expert opinion:* No *Views of stroke patients considered:* No
Item selection	A draft questionnaire (76 items) based on a combination of the VQOL and VCM1, excluding items on ocular symptoms and disability, with the addition of focus group suggestions. A reduction in items to 45 due to high correlation (167). A further 13 items were excluded due to redundancy (items in emotional domain) and floor and ceiling effects (eating and driving); factor analysis was unable to highlight items for exclusion (334). The items were reduced further by Rasch analysis to 28 due to irrelevance (work and sporting events) and ceiling effects (hobbies and reading street signs) (168). Further Rasch analysis suggested the removal of 'worry about your eyesight getting worse' due to misfit (173).
Population with which instrument was validated	People with visual impairment including ARMD, retinopathies, glaucoma, other conditions and cataract (165, 167-169, 171, 172) Patients awaiting cataract surgery (173)
Actual content area	Emotional reaction to vision loss Household care Personal care Leisure and work Mobility Social and consumer interactions Emotional well being Reading and accessing information Mobility and independence (170)
Scale	Ordinal 6-point scale: 0 = 'not at all' to 5 'all the time' (14 items) Ordinal 7-point scale: 0 'not at all' to 5 'can't do this because of eyesight' plus 8 'don't do this for other reasons' (19 items). (334) Rasch 4-point scale: 0 'low participation' to 3 'high participation' (26 items). Rasch 3-point scale: 0 'low participation' to 2 'high participation' (2 items – reading ordinary sized print and getting needed information) (168)
Method of administration	Interview (165, 167, 169, 171) Combination of interview and self-administration (168, 170, 173)

Indian Visual Function Questionnaire (IND-VFQ)	
Aim	To develop a patient defined vision function questionnaire in a population of visually impaired and blind people living in a low income country Intended population: patients with vision loss in a low income country
Item identification	*Literature review/other instruments:* No *Lay focus group:* 10 patients per group, 40 specific to diagnosis (cataracts, glaucoma, ARMD, diabetic retinopathy) and 6 mixed groups. *Expert focus group:* No *Expert opinion:* No (335) *Views of stroke patients considered:* No
Item selection	The initial pilot questionnaire (103 items) was tested with the aim of item reduction. Pre-designed exclusion criteria for items – not relevant >10% of patients (18 items excluded) and no difficulty reported by >30% of patients (40 items excluded). Resulting in a 45-item instrument. Further item reduction using missing data, redundancy and item convergent and discriminant validity producing the 33-item instrument (336). Rasch analysis resulted in a further 5 item reduction (129). Another Rasch analysis excluded one item from the visual functioning scale or activity limitation subscale (337).
Population with which instrument was validated	Patients with cataract, glaucoma, diabetic retinopathy, ARMD and no visual condition (336)
Actual content area	Visual symptoms Psychosocial impact General functioning (336) Rasch analysis altered subscales: Mobility Activity limitation or visual functioning Visual symptoms Psychosocial impact (129, 337)
Scale	Ordinal 5-point scale: 1 ‘not at all’ to 4 ‘a lot’ plus x ‘unable to carry out because of vision impairment’ (336) Rasch scale 4-point scale: 1 ‘not at all’ to 3 ‘a lot’ plus x ‘unable to carry out because of vision impairment’ (129). Rasch analysis approved original rating scale (337)
Method of administration	Interview (336, 337)

Low Vision Quality of Life questionnaire (LVQoL)	
Aim	To assess the quality of life in patient with low vision and allow evaluation of rehabilitation strategies Intended population: patients with non-treatable vision loss
Item identification	*Literature review/other instruments:* Yes – existing questionnaires assessed *Lay focus group:* No but opinion of patients with low vision sort with multidisciplinary team (MDT). *Expert focus group:* No *Expert opinion:* MDT (ophthalmologists, optometrists, orthoptists, OTs, welfare officers, audiologists and patients with low vision) (179) *Views of stroke patients considered:* No
Item selection	A pilot questionnaire was developed using questions from existing questionnaires found in literature review resulting in 74 items. Pre-designed exclusion criteria for items – not relevant >33% of patients, little or great difficulty by >65% of patients and reliability of items <0.60 – resulted in a reduction to 25 items (179).
Population with which instrument was validated	Patients with low vision diagnosed with a variety of conditions.
Actual content area	General vision Mobility Lighting issues Psychological adjustment Reading and fine work Activities of daily living
Scale	Ordinal 6-point scale: 5 ‘no difficulty’ to 0 ‘could no longer performed because of vision’ plus a ‘no longer perform because of vision’ and a ‘not relevant’ option (179)
Method of administration	RCT comparison of postal, telephone or interview (146). Self-administration (338)

Melbourne Low Vision ADL Index (MLVAI)	
Aim	Assess ability to perform activities of daily living Intended population: patients with low vision
Item identification	*Literature review/other instruments:* Yes *Lay focus group:* No *Expert focus group:* No *Expert opinion:* No *Views of stroke patients considered:* Unclear
Item selection	A pilot tool was developed which consisted of nine self-reported items and 18 observed items. Factor analysis resulted in two items (shirt buttoning, naming colours) being eliminated. Rasch analysis was also performed which highlighted redundant items, however, further item reduction did not occur at this stage due to a small sample size (339). A weighted version of the tool was created to produce personal impact estimates by completing a personal importance scale (340).
Population with which instrument was validated	Adults with ocular disease and stable visual impairment (339). Patients with ARMD (341).
Actual content area	-
Scale	Ordinal 5-point scale: 0 'very unsatisfactory' to 4 'very satisfactory' (339)
Method of administration	Clinical assessment (340, 341)

Mobility questionnaire	
Aim	To assess subjective reporting of mobility function in patient with retinitis pigmentosa Intended population: patients with retinitis pigmentosa
Item identification	*Literature review/other instruments:* Critical review – no details published *Lay focus group:* No *Expert focus group:* No *Expert opinion:* One experience mobility instructor *Views of stroke patients considered:* No
Item selection	Forty-seven items were chosen and split into two parts. Validity demonstrated by Rasch analysis, no resulting item reduction (342).
Population with which instrument was validated	Patients with retinitis pigmentosa (342) and open-angle glaucoma (343)
Actual content area	Mobility Mobility related behaviour
Scale	5-point scale: 1 'no difficulty' to 5 'extreme difficulty' plus 'not applicable' (342)
Method of administration	Self-administered (342) Interview (343)

National Eye Institute Refractive Error Correction Quality of Life Questionnaire (NEI RQL)	
Aim	To assess vision-targeted health-related quality of life for persons with well corrected refractive error Intended population: patients with refractive error
Item identification	*Literature review/other instruments:* Yes *Lay focus group:* Yes, 52 groups with a mean of 8 patients per group *Expert focus group:* No *Expert opinion:* No *Views of stroke patients considered:* Unclear
Item selection	A pilot questionnaire (94 items) created using focus groups were reduced during testing to a 42-item questionnaire (344). Rasch analysis highlighted 13 misfitting items and suggested the removal of these items (345).
Population with which instrument was validated	Patients requiring refractive correction and emmetropes (344). Patients awaiting refractive surgery (345)
Actual content area	Clarity of vision Expectations Near vision Far vision Diurnal fluctuations Activity limitations Glare Symptoms Dependence on corrections Worry Suboptimal correction Appearance (344)
Scale	Sixteen options of response scale depending on item, varying between dichotomous and 6-point ordinal scale (344) Rasch analysis highlighted the need to remove categories 2 and 3 in the 6-point scales to create a 4-point scale (345)
Method of administration	Self-administered (344, 345)

National Eye Institute Visual Functioning Questionnaire (NEI VFQ) and Long Form Visual Functioning Scale (LFVFS-39)	
Aim	To assess the impact of visual impairment on health-related quality of life across various eye conditions Intended population: patients with visual impairment
Item identification	*Literature review/other instruments:* Existing questionnaires *Lay focus group:* 246 eye clinic patients with various ophthalmic diagnoses *Expert focus group:* No *Expert opinion:* No *Views of stroke patients considered:* NEI VFQ – Unclear Neuro 10 supplement - Yes
Item selection	Focus group analysis resulted in the 51-item pilot version of the NEI VFQ (346). The pilot version underwent item reduction by qualitative criteria and linear regression to resulting in 25 items (347). A 10 item Neuro-Ophthalmic Supplement (Neuro 10) to the NEI VFQ-25 was developed using survey and focus group methods. A decision to delay item reduction (possibly – 'eye/eyelid appearance is unusual' and 'ptosis') until further testing has taken place (144, 145). Ceiling effects were found in three subscales: general vision, ocular pain and vision-specific mental health. Rasch analysis was performed on a 7-item version of the questionnaire created by author's choice (348). The NEI VFQ was re-engineered using Rasch analysis and renamed Long-Form Visual Functioning Scale (LFVFS) with the number items being reduced to 8 and Short-Form Visual Functioning Scale (SFVFS) with 6 items (349). Rasch analysis of the 25 item version suggested item reduction resulting in a 19-item version (350). Rasch analysis has also been used to create a 6-item utility index (351).
Population with which instrument was validated	Multi-condition population (cataracts, ARMD, diabetic retinopathy, glaucoma and low vision) (152, 347, 352). Optic neuritis (353). Multi-condition and visually normal population (354). Multiple sclerosis and other neuro-ophthalmic disorders with Neuro 10 supplement (144). Patients with cataracts (349), age-related macular degeneration (355) and uveitis (356).
Actual content area	General health General vision Near visual activities Distance visual activities Ocular pain Vision specific social function Vision specific role difficulties Vision specific mental health Vision specific dependency Driving Colour vision Peripheral vision Reduced to four subscales using Rasch analysis: General health Near activities Distance activities Role difficulties (349) An alternative subscale structure was suggested: Visual functioning Socio-emotional (350)
Scale	Ordinal 5-point scale: 1 'all of the time' to 5 'none of the time' or 1 'no difficulty at all' to 5 'stopped doing because of your eyesight' plus a 'stopped doing for other reasons or not interested in doing this option' Rasch analysis recommended the collapse of categories 1 and 2 to create a 4-point scale (312) Rasch analysis suggested collapsing options: 0 'no difficulty' and 1 'a little difficulty' (348) Rasch analysis suggested collapsing middle options to create a dichotomous scale: 1 'always' and 2 'never' , 1 'true' and 2 'false' plus the 'not sure' option (350)
Method of administration	Interview (152, 347, 350, 354, 357) Self-administered (144, 348, 349, 353)

Nursing Home Vision Targeted Health-related Quality of Life questionnaire (NHVQoL)	
Aim	Evaluate vision-targeted health-related quality of life in older adults who live in nursing homes Intended population: older adults who live in nursing homes
Item identification	*Literature review/other instruments:* Yes *Lay focus group:* No, structured interviews *Expert focus group:* No *Expert opinion:* No *Views of stroke patients considered:* Unclear
Item selection	A pilot questionnaire with 57 items was developed using themes which emerged from interviews (358). An adapted version of the questionnaire was created to produce personal impact by the addition of bother subscales as a part B to the original version (359).
Population with which instrument was validated	Residents of nursing homes (358, 360)
Actual content area	Reading Ocular symptoms General vision ADLs Mobility Social activities/hobbies Psychological distress Adaptation/coping Social interaction During Rasch analysis the adaptation/coping subscale was added to psychological distress (360)
Scale	5-point scale: 'no difficulty at all' to 'stopped doing this because of your eyesight' or 'none of the time' to 'all of the time' or 'definitely true' to 'definitely false' plus many items had additional options of 'not sure', 'stopped doing this for other reasons or not interested in doing this' and 'could do this but not given the opportunity' (358).
Method of administration	Interview (358-360)

Quality of Life and Visual Function Questionnaire (QoL-VFQ)	
Aim	To evaluate self-reported visual satisfaction Intended population: patients with chronic eye disease causing visual impairment
Item identification	*Literature review/other instruments:* Yes *Lay focus group:* No *Expert focus group:* No *Expert opinion:* No *Views of stroke patients considered:* No
Item selection	A pilot questionnaire was developed consisting of 17 items selected by consensus of the authors (361). Rasch analysis required the reduction of two items (lights of oncoming cars and recognising colour) resulting in a 15-item questionnaire (362).
Population with which instrument was validated	Patients with cataract, glaucoma, ARMD, branch retinal vein occlusion, minor refractive error or presbyopia (361) Patients awaiting cataract surgery (362)
Actual content area	Overall self-assessment of visual satisfaction Self-assessment of: visual field distance visual acuity near visual acuity sensory adaptation colour vision Rasch analysis revealed poor performance of the subscales and recommended addition of items to subscales or that the subscales not be used (362)
Scale	3-point scale: 1 'not at all' to 3 'very much' (361) Rasch analysis confirmed optimal use of the scale (362)
Method of administration	Interview (361) Self-administration (362)

Quality of Vision (QoV)	
Aim	Evaluate quality of vision Intended population: patients with or without refractive correction and/or eye disease
Item identification	*Literature review/other instruments:* Yes *Lay focus group:* Yes x3 (5 non-experts) plus 15 subject interviews *Expert focus group:* Yes x3 (5 experts) *Expert opinion:* No *Views of stroke patients considered:* No
Item selection	A 23-item instrument underwent discussion within a focus group for item redundancy, representation and face validity to reduce items to create a 30-item questionnaire focused on 10 symptoms. The pilot questionnaire developed was tested using conventional statistics and Rasch analysis (363).
Population with which instrument was validated	Patients with or without refractive correction and patients with cataracts (363). Patients awaiting refractive surgery (364)
Actual content area	Frequency Severity Bothersomeness Further analysis of the subscales recommended continuing using all three (365)
Scale	4-point scale: Frequency: 0 ‘never’ to 3 ‘very often’ Severity: 0 ‘not at all’ to 3 ‘severe’ Bothersomeness: 0 ‘not at all’ to 3 ‘very’ (363)
Method of administration	Self-administration (366)

Self-Report Assessment of Functional Visual Performance (SRA-VFP)	
Aim	Measure the performance of vision dependant ADLs in older adults with low vision Intended population: older adults with age related ocular disease
Item identification	*Literature review/other instruments:* No *Lay focus group:* No *Expert focus group:* No *Expert opinion:* Yes *Views of stroke patients considered:* No
Item selection	A group of experts developed a list of common ADLs and a 5-point rating scale. A separate panel of experts reviewed the list and rating scale. The pilot questionnaire consisted of 39 items (367).
Population with which instrument was validated	Patients with homonymous hemianopia (131).
Actual content area	Reading Writing Money management Telephone usage Reading a timepiece Personal care Clothing care Meal Preparation Leisure Functional mobility (368) Reading Writing Communication Financial and health management Feeding Personal hygiene Dressing Clothing care Meal Preparation Shopping Functional mobility Community or social and leisure participation (131)
Scale	5-point scale: 1 ‘unable’ to 5 ‘independent’ plus a ‘not applicable’ option. Rasch analysis suggested the need to collapse the middle ratings (2, 3 and 4) to create: a 3-point scale: 1 ‘unable: dependant on other to perform task, would perform task if able’ to 3 ‘independent: experiences no difficulty performing task safely, accurately and efficiently’ (368).
Method of administration	Interview (131, 368)

Severity of visual field damage	
Aim	To assess subjective disability associated with visual field loss Intended population: patients with glaucoma
Item identification	*Literature review/other instruments:* No *Lay focus group:* Yes – interviews *Expert focus group:* No *Expert opinion:* Yes – physicians and visual field technicians *Views of stroke patients considered:* No
Item selection	The original question consisted of 15 items developed from expert and patient input (369). The instrument was modified, rewording of questions and the removal of items resulted in a 10-item questionnaire (370).
Population with which instrument was validated	Patients with glaucoma (369, 370)
Actual content area	-
Scale	Ordinal 3-point scale: 1 'no', 2 'uncertain' and 3 'yes' (369)
Method of administration	Interview (369, 370)

Veterans Affairs Low Vision Visual Functioning Questionnaire (VA LV VFQ)	
Aim	To measure functional ability of low vision patients and measure patient-centred outcomes of low vision rehabilitation Intended population: veterans with low vision
Item identification	*Literature review/other instruments:* Yes – clinical guidelines *Lay focus group:* No – structure interviews with patients *Expert focus group:* No *Expert opinion:* Yes – consensus panel recommendations *Views of stroke patients considered:* No
Item selection	The second round of modified Delphi analysis selected 48 items for the pilot questionnaire (153). The questionnaire was tested using Rasch analysis (158). Some items were identified as poor fit during Rasch analysis, however, any item change was deferred (157). A short form of the questionnaire was developed by reducing items based on Rasch analysis and clinical relevance, resulting in a 20-item questionnaire (371, 372).
Population with which instrument was validated	Patients with low vision (ARMD, glaucoma, diabetic retinopathy and other) (153, 157, 158). Patients with macular disease (372). Patients with homonymous hemianopia (132)
Actual content area	Visual ability Mobility Reading Visual motor Visual information
Scale	Identical response scales for all items: 5-point scale – 1 = 'not difficult' to 5 = 'impossible' Rasch analysis indicated the collapse of categories 2 'slightly difficult' and 3 'moderately difficult' resulting in a 4-point scale (157)
Method of administration	Interview (153, 157, 158)

Vision and Quality of Life index (VisQoL)	
Aim	Economic evaluation of eye care and rehabilitation programs Intended population: patients with visual impairment
Item identification	*Literature review/other instruments:* Yes *Lay focus group:* Yes – 3 groups with 8-9 patients *Expert focus group:* No *Expert opinion:* No *Views of stroke patients considered:* No
Item selection	An item bank of 33 was created from the results of the focus groups. Item reduction was achieved through factor analysis and item response theory. A pilot study was then conducted using this item bank. Factor analysis retained 13 items. The final version contained 6 items following iterative structural equation modelling (149).
Population with which instrument was validated	Patients with visual impairment (149)
Actual content area	Physical well-being Independence Social well-being Emotional well-being Self-actualisation Planning and organisation
Scale	Range of between 5 and 7-point scales, different for each item (149)
Method of administration	Self-administration (149)

Vision Function and Quality of Life questionnaires (VF and QOL)	
Aim	To assess improvement in functioning following cataract surgery Intended population: patients with cataracts
Item identification	*Literature review/other instruments:* Yes *Lay focus group:* No *Expert focus group:* No *Expert opinion:* Yes – 3 ophthalmologists and 2 social workers *Views of stroke patients considered:* No
Item selection	Two pilot questionnaires VF (13 items) and QOL (12 items) were developed and tested (373). Rasch analysis found the VF questionnaire to be valid. However, despite removal of items the QOL questionnaire was found to be limiting precision and could not be deemed valid (374).
Population with which instrument was validated	Patients with cataract, glaucoma, iritis, ARMD or corneal disease (373). Patients with cataracts (374)
Actual content area	Overall visual function Visual perception Limitation in everyday activities and visual acuity Peripheral vision Sensory adaptation, light dark adaptation, visual search, colour discrimination and glare disability Depth perception Self-care Mobility Social Mental (373) Rasch analysis recommended these subscales not to be used (374)
Scale	Ordinal 4-point scale: 1 'not at all' to 4 'a lot' (373).
Method of administration	Interview (373) Self-administration (374)

Vision related Quality of Life (VQoL) or Vision-related Quality of Life Core Measure (VCM1)	
Aim	To assess vision related quality of life Intended population: patients with visual impairment
Item identification	*Literature review/other instruments:* Yes *Lay focus group:* No – semi structured interviews with 38 patients *Expert focus group:* No – 11 interviews with support workers and professionals *Expert opinion:* Consultation with 26 professionals *Views of stroke patients considered:* No
Item selection	Pre-testing finalised the 'parent' version with of the questionnaire containing 139 items. The selection of items took a modular approach to enable to questionnaire to meet the requirements of different groups of patients. Ten items were identified as core items and named VCM1 (164). Rasch analysis did not change any included items of the VCM1 (166).
Population with which instrument was validated	Patients with cataract, ARMD, glaucoma, aphakia, amblyopia, corneal lesions, diabetic retinopathy, thyroid eye disease, retinal detachment, iritis, ocular hypertension, ocular trauma, ocular tumour, optic neuropathy, retinitis pigmentosa, retinal vascular occlusions and no pathology (164). Patients awaiting cataract surgery (166)
Actual content area	Overall vision Visual symptoms Self esteem Emotion Safety General Self-care Domestic Financial Reading Miscellaneous information Mobility Social interaction Leisure
Scale	Ordinal 6-point scale: 0 'not at all' to 5 'can't do because of eye-sight' plus a 'don't do for other reasons' option Ordinal 5-point scale: 0 'not at all' to 5 'all the time' – the latter used by all VCM1 items (164) Rasch analysis indicated the need to collapse categories 4 'very rarely' and 5 'all the time' resulting in a 4-point scale (166)
Method of administration	Self-administered (338)

Visual Activity Questionnaire (VAQ)	
Aim	To assess individual's problems in performing visual activities typical of everyday life Intended population: elderly population
Item identification	*Literature review/other instruments:* No *Lay focus group:* No *Expert focus group:* No *Expert opinion:* No *Views of stroke patients considered:* No
Item selection	The pilot questionnaire contained 100 items spilt into 10 areas. Items were reduced by removing those that did not provide further information and items with unclear wording. Factor analysis resulted in reduction of items to 33 (375). Rasch analysis reduced the number of items to 13 due to multidimensionality. This reduction in items results in floor-effects (376).
Population with which instrument was validated	Adults aged 17 to 89 Drivers aged 55 and over (375) Patients with cataracts (376)
Actual content area	Glare disability Light and dark adaptation Acuity and spatial vision Visual search Visual processing speed Depth perception Colour discrimination Peripheral vision Reduced to in the 13-item version: Visual search Visual processing speed Depth perception Peripheral vision (376)
Scale	Ordinal 5 point scale: 1 'never' to 5 'always' (375) Rasch analysis recommended the collapse of categories 2 and 3 resulting in a 4-point scale (312)
Method of administration	Self-administration (376)

Visual Disability Assessment (VDA)	
Aim	Assess subjective visual disability Intended population: patients with cataracts
Item identification	*Literature review/other instruments:* Yes *Lay focus group:* No *Expert focus group:* No *Expert opinion:* No *Views of stroke patients considered:* No
Item selection	A pilot questionnaire of 37 items was developed. Item reduction was performed by eliminating redundant items, resulting in an 18-item questionnaire (377).
Population with which instrument was validated	Patients with cataracts (377, 378)
Actual content area	Mobility Distance/Lighting/Reading Near and related tasks (377) In order to achieve unidimensionality Rasch analysis suggested the segregation of the mobility subscale and activity limitation subscale (378)
Scale	4 point scale: 1 'not at all' to 4 'a lot' (377)
Method of administration	Self-administration (378)

Visual Disability Questionnaire (VDQ)	
Aim	Aid with prioritising rehabilitation goals Intended population: patients with visual impairment
Item identification	*Literature review/other instruments:* Yes *Lay focus group:* Yes – 3 groups (8 participants per group) *Expert focus group:* No *Expert opinion:* Yes *Views of stroke patients considered:* No
Item selection	A pilot questionnaire (28 items) was created. The pilot testing resulted in removal unnecessary items and addition of new items (379).
Population with which instrument was validated	Patients with retinitis pigmentosa, macular degeneration, diabetic retinopathy, glaucoma, optic atrophy, refractive error, corneal disorders, developmental disorders, albinism and other diseases
Actual content area	-
Scale	Ordinal 5-point scale: 0 'not important' to 4 'extremely important' and ordinal 5-point scale: 0 'not difficult' to 4 'impossible' Rasch analysis suggested the collapse of categories 1 and 2 resulting in a 4-point scale (379)
Method of administration	Self-administration (174)

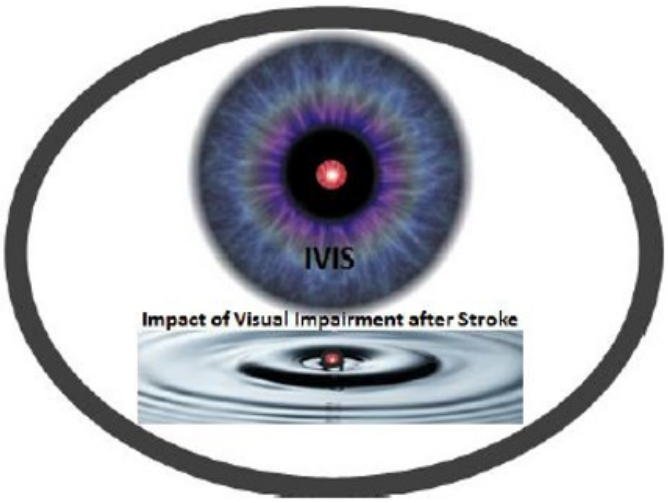
Visual Function Index (VFI)	
Aim	Evaluate the amount of improvement obtained by cataract surgery Intended population: patients with awaiting cataract surgery
Item identification	*Literature review/other instruments:* No *Lay focus group:* No *Expert focus group:* No *Expert opinion:* Yes *Views of stroke patients considered:* No
Item selection	Items were chosen from those used to routinely interview cataract patients but with the aim of standardisation an 11-item questionnaire was created (380). Rasch analysis found this questionnaire not valid for use in a modern cataract population in a developed country (381).
Population with which instrument was validated	Patients awaiting cataract surgery (380, 381)
Actual content area	Direct visual limitations Mobility limitations Social role limitations (380)
Scale	Dichotomous – 'yes/no' or 'sufficient/insufficient' Only two items use an ordinal 3-point scale. (380)
Method of administration	Self-administration (381)

Visual Symptom and Quality of Life questionnaire (VSQ)	
Aim	To assess the outcome following second-eye cataract surgery Intended population: patients awaiting second-eye cataract surgery
Item identification	*Literature review/other instruments:* Yes *Lay focus group:* No – individual interviews with 40 patients were conducted *Expert focus group:* No *Expert opinion:* Yes – 6 ophthalmologists, 6 ophthalmic nurses, 4 optometrists, 1 social worker and 1 OT *Views of stroke patients considered:* No
Item selection	A 32-item draft questionnaire was devised using the data obtained from clinical experts and patients. Results from pilot testing resulted in some reorganisation and rewording of items, most commonly clarifying the question with 'in the past month' and 'because of trouble with your eyesight'. Factor analysis resulted in the removal of four items (perception of colour, diplopia, blinkered vision and watering eyes). A short (14-item) and a long (26-item) final version were created (162). Rasch analysis was performed on the 26-item version, due to lack of unidimensionality all items from the subscales visual symptoms and vision-specific quality of life were removed. Two further items were removed from the remaining subscale due to misfit, creating a 14-item questionnaire (174).
Population with which instrument was validated	Patients awaiting cataract surgery or recently undergone cataract surgery (162, 174)
Actual content area	Visual symptoms/disability Vision-specific quality of life
Scale	Ordinal 4 or 5-point scale – 13 formats (162) Rasch analysis indicated the collapse of options 3 and 4 for the question do you have difficulty recognising people's faces (174)
Method of administration	Self-administration (174)

Appendix 2

Pilot questionnaire – version one

Version 1 27th June 2014



IVIS

Impact of Visual Impairment after Stroke Questionnaire

Patient ID: _____

Date of completion: _____

Method of completion: Interview / Self-administered

cc Dr Fiona Rowe, University of Liverpool

Instructions:

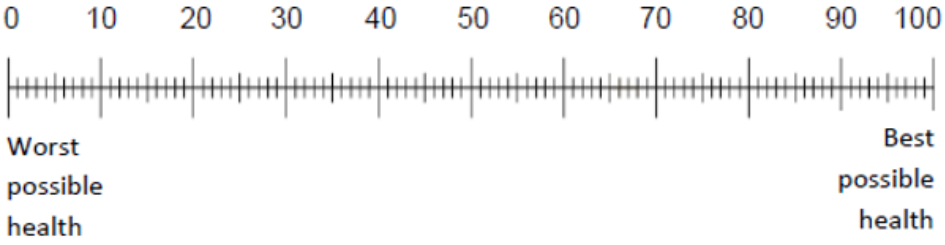
This questionnaire aims to document the impact of vision problems following a stroke and how they affect your quality of life.

- You will be asked to read questions about problems which involve your vision and/or feelings that you have about your visual condition.
- After each question there is a list of possible answers. Please choose the response that best describes your situation and place a mark in that box.
- Please answer all the questions as if you were wearing your glasses or contact lenses (if any).
- The choices include a "not applicable" option. Please choose this option if the reason is not related to your visual impairment, you are not interested in the activity or it does apply to you for any other reason.
- If you answer "not applicable" please state the reason in the box provided.
- You may not need to answer all questions depending on your responses; please follow the directions to the next question you need to answer.
- Please take as much time as you need to answer each question.

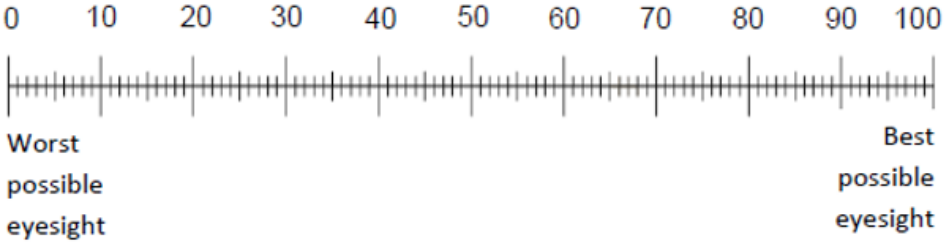
Statement of Confidentiality

All information that would permit identification of any person who completed this questionnaire will be regarded as strictly confidential. Such information will be used only for the purpose of this study and will not be disclosed or released for any other purpose without prior consent, except as required by law.

i. How would you rate your overall health?



ii. How would you rate your eyes/eyesight overall?



PART 1 – Vision/Eyes

B. General vision

1. How much difficulty have you found with blurred vision?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

→ Why?

2. How much difficulty have you found with distortion of your vision?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

→ Why?

3. How much difficulty have you found with objects jumping around?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

→ Why?

4. How much difficulty have you found with deterioration of your eyes or eyesight?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

→ Why?

5. How much difficulty have you found with fluctuation of your eyesight?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

Why?

6. How much difficulty have you found with your eyes getting tired?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

Why?

7. How much difficulty have you found with your two eyes seeing differently?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

Why?

8. How much difficulty have you found with double vision?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

→ Why?

9. How much difficulty have you found, due to your eyes or eyesight, with judging how close or far things are from you?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

10. How much do you feel your eyes have an unusual appearance, because of your eyes or eyesight?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

→ Why?

C. Distance Vision

11. How much difficulty have you found, due to your eyes or eyesight, with recognising people from a distance?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

12. How much difficulty have you found, due to your eyes or eyesight, with reading road and street signs?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

13. How much difficulty have you found, due to your eyes or eyesight, with reading bus numbers?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

14. How much difficulty have you found, due to your eyes or eyesight, with telling the time on a clock?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

D. Near Vision

15. How much difficulty have you found, due to your eyes or eyesight, with recognising faces up close and/or seeing facial expressions?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

16. How much difficulty have you found, due to your eyes or eyesight, with writing?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

17. How much difficulty have you found, due to your eyes or eyesight, with doing work or hobbies that require you to see well up close?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

18. How much difficulty have you found, due to your eyes or eyesight, with finding something when it is surrounded by a lot of other things?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

19. How much difficulty have you found, due to your eyes or eyesight, with identifying coins and bank notes?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

20. How much difficulty have you found, due to your eyes or eyesight, with telling the time on a wristwatch?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

21. How much difficulty have you found, due to your eyes or eyesight, with using a telephone?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

E. Reading

22. How much difficulty have you found, due to your eyes or eyesight, with following a line of print or finding the next line when reading?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

23. How much difficulty have you found, due to your eyes or eyesight, with reading ordinary sized print?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

24. How much difficulty have you found, due to your eyes or eyesight, with reading small print?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

25. How much difficulty have you found, due to your eyes or eyesight, with reading large print, such as newspaper headlines?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

F. Television

26. How much difficulty have you found, due to your eyes or eyesight, with watching television?

Not Applicable 0	None at all 1	A little bit 2	A moderate amount 3	A lot 4	So much I can't do this activity 5

→ Why?

27. How much difficulty have you found, due to your eyes or eyesight, with reading text on the television?

Not Applicable 0	None at all 1	A little bit 2	A moderate amount 3	A lot 4	So much I can't do this activity 5

→ Why?

28. How much difficulty have you found, due to your eyes or eyesight, with watching a film at the cinema?

Not Applicable 0	None at all 1	A little bit 2	A moderate amount 3	A lot 4	So much I can't do this activity 5

→ Why?

29. How much difficulty have you found, due to your eyes or eyesight, with using a computer?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

G. Peripheral vision

30. How much difficulty have you found, due to your eyes or eyesight, with objects suddenly appearing in front of you?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

31. How much difficulty have you found with missing patches in your vision?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

32. How much difficulty have you found, due to your eyes or eyesight, with noticing objects off to the side?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

→ Why?

H. Lighting

33. How much difficulty have you found, due to your eyes or eyesight, with seeing in poor or dim light?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

→ Why?

34. How much difficulty have you found, due to your eyes or eyesight, with seeing in bright light or glare?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

→ Why?

35. How much difficulty have you found, due to your eyes or eyesight, with adjusting to brightness after being in dim light?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

→ Why?

36. How much difficulty have you found, due to your eyes or eyesight, with adjusting to darkness after being in bright light?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

37. How much difficulty have you found with noticing haloes?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

→ Why?

I. Colour

38. How much difficulty have you found, due to your eyes or eyesight, with recognising colours?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

39. How much difficulty have you found, due to your eyes or eyesight, with picking out and matching clothes?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

40. How much difficulty have you found, due to your eyes or eyesight, with noticing if colours are dull or faded?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

J. Discomfort

41. How much difficulty have you found with pain or discomfort in or around your eyes?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

Why?

42. How much difficulty have you found with your eyes feeling strained?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

Why?

43. How much difficulty have you found with headaches related to vision?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

Why?

44. How much difficulty have you found with dryness of your eyes?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

→ Why?

45. How much difficulty have you found with your eyes watering?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

→ Why?

PART 2 - Functioning

K. Walking

46. How much difficulty have you found, due to your eyes or eyesight, with seeing and/or using steps, curbs or stairs?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

47. How much difficulty have you found, due to your eyes or eyesight, with tripping over objects and falling?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

→ Why?

48. How much difficulty have you found, due to your eyes or eyesight, with crossing the road?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

49. How much difficulty have you found, due to your eyes or eyesight, with moving around in familiar areas?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

50. How much difficulty have you found, due to your eyes or eyesight, with moving around in unfamiliar areas?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

51. How much difficulty have you found, due to your eyes or eyesight, with bumping into or against in crowded areas?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

→ Why?

52. How much difficulty have you found, due to your eyes or eyesight, with walking around indoors?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

53. How much difficulty have you found, due to your eyes or eyesight, with walking around outdoors?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

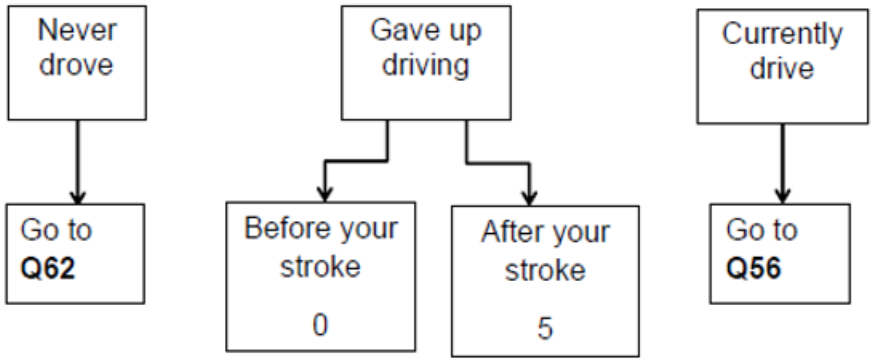
54. How much difficulty have you found, due to your eyes or eyesight, with walking on uneven ground?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

L. Driving

55. Have you ever driven a car?



56. How much difficulty have you found, due to your eyes or eyesight, with driving during the daytime?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

57. How much difficulty have you found, due to your eyes or eyesight, with driving at night?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

58. How much difficulty have you found, due to your eyes or eyesight, with seeing cars in the next lane?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

59. How much difficulty have you found, due to your eyes or eyesight, with driving in difficult conditions?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

60. How much difficulty have you found, due to your eyes or eyesight, with driving with oncoming headlights?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

61. How much difficulty have you found, due to your eyes or eyesight, with parking your car?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

M. Travelling

62. How much difficulty have you found, due to your eyes or eyesight, with travelling in car as a passenger?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

63. How much difficulty have you found, due to your eyes or eyesight, with travelling somewhere alone?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

64. How much difficulty have you found, due to your eyes or eyesight, with using public transport?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

N. Socialising

65. How much difficulty have you found, due to your eyes or eyesight, with visiting or meeting with friends and family?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

66. How much difficulty have you found, due to your eyes or eyesight, with making eye contact with people during conversations?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

67. How much difficulty have you found, due to your eyes or eyesight, with dealing with strangers?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

68. How much difficulty have you found, due to your eyes or eyesight, with social activities?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

69. How much difficulty have you found, due to your eyes or eyesight, with entertaining friends and family in your own home?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

70. How much difficulty have you found, due to your eyes or eyesight, with taking part in outdoor activities?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

71. How much difficulty have you found, due to your eyes or eyesight, with making new friends?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

O. Role Limitations

72. How much difficulty have you found, due to your eyes or eyesight, with performing your usual activities?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

→ Why?

73. How much difficulty have you found, due to your eyes or eyesight, with loss of confidence in doing your usual activities?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

→ Why?

74. How much difficulty have you found, due to your eyes or eyesight, with accomplishing as much as you would like?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

→ Why?

75. How much difficulty have you found, due to your eyes or eyesight, limiting how long you can work or do other activities?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

→ Why?

76. How much difficulty have you found, due to your eyes or eyesight, with people limiting your opportunities?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

→ Why?

77. How much difficulty have you found, due to your eyes or eyesight, with doing your usual work to your usual standard?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

→ Why?

P. Self-care

78. How much difficulty have you found, due to your eyes or eyesight, with toileting unaided?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

79. How much difficulty have you found, due to your eyes or eyesight, with getting dressed unaided?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

80. How much difficulty have you found, due to your eyes or eyesight, with eating unaided?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

81. How much difficulty have you found, due to your eyes or eyesight, with taking your medication?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

82. How much difficulty have you found, due to your eyes or eyesight, with pouring yourself a drink?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

83. How much difficulty have you found, due to your eyes or eyesight, with preparing something to eat?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

84. How much difficulty have you found, due to your eyes or eyesight, with generally looking after your appearance, for example styling your hair, shaving, putting on make-up?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

85. How much difficulty have you found, due to your eyes or eyesight, with completing household chores?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

86. How much difficulty have you found, due to your eyes or eyesight, with shopping?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

87. How much difficulty have you found, due to your eyes or eyesight, with bathing or showering?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much I can't do this activity
0	1	2	3	4	5

→ Why?

Q. Well-being

88. How much do you feel sad or low, because of your eyes or eyesight?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

→ Why?

89. How much do you feel frustrated, because of your eyes or eyesight?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

→ Why?

90. How much do you feel vulnerable, because of your eyes or eyesight?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

→ Why?

91. How much do you feel anxious, because of your eyes or eyesight?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

→ Why?

92. How much do you worry, because of your eyes or eyesight?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

→ Why?

93. How much do you feel isolated, because of your eyes or eyesight?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

→ Why?

94. How much do you feel you have less control, because of your eyes or eyesight?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

→ Why?

95. How much do you feel stressed, because of your eyes or eyesight?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

→ Why?

96. How much do you feel you are not coping with everyday life, because of your eyes or eyesight?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

→ Why?

97. How much do you feel self-conscious, because of your eyes or eyesight?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

→ Why?

98. How much do you feel you are a burden to others, because of your eyes or eyesight?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

→ Why?

99. How much do you feel you need help from others, because of your eyes or eyesight?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

→ Why?

100. How much do you feel you stay at home, because of your eyes or eyesight?

Not Applicable	None at all	A little bit	A moderate amount	A lot	So much it limits my activity
0	1	2	3	4	5

Why?

Thank you for completing this questionnaire.

Quick Analysis Instructions

To obtain a quick overview:

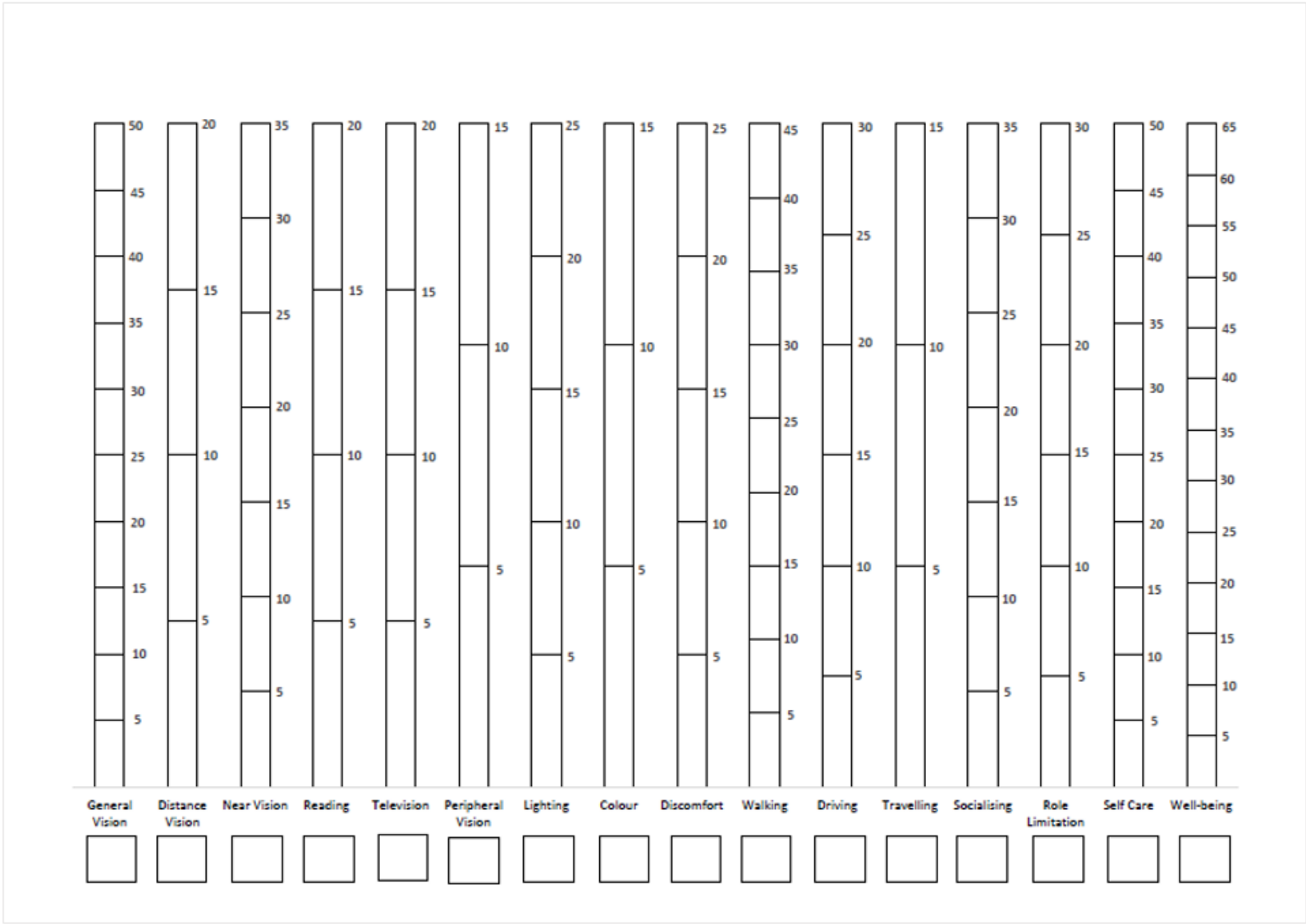
- Write the score for each section in the corresponding box
- Mark each score on the graph
- Join the points together

Ratings:

General Health score - 100 = ☐

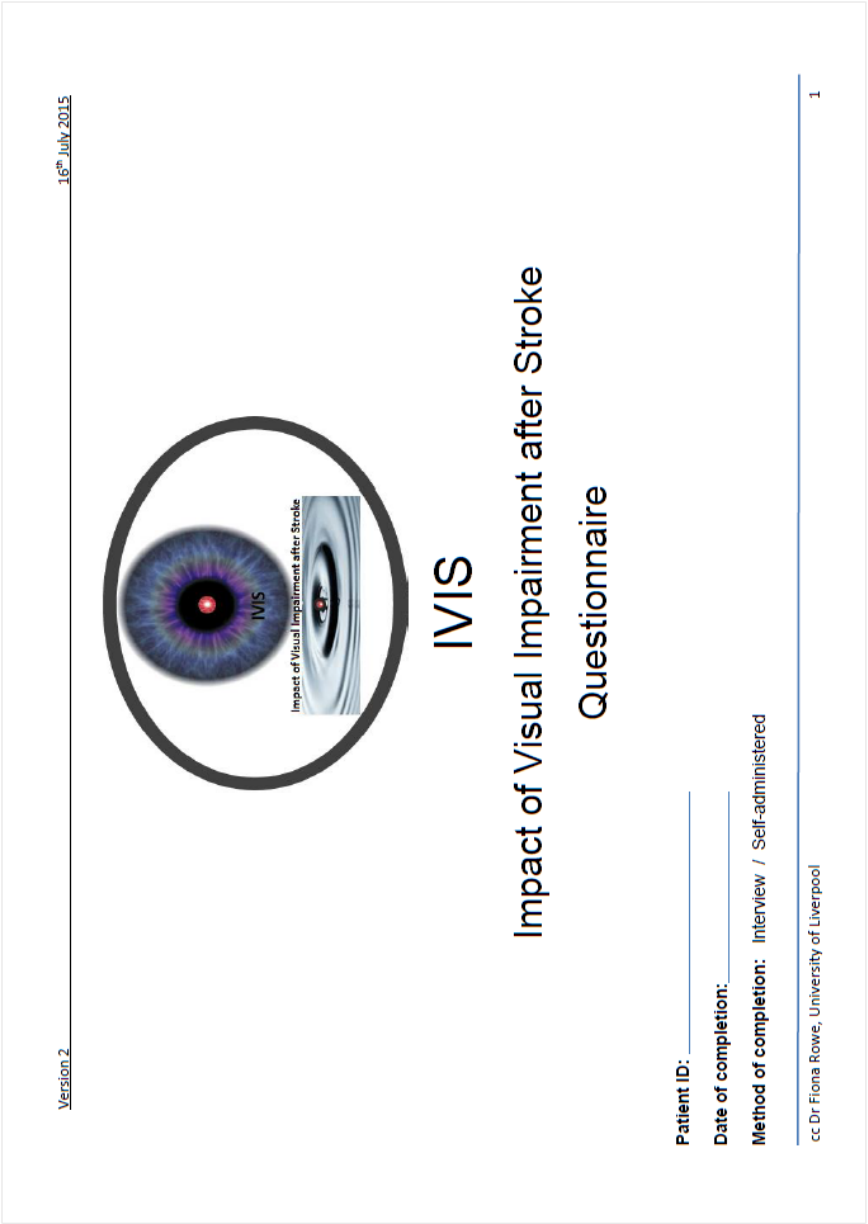
Record **without** + or – symbol

General Vision score – 100 = ☐


General Vision
Distance Vision
Near Vision
Reading
Television
Peripheral Vision
Lighting
Colour
Discomfort
Walking
Driving
Travelling
Socialising
Role Limitation
Self Care
Well-being

Appendix 3

Pilot questionnaire – version two



Version 2 16th July 2015

IVIS

Impact of Visual Impairment after Stroke

Questionnaire

Patient ID: _____

Date of completion: _____

Method of completion: Interview / Self-administered

cc Dr Fiona Rowe, University of Liverpool 1

Instructions:

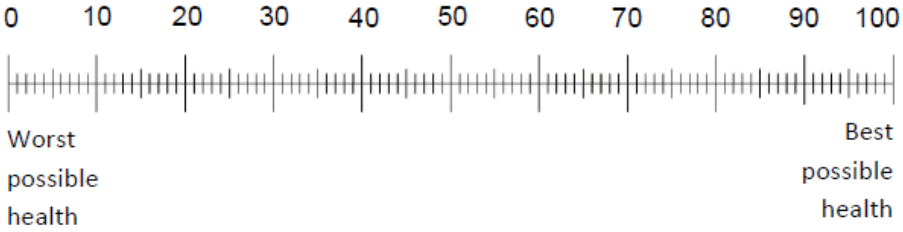
This questionnaire aims to document the impact of vision problems following a stroke and how they affect your quality of life.

- You will be asked to read questions about problems which involve your vision and/or feelings that you have about your visual condition.
- The first part to each question requires a 'Yes' or 'No' answer. Please choose the 'No' option if the question is not related to your visual impairment, you are not interested in the activity or it does apply to you for any other reason.
- The second part of the question asks how much difficulty you are having, with a list of possible answers. Please choose the response that best describes your situation and place a mark in that box.
- Please answer all the questions as if you were wearing your glasses or contact lenses (if needed).
- Please take as much time as you need to answer each question.

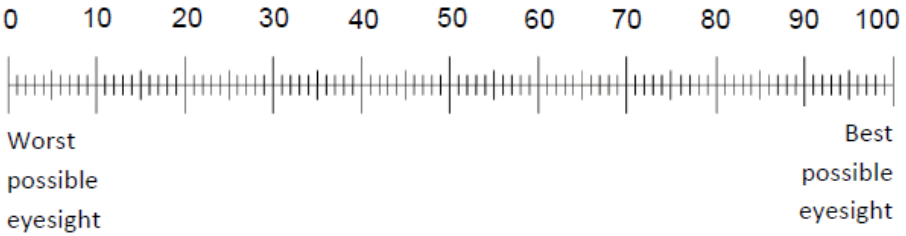
Statement of Confidentiality

All information that would permit identification of any person who completed this questionnaire will be regarded as strictly confidential. Such information will be used only for the purpose of this study and will not be disclosed or released for any other purpose without prior consent, except as required by law.

i. How would you rate your overall health today? (please circle)



ii. How would you rate your eyes/eyesight overall today? (please circle)



PART 1 – Vision/Eyes

B. General vision: In this section we are asking if any of the following symptoms have an impact on your life.

	Do you have? (please tick)			If yes, how much difficulty do you have on this scale from 0 to 4?				
		No	Yes	None at all 0	A little bit 1	A moderate amount 2	A lot 3	It limits my activity 4
1.	Blurred vision							
2.	Objects jumping around							
3.	Deterioration of your vision							
4.	Fluctuation of your vision							
5.	Your eyes getting tired							
6.	Your two eyes seeing differently							
7.	Double vision							
8.	Judging how close or far things are from you							
9.	Your eyes having an unusual appearance							

C. Distance vision: In this section we are asking if you are having any difficulty with your distance vision when you are wearing the correct glasses if needed, and if it is having an impact on your life.

	Do you have? (please tick)			If yes, how much difficulty do you have on this scale from 0 to 4?				
		No	Yes	None at all 0	A little bit 1	A moderate amount 2	A lot 3	It limits my activity 4
10.	Difficulty seeing something on the far side side of a room e.g. TV, people							
11.	Difficulty seeing something far away e.g. street signs, looking out of a window							

D. Near vision: In this section we are asking if you are having any difficulty with your close up vision when you are wearing the correct glasses if needed, and if it is having an impact on your life.

	Do you have, due to your **eyes or eyesight**? (please tick)		If yes, how much difficulty do you have on this scale from 0 to 4?				
		No	Yes	None at all 0	A little bit 1	A moderate amount 2	A lot 3	It limits my activity 4
12.	Difficulty seeing faces or facial expressions up close							
13.	Difficulty with writing							
14.	Difficulty with close up vision e.g. telephone							
15.	Difficulty finding something when it is surrounded by a lot of other things							
16.	Difficulty using a desktop computer, laptop or tablet computer?							

E. Reading: In this section we are asking if you are having any difficulty with reading when you are wearing the correct glasses if needed, and if it is having an impact on your life.

	Do you have? (please tick)			If yes, how much difficulty do you have on this scale from 0 to 4?				
		No	Yes	None at all 0	A little bit 1	A moderate amount 2	A lot 3	It limits my activity 4
17.	Difficultly following a line of print or finding the next line when reading							
18.	Difficulty reading the size of print you were able to read before							

F. Peripheral vision: In this section we are asking if you are having any difficulty with your side vision and if it is having an impact on your life.

	Do you have? (please tick)			If yes, how much difficulty do you have on this scale from 0 to 4?				
		No	Yes	None at all 0	A little bit 1	A moderate amount 2	A lot 3	It limits my activity 4
19.	Objects suddenly appearing in front of you							
20.	Missing patches in your vision							
21.	Difficulty noticing objects off to the side							

G. Light: In this section we are asking if you are having any difficulty with coping with different lighting conditions and if it is having an impact on your life.

	Do you have? (please tick)			If yes, how much difficulty do you have on this scale from 0 to 4?				
		No	Yes	None at all 0	A little bit 1	A moderate amount 2	A lot 3	It limits my activity 4
22.	Difficulty with seeing in poor or dim light							
23.	Difficulty with seeing in bright light or glare							
24.	Difficulty with adjusting to different lighting, e.g. bright to dim or dim to bright light							
25.	A change in how you see colours							

H. Discomfort: In this section we are asking if you are experiencing any pain or discomfort of your eyes and if it is having an impact on your life.

	Do you have? (please tick)			If yes, how much difficulty do you have on this scale from 0 to 4?				
		No	Yes	None at all 0	A little bit 1	A moderate amount 2	A lot 3	It limits my activity 4
26.	Dry eyes							
27.	Watery eyes							

PART 2 - Functioning

I. Moving around: In this section we are asking if you are having any difficulty moving around, whether this is by walking or using a wheelchair and if it is having an impact on your life.

	Do you have, due to your **eyes or eyesight**? (please tick)			If yes, how much difficulty do you have on this scale from 0 to 4?				
		No	Yes	None at all 0	A little bit 1	A moderate amount 2	A lot 3	It limits my activity 4
28.	Difficulty moving around on uneven ground e.g. seeing steps, curbs or stairs							
29.	Trips and falls							
30.	Difficulty crossing the road							
31.	Difficulty moving around in familiar areas							
32.	Difficulty moving around in unfamiliar areas							
33.	Bumps into or against objects or people in crowded areas							

I. Moving around continued

	Do you have, due to your **eyes or eyesight**? (please tick)			If yes, how much difficulty do you have on this scale from 0 to 4?				
		No	Yes	None at all 0	A little bit 1	A moderate amount 2	A lot 3	It limits my activity 4
34.	Difficulty moving around indoors							
35.	Difficulty moving around outdoors							
36.	Difficulty travelling in a vehicle as a passenger							

J. Socialising: In this section we are asking if you are having any difficulty with socialising and activities you used to do and if it is having an impact on your life.

	Do you have, due to your **eyes or eyesight**? (please tick)			If yes, how much difficulty do you have on this scale from 0 to 4?				
		No	Yes	None at all 0	A little bit 1	A moderate amount 2	A lot 3	It limits my activity 4
37.	Difficulty with making eye contact with people during conversations							
38.	Difficulty dealing with strangers							
39.	Difficulty with participating in indoor social activities							
40.	Difficulty with participating in outdoor social activities							

K. Role Limitations: In this section we are asking if you are having any difficulty with everyday activities you used to do, these could include going to work or activities you enjoyed doing and if it is having an impact on your life.

	Do you have, due to your **eyes or eyesight**? (please tick)	No	Yes	If yes, how much difficulty do you have on this scale from 0 to 4? None at all 0	A little bit 1	A moderate amount 2	A lot 3	It limits my activity 4
41.	A loss of confidence in doing your usual activities							
42.	Difficulty accomplishing as much as you would like							
43.	A limit of how long you can do your role or activities for							
44.	Difficulty doing your role or activities to your usual standard							

L. Independent Living: In this section we are asking if you are having any difficulty you have looking after yourself without additional help from others and your return of dignity and if it is having an impact on your life.

	Do you have, difficulty, due to your **eyes or eyesight,** with..? (please tick)	No	Yes	If yes, how much difficulty do you have on this scale from 0 to 4? None at all 0	A little bit 1	A moderate amount 2	A lot 3	It limits my activity 4
45.	Toileting unaided							
46.	Getting dressed unaided							
47.	Eating unaided							
48.	Taking your medication							
49.	Pouring a drink							
50.	Preparing something to eat							
51.	Looking after your appearance, e.g. hair, shaving, make-up							
52.	Completing household chores							
53.	Shopping							
54	Bathing or showering							

M. Well-being: In this section we are asking how you feel in yourself and your effect on others and if it is having an impact on your life.

	Due to your, **eyes or eyesight,** do you feel…? (please tick)	No	Yes	If yes, how much difficulty do you have on this scale from 0 to 4? None at all 0	A little bit 1	A moderate amount 2	A lot 3	It limits my activity 4
55.	Negative emotions e.g. sad, frustrated, stressed, worried							
56.	Vulnerable							
57.	You are not coping with everyday life							
58.	Self-conscious							
59.	You are burden to others							
60.	You stay at home							

Thank you for completing this questionnaire.

Quick Analysis Instructions: (For Office Use Only)

To obtain a quick overview:

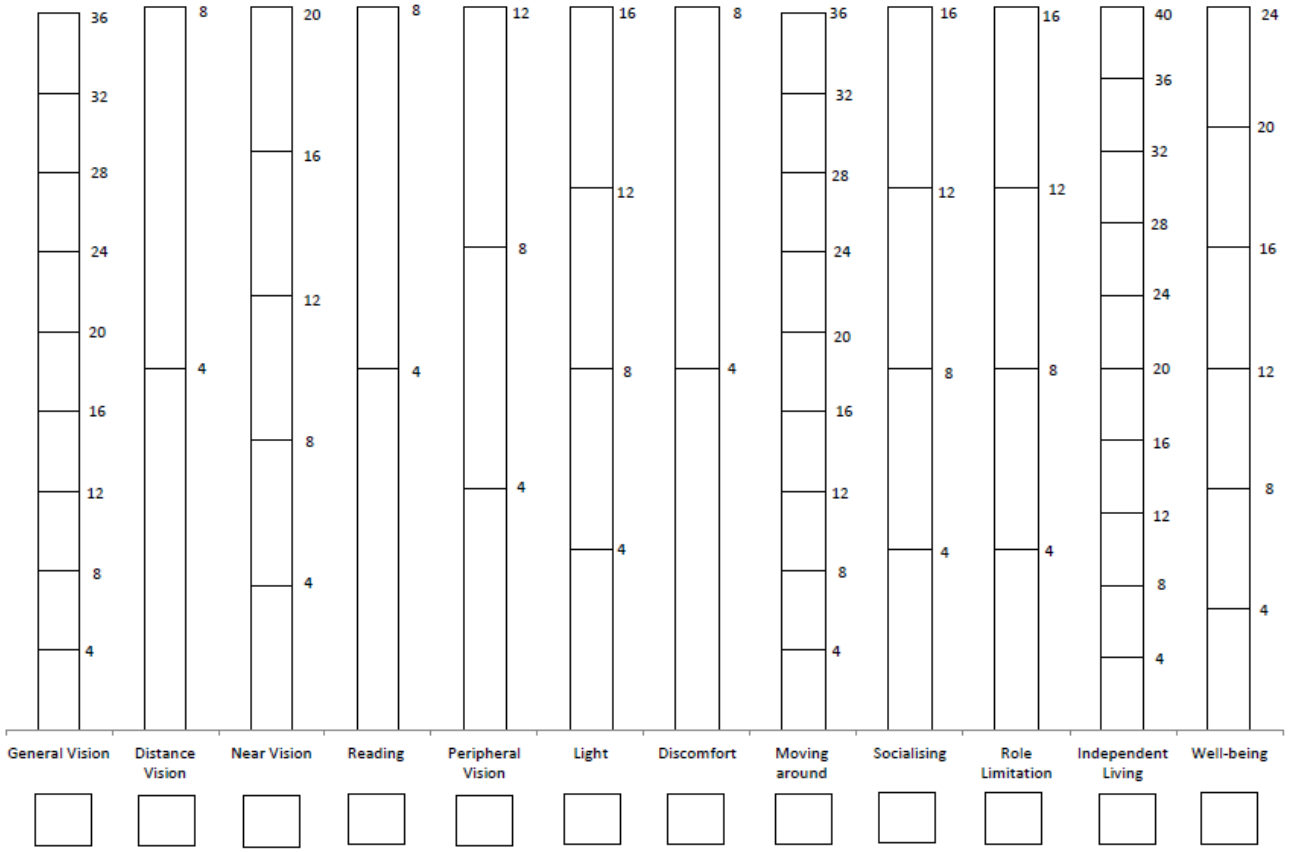
- Write the score for each section in the corresponding box
- Highlight up to the recorded score on the graph

Ratings:

General Health score - 100 = ☐

Record **without** + or – symbol

General Vision score - 100 = ☐


36 32 28 24 20 16 12 8 4
8 4
20 16 12 8 4
8 4
12 8 4
16 12 8 4
8 4
36 32 28 24 20 16 12 8 4
16 12 8 4
16 12 8 4
40 36 32 28 24 20 16 12 8 4
24 20 16 12 8 4
General Vision
Distance Vision
Near Vision
Reading
Peripheral Vision
Light
Discomfort
Moving around
Socialising
Role Limitation
Independent Living
Well-being

Appendix 4

Brain Injury related Visual Impairment Quality of Life questionnaire

VISION

Vision, Orthoptic and Brain Injury
Research Unit

BIVI-QoL

Brain Injury related Visual Impairment

Quality of Life questionnaire

Patient ID:_____ **Date of completion:**_____

Self-administered / Interview

cc Dr Fiona Rowe, University of Liverpool

Instructions:

This questionnaire aims to document the impact of vision problems following a brain injury and how they affect your quality of life.

- The first part to each question requires a 'Yes' or 'No' answer. Please choose the 'No' option if the question is not related to your visual impairment, you are not interested in the activity or it does not apply to you for any other reason.

- The second part of the question asks how much difficulty you are having, with a list of possible answers. Please choose the response that best describes your situation and place a mark in that box.

- Please answer all the questions as if you were **wearing your glasses or contact lenses** (if needed).

cc Dr Fiona Rowe, University of Liverpool

	Do you have, difficulty, due to your **eyes or eyesight,** with..? (please tick)	No	Yes	If yes, how much difficulty do you have due to your **eyes or eyesight**? None 0	Some 1	A lot 2	Unable to do 3
1.	finding an item when surrounded by others e.g. supermarket shelf, cluttered table						
2.	using a desktop computer, laptop, tablet or mobile device						
3.	looking after your appearance e.g. hair, shaving, make-up						
4.	getting about e.g. the ward, your home, further afield						
5.	socialising e.g. visiting time, seeing friends and family						

cc Dr Fiona Rowe, University of Liverpool

BIVI-QoL – Brain Injury associated Visual Impairment Quality of Life questionnaire

	Do you have, difficulty, due to your **eyes or eyesight,** with..? (please tick)			If yes, how much difficulty do you have due to your **eyes or eyesight**?			
		No	Yes	None 0	Some 1	A lot 2	Unable to do 3
6.	doing what you want to do						
7.	getting dressed e.g. picking out clothes, seeing fastenings						
8.	a fear of tripping or falling						
9.	feeling negative emotions e.g. sad, frustrated, stressed, worried, vulnerable						
10.	doing things for yourself						

cc Dr Fiona Rowe, University of Liverpool

BIVI-QoL – Brain Injury associated Visual Impairment Quality of Life questionnaire

	Do you have difificuty? (please tick)			If yes, how much difficulty do you have?			
		No	Yes	None 0	Some 1	A lot 2	Limits activity 3
11.	with your eyes getting tired						
12.	judging how close or far things are from you						
13.	seeing something far away e.g. TV, street signs, looking out of a window						
14.	following a line of print or finding the next line						
15	adjusting to different lighting e.g. bright to dim or dim to bright light						

Thank you for completing this questionnaire.

Total = /60

cc Dr Fiona Rowe, University of Liverpool