

Measuring visual and quality of life outcomes in nystagmus: a scoping review

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ABSTRACT

Introduction Pathological nystagmus of all aetiologies can cause visual disability and reduced quality of life. Recent research has characterised the dynamic nature of the condition and questioned the validity of widely used outcome measures, such as visual acuity (VA), as an accurate measure of visual function in nystagmus. VA only describes the spatial resolving capacity of the visual system for high contrast stimuli, whereas good visual function requires numerous components including contrast sensitivity, colour vision, depth perception and oculomotor functions. For these reasons, the literature on nystagmus, particularly interventional studies, has been inconsistent with regard to the outcome measures used.

Methods We performed a scoping literature review to characterise all published measures and instruments for determining functional vision and quality of life in patients with nystagmus.

Results A total of 235 articles were included in the study, accounting for 5880 patients with nystagmus. Articles spanned six continents and eight decades of research. We identified 10 grouped outcome measures including VA (27 outcomes, 84 instruments), nystagmus features (33 outcomes, 4 instruments), visual function (11 outcomes, 30 instruments), ocular morphology (3 outcomes, 5 instruments), orthoptic and ocular alignment features (20 outcomes, 63 instruments), reading assessment (8 outcomes, 6 instruments), visual search assessment (4 outcomes, 4 instruments), foveation/function models (8 outcomes), patient-reported outcomes (30 outcomes) and non-ocular features (6 outcomes).

Conclusion We have confirmed that there is significant heterogeneity in visual function and quality of life outcome measures in the nystagmus literature. It is evident that one or few measures are insufficient to measure all the relevant outcomes from interventional nystagmus studies. Therefore, we propose a Delphi project using our data to determine a standardised core outcome set for interventional nystagmus studies.

INTRODUCTION

Pathological nystagmus is characterised by involuntary oscillatory eye movements, involving a slow phase that disrupts steady fixation.¹ It has a prevalence of 24.0 per 10 000 population and is typically classified into infantile and acquired forms as defined

WHAT IS ALREADY KNOWN ON THIS TOPIC

- ⇒ Nystagmus affects visual function and quality of life, but visual acuity alone does not fully capture its impact.
- ⇒ Outcome measures used in nystagmus research are highly variable, limiting comparison across studies.

WHAT THIS STUDY ADDS

- ⇒ This scoping review identified 145 outcome measures and 196 measurement instruments across 235 studies.
- ⇒ Outcome assessment in nystagmus extends beyond visual acuity, and included nystagmus characteristics, visual function, reading performance, visual search, patient-reported outcomes, quality of life, ocular alignment and non-ocular functional measures.
- ⇒ Considerable heterogeneity exists in how outcomes are measured and reported.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

- ⇒ These findings provide a comprehensive catalogue of candidate outcome domains to inform development of a core outcome set for nystagmus research.

by the Committee for the Classification of Eye Movement Abnormalities and Strabismus (CEMAS).^{2 3}

Infantile nystagmus develops at birth or shortly afterwards, most commonly between 4 and 6 months of age. It is often idiopathic; however, it can be secondary to underlying ocular or non-ocular pathologies including albinism, neurological conditions and retinal disorders.⁴

Acquired nystagmus can be transient or persistent and has a multitude of underlying causes. These are broadly secondary to either central nervous system pathology (eg, brain-stem dysfunction) or vestibular pathology (eg, Ménière's disease).⁵

It is well-documented that nystagmus causes visual disability and has significant effects on quality of life.⁶ Reduced visual acuity (VA) is common and corresponds to nystagmus



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waveform characteristics across observers.⁷ However, a fundamental difference between infantile and acquired nystagmus is that people with acquired nystagmus are far more likely to report the presence of oscillopsia (an oscillating visual scene).⁸

Visual function varies between patients due to a multitude of factors including nystagmus type, underlying cause and extent of visual adaptation. Further, it can be affected by many dynamic factors including gaze position, stress and simply the time of day or week.^{9 10} Those affected typically have difficulties with crowded letters and require additional time to see targets (slow-to-see phenomenon).^{11 12} They often develop a compensatory head turn or tilt in order to benefit from a null zone, a visual angle where oscillations are reduced and visual function is maximised, which can lead to torticollis and neck strain.¹³ These factors can result in significant difficulties with daily function and so restrict the quality of life of affected patients further.

Given the dynamic nature of nystagmus on both visual function and quality of life, it is widely accepted that basic quantitative measures, such as VA, alone are imperfect measures.¹⁴ Therefore, research groups have developed mathematical models to provide predicted functional VA for infantile nystagmus patients based on eye movement recordings.¹⁵ However, these have not been universally adopted and require sufficient patient data and costly equipment for accuracy.¹⁶

This lack of consensus on outcome measures has additional implications for developing and evaluating interventions for nystagmus. There are currently some management options for nystagmus including extraocular muscle surgery to adjust the position of an eccentric null zone to a more central position, contact lenses and pharmacological therapy.¹⁷ However, published studies that assess their effectiveness are inconsistent in their use of outcome measures.¹⁴ Therefore, we aimed to perform a scoping review of the nystagmus literature to determine all published visual function and quality of life outcome measures and the methods by which they are measured.¹⁸ This will facilitate work towards a standardised core outcome set (COS) development programme.

METHODS

Development of the search query

A preliminary data search of relevant articles through Scopus and Google Scholar informed the development of the search query.

We limited the term 'nystagmus' to the title given the findings of our preliminary data search and an abstract, keyword and full text review of a sample of the broad published literature.

Given the potential number of visual and quality of life outcomes, we used the following key terms to ensure all relevant studies were identified: vis* (vision, visual), measur* (measuring, measurement), therapy and treatment.

This resulted in the generation of the following search query: (TITLE (nystagmus) AND TITLE-ABS-KEY (vis*) OR TITLE-ABS-KEY (treatment) OR TITLE-ABS-KEY (therapy) OR TITLE-ABS-KEY (measur*) AND (LIMIT-TO (LANGUAGE, 'English'))).

The search query was run through Scopus, Medline and Embase on 24 April 2024 to ensure a thorough analysis of the known literature. The date of article publication was not restricted to ensure all relevant outcome measures were included, even though some associated instruments may be outdated. The search was repeated on 3 April 2026 with the same criteria. An additional 17 papers met the inclusion criteria; however, on outcome analysis, no newly reported outcomes were identified.

Further, the grey literature was assessed through reviewing systematic reviews, checking reference lists and inclusion of conference proceedings.

Eligibility criteria

Included studies were required to include at least one visual function measurement or quality of life outcome. Articles were either interventional studies or measurement studies that measured nystagmus outcomes (characteristics or visual function) under differing conditions.

We defined visual function as a measurable performance of the visual system in interpreting a target stimulus.¹⁹ Visual disability and visual-related quality of life relate to the effect of vision on a person's daily functioning and well-being.²⁰

The following types of studies were included: case reports, case series, conference papers/abstracts, letters to the editor and original research (cohort studies, case control, randomised control trials, etc) articles.

Exclusion criteria included animal studies, book chapters, systematic reviews and case series without explicitly defined outcomes.

Studies were restricted to the English language.

Protocol registration and reporting

We used the Joanna Briggs Institute's manual to develop our scoping review protocol which we published in the International Platform of Registered Systematic Review and Meta-analysis Protocols.^{21 22}

Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) for Scoping Review was used to report our study outcomes.²³

Article screening and data extraction

Title, abstract and full-text screen was performed by NC with any uncertainty checked and confirmed by HL.

The data extraction form was developed during protocol development after consensus between authors to ensure alignment with the study aims. It was completed by two independent researchers (NC and HL) for each paper with all discrepancies between the forms resolved through discussion. A third reviewer was available for

consultation; however, consensus was reached through discussion on every occasion.

Data extraction included the following:

1. Bibliographical information (author, year, doi, country).
2. Nystagmus aetiology (age, type, underlying diagnosis).
3. Aim of the article.
4. Outcome measure(s) of visual function or quality of life (eg, best-corrected monocular VA) and working definition if ambiguous.
5. Instrument(s) used for outcome measure.

We defined an instrument as a process or tool by which an outcome measure is quantified and does not necessitate a physical device. Different variations of instruments were counted separately to ensure all variables are recorded.

The quality of the evidence through a bias assessment was not performed given the scoping nature of the review and our aim to compile all outcome measures regardless of their evidence.

Non-ophthalmic outcomes related to determining underlying diagnoses (eg, genetic analysis) were not included as they do not directly relate to visual function or quality of life.

The outcome measures and instruments generated by the scoping review were summarised and a candidate list was generated.

Literature review software and data analysis

Papers generated by the literature search were exported into Rayyan software (Rayyan Systems, USA).²⁴ This facilitated the removal of duplicates and was used for the title, abstract and full-text screens.

Data were exported into Microsoft Excel to facilitate analysis and graphic production.

Outcome measures were grouped based on similar characteristics after discussion between authors.

RESULTS

Study selection and included articles

A total of 235 articles met the inclusion criteria, accounting for 5880 patients with nystagmus.

Figure 1 shows the PRISMA flowchart for our literature review.

The majority of articles (173 articles) included were original research. A further 25 case series, 28 case reports and 9 conference abstracts were also included.

Included articles were published from a diverse group of countries spanning six continents. The most common countries of origin were USA (97 articles), UK (46 articles), Australia (11 articles), Germany (11 articles) and India (10 articles).

The following countries published more than one included article: The Netherlands (n=6), Iran (n=5), Türkiye (n=5), Switzerland (n=5), Canada (n=5), Japan (n=4), China (n=4), Spain (n=4), Italy (n=4), Egypt (n=3), Malaysia (n=2), Israel (n=2) and South Korea (n=2). The following countries published one included

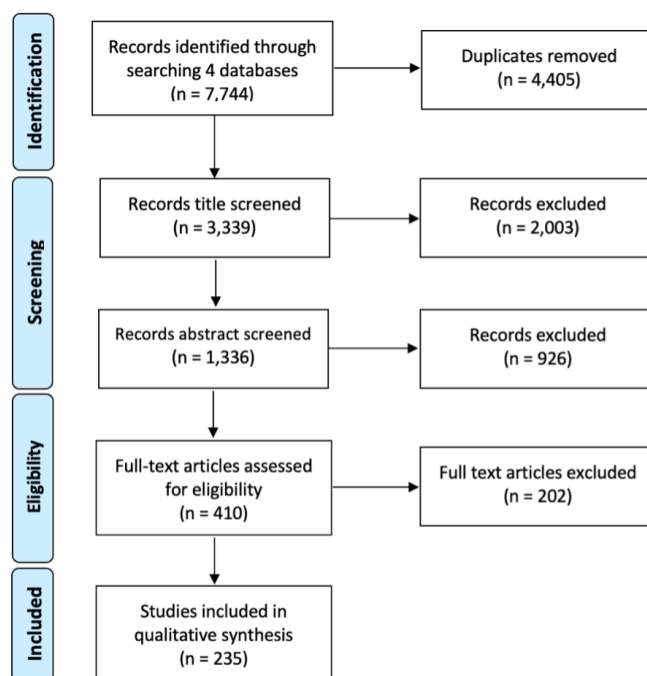


Figure 1 PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram representing the search process.

article: Mexico, Puerto Rico, Belgium, France, Hungary, Portugal, Slovenia, Brazil and Sweden.

Most articles (180 articles; 3916 patients) assessed only patients with infantile nystagmus. Thirty-two articles (260 patients) solely included patients with acquired nystagmus and 23 articles (1704 patients) had no restriction on underlying nystagmus aetiology.

Articles tended to define sub-diagnoses of patients with nystagmus. For patients with infantile nystagmus, 36 underlying diagnoses were extracted from articles with the most common being idiopathic (150 studies), albinism (89 studies), optic nerve hypoplasia/dysplasia (27 studies), congenital cataract (16 studies) and retinal dystrophy (12 studies). Thirty-one underlying causes of acquired nystagmus were defined with the most common being multiple sclerosis (23 studies), cerebellar degeneration (13 studies) and brainstem infarction/haemorrhage (9 studies). The full list of sub-diagnoses can be found in online supplemental appendix 4.

Articles tended not to restrict the age of patients with this being the case for 101 articles (3265 patients). However, 48 articles only included paediatric (<18 years old) patients (1728 patients), and 76 articles included only adult (>18 years old) patients (741 patients). Ten articles (146 patients) did not state the age of patients included.

Eighty-nine (37.8%) articles aimed to measure nystagmus characteristics or visual function under different conditions and 146 (62.2%) articles reviewed outcomes of an intervention on nystagmus. These interventions included variants of extra-ocular muscle surgery (75 articles), pharmacological therapy (31 articles),

Table 1 Grouped outcomes measures extracted from included studies with associated number of individual outcomes and instruments

Grouped outcome measure	Definition	Total number of outcomes	Number of instruments (including different working distances)	Number of articles assessing grouped outcome
Visual acuity	Highest resolvable spatial frequency at maximum contrast	27	84	221
Nystagmus features	Characteristics or qualities of the nystagmoid movements	33	4	158
Foveation/function models (<i>Nystagmus features subset</i>)	Mathematical algorithms utilising nystagmus characteristics to derive predicated optimal vision		8	12
Visual function (VF)	Psychophysical response to stimuli (not including VA)	11	30	76
Reading assessment (<i>VF subset</i>)	Assessment of functional ability to use near text	8	6	15
Visual search assessment (<i>VF subset</i>)	Functional ability to engage with a visual environment in a fixed timeframe	4	4	11
Ocular morphology	Assessment of structural components of the eye	3	5	116
Orthoptic and ocular alignment features	Identification of defects in eye movements (except nystagmus), head posture and binocularity	20	63	154
Patient-reported outcomes	Personal opinions and feelings delivered in a questionnaire or free text		30	75
Non-ocular features	Assessments of non-ocular but integrated systems for neurological nystagmus (eg, gait assessment)		6	16

All data extracted from each individual article can be found in online supplemental appendix 1.
VA, visual acuity.

biofeedback techniques (11 articles), optical correction (13 articles) and others (16 articles).

Outcome measures

Outcome measures were grouped into similar categories which are summarised in [table 1](#).

Full outcome measures and instruments are summarised in online supplemental appendices 2 and 3 with definitions of ambiguous outcomes.

Visual acuity

Twenty-seven different VA measurements were identified across the articles. These took into account the following factors: binocularity, refractive correction, null zone utilisation, gaze position, time restriction, luminosity, contour interaction, crowded letters, time of day, stress level and retinal image motion.

Fifty-six different instruments were used to measure these VA outcomes. Forty-three were generic instruments and 13 were custom as specified by their individual articles.

Twenty-six generic instruments had working distances defined by at least one study. If the same instrument with different working distances is counted separately, this would result in 84 total instruments. Working distances for instruments are shown in online supplemental appendix 3.

Nystagmus features

Nystagmus features were identified by either video-oculography, electro-oculography or by direct visualisation of eye movements by an examiner. Micro-perimetry was additionally used to determine fixation stability and preferred retinal locus.

Video-oculography encompasses a variety of recording techniques including infrared, high-speed video cameras, scleral search techniques and more.

Modifications to the patient state during recording included: eyes open/closed, addition of Fresnel prisms, convergence, differing gazes, induced vestibular response, visual demand/stress, monocular cover (using opaque occluder, fogging, filters).

Fixation distances for subjects varied significantly and when defined by studies included 12 different near fixation points ranging from 18 to 80 cm, and 18 different distance fixation points ranging from 1 to 7 m.

Gaze fixation also varied significantly between studies. For horizontal gaze, common fixation points included $0\pm 20^\circ$, 30° or 50° , and for vertical gaze, common fixation points included $0\pm 20^\circ$, 25° . Increments tended to be in 5° or 10° steps across these ranges.

These instruments were used to determine 33 unique features of the nystagmoid movements including amplitude, frequency, waveform (including identification of periodic alternating and latent pathologies), intensity, velocity, dominant plane, foveation characteristics, null zones, direction, saccades, gaze fixation, gaze preference, voluntary control, fixation stability, preferred retinal locus and dynamic movement analysis.

Visual function (excluding VA)

Visual function assessed 11 outcomes including: contrast sensitivity, visual field, colour vision, dark adaptation response, retinal functional response and micropertometric sensitivity, velocity discrimination thresholds, coherent motion perception, dominant eye determination and pupillary response (although pupillary responses are not consciously perceived by the patient, we also included them in this category as it evaluates afferent visual pathway function).

These were measured using 30 different instruments, 3 of which were custom to specific articles.

Ocular morphology

Ocular morphology assessed the structure of the eye and includes the following three outcomes: anterior segment structure, posterior segment structure and refraction.

Instruments to facilitate these outcomes included: refraction, slit lamp examination, ophthalmoscope (direct and indirect) and ocular coherence tomography.

Orthoptic and ocular alignment features

Orthoptic and ocular alignment features incorporated 20 outcomes and included measures of ocular alignment, motility, binocularity (stereopsis, fusion amplitude, retinal correspondence, ocular suppression), head posture, convergence, optokinetic reflex response, vestibulo-ocular reflex response and accommodation. Fifty-three unique instruments were used for orthoptic examination.

Eleven instruments had defined working or fixation distances. If the same instrument with a different working or fixation distance is counted separately, this would result in 63 total instruments. A full list of these can be found in online supplemental appendix 3.

Reading assessment

Objective reading assessment was performed by 15 different studies and assessed the following characteristics: reading acuity (static and gaze-contingent), reading speed, time to read set length paragraph, critical print

size, reading acuity reserve, word reading latency and percentage of words skipped.

This was facilitated using the following instruments: logMAR chart, Radner reading chart, international reading speed texts, Smith-Kettlewell charts, vertical text (Hebrew) charts and stopwatch timed exercises.

Visual search assessment

Visual search assessment characterises the ability to locate a desired object among distracting visual stimuli. It is impaired in the 'slow-to-see' phenomenon where individuals take longer to visualise a target. Eleven studies assessed these characteristics and outcomes included: response time to stimulus (acquisition/search time), harmonicity index, target search accuracy.

These outcomes were facilitated utilising stopwatch timed exercises ($n=1$), oculography when presented with optotypes ($n=4$), reading text ($n=3$), tablet/computer-based task ($n=3$).

Foveation/visual function models

There were seven statistical or mathematical models identified that defined predicted functional VA or foveation characteristics.

These included expanded nystagmus acuity function (NAFX) ($n=19$), nystagmus optimal fixation function ($n=5$), nystagmus acuity function for position only, nystagmus foveation function ($n=1$), automated nystagmus acuity function ($n=1$), Daroff-Dell'Osso Behaviour Ocular Motor System Models ($n=2$) and gaze-dependent functional vision space ($n=1$).

Patient-reported outcomes

Patient-reported outcomes were common across articles and were identified by either free text questions or a formal questionnaire. 75 studies included these outcomes, with 13 studies utilising an established questionnaire (eg, National Eye Institute Visual Functioning Questionnaire 25). Sixteen questionnaires were used and 12 free test questions looking at subjective opinions of the following: VA, contrast sensitivity, oscillopsia and associated symptoms, reading ability, cosmesis, quality of life, anomalous head position, neck discomfort, effect on driving, visual vertical, associated vestibular symptoms and visual fatigue.

Non-ocular features

Non-ocular features were nystagmus associated outcomes not related to visual function. The majority of these were for patients with acquired nystagmus. These features were assessed through the following examinations: basic neurological, audiological, neuro-vestibular, gait/locomotor, posturographic and neuropsychological (cognitive, visual-cognitive and learning abilities).

DISCUSSION

Lack of consensus for nystagmus outcomes

Our study has confirmed that there are a significant number of outcomes that can be used to measure visual

function and quality of life in nystagmus. Across all our broad domains, we identified 150 different outcome measures characterised by 196 instruments measured in subjects with 67 different sub-diagnoses of nystagmus. Further, we identified significant heterogeneity in outcomes measured by research groups, especially for studies assessing nystagmus interventions. These range from solely measuring distance VA to assessing factors across most of the domains we identified.^{25 26}

Articles included in our study encompassed a significant time period, ranging from 1948 to present day. Therefore, it is likely some of these differences can be attributed to a developing understanding of the effect of nystagmus on visual function over time. This can be seen in the greater prioritisation of outcomes related to the 'slow-to-see' phenomenon or the effect of nystagmus on reading in more recent articles. However, even in articles with similar published dates and locations, outcome measures can vary significantly.

This not only highlights the heterogeneity of outcome prioritisation but also the clear varied effect on visual function and quality of life posed by nystagmus. Studies assessing torticollis and neck strain may report this as the factor limiting quality of life in their cohort, while this may not even be a feature in other cohorts. Studies universally cited VA can be significantly affected in nystagmus patients with acuities varying from normal to severely impaired.¹⁷ This emphasises the individualised experience of nystagmus on those affected.¹⁴

Additionally, while excluded from our study, a number of articles identified during screening solely looked at eye movement characteristics as opposed to visual function as their outcome measures.

Given the varied impact of nystagmus on patients, it is unclear which outcomes are important to prioritise in research studies and nystagmus research groups are yet to formalise a COS.

Functional assessments of nystagmus

For all medical conditions, measurement of patient-centric factors is important for both determining its burden and to aid in decisions about management; especially as evidence-based medicine is increasingly practised.²⁷ These factors can be either objective (eg, numerical logMAR visual acuity) or subjective (eg patient questionnaires) and may or may not determine the functional outcome of patients. This has been studied extensively in conditions such as spinal stenosis, where the current methods of visualising pathology do not always clearly correlate with the patient experience.²⁸

This phenomenon can also be seen in nystagmus given the dynamic nature of the condition and diversity of types. Almagren *et al* identified four domains that can significantly affect visual function in nystagmus, namely, eye movement, psychological state, gaze angle and crowding.¹⁵ Inadvertent changes in any of these may give a static objective outcome that does not mirror the patient's lived experience with nystagmus.

Further, as the compiled outcomes from our included studies span ten broad domains of visual function and quality of life, there are lots of functional outcomes that need to be assessed for a holistic overview of nystagmus. Studies have alluded to the necessity of identifying the most important outcome for measuring nystagmus¹⁴; however, it is likely one or few outcomes will likely be insufficient given the dynamic patient experience.

Nystagmus can affect the quality of life of patients in a significant and varied manner. From an early age, children with nystagmus may be affected by visual processing delays that are not well accommodated for in a school environment.²⁹ This may extend into the workplace, especially as public knowledge about the condition is limited.^{6 30} As the effects of nystagmus can be broad, a patient's primary concern may not be directly visual, for example, torticollis secondary to an abnormal head posture. We believe more research is needed to further characterise the impact of nystagmus on quality of life which could be facilitated by a formal systematic review on this topic.

Functional assessments are also likely to vary between infantile and acquired nystagmus. While experienced by some patients with infantile nystagmus, oscillopsia is common in acquired nystagmus and can be severely disabling to affected patients.⁸ Further, patients with acquired nystagmus usually have concurrent pathology restricting their quality of life.³¹ Therefore, it is likely that prioritised outcomes in acquired nystagmus may differ, further emphasising the necessity for a combination of subjective, objective and dynamic outcomes.

Our study included articles that assessed 67 different sub-diagnoses of infantile and acquired nystagmus, of which some were highly prevalent. These subtypes can have additional effects on visual function and so, are likely to require specific functional outcomes that are less appropriate for idiopathic cases. An example of this is in albinism; photosensitivity is a prominent feature due to concurrent ocular changes and would need to be prioritised.³² However, in idiopathic infantile nystagmus, this feature is less frequently seen and so poses less value as an outcome measure in these patients. Therefore, for common nystagmus subtypes, they would likely benefit from their own unique visual function and quality of life outcomes.

Additionally, while it is likely paediatric cohorts would prioritise similar domains, they will require tailored instruments to facilitate accurate measurement of outcomes.

Mathematical models for VA

Basic measures of VA, such as a distance Snellen chart, have been widely accepted as an imperfect measure of VA and function in patients with nystagmus.³³ There are many components of the nystagmus waveform that affect the VA and so accurate acuity is unachievable with these measures alone.

Research groups have developed mathematical models such as the NAFX to address this issue.³⁴ As optimal VA in patients with infantile nystagmus is presumed to be obtained during foveation periods, they use eye movement recordings to derive predicted VA and the quality of foveation. Foveation quality is important given it directly corresponds to visual outcomes and is a combination of repeated target object foveation and sufficient times of low retinal slip velocity.¹⁵

These models are often developed to use a variety of input recording to ensure accessibility; however, they can require significant data to produce valid results.³⁵ They address many of the problems with basic VA techniques; however, they only represent a predicted optimised vision and do not take into account some of the functional outcomes, such as the slow-to-see phenomenon, which other studies prioritised.

Therefore, these models can be seen as useful tools to derive an accurate predicted VA in nystagmus patients, especially for interventional cases, but should be used with other outcome measures.

Limitations

Our methodology facilitated a detailed and extensive scoping review successfully achieving our aim and identifying a significant number of outcomes measures and instruments from a wide range of studies published across the globe. We attempted to mitigate as many external factors affecting the quality of our results and data; however, a few limitations remained.

As we performed a scoping review, there was no assessment of bias within the study, therefore, we have not provided the value of the outcomes assessed. Further, we identified significantly more articles related to infantile nystagmus compared with acquired nystagmus. This is likely due to a lack of literature; however, our search query may have favoured infantile nystagmus as acquired nystagmus is more likely part of a constellation of symptoms as opposed to the primary complaint. Further, we would not have identified quality of life outcomes not secondary to visual outcomes, which may be more relevant in some patients with acquired nystagmus.

Many articles lacked detail in their description of outcomes or instruments and often did not report the instrument used to assess an outcome. Therefore, while we have extracted a significant number of outcomes and instruments, this has been limited by the varied quality of methodology reporting.

We primarily used one author for article screening with any uncertainty discussed with a second author given the broad nature of the scoping review. While discussion was frequent, this may represent a potential source of selection bias. Further, our language restriction to English meant that articles from a variety of research groups, especially those in Japan and China, were excluded. The databases used in our

search strategy, while extensive, did not include those focused specifically on psychology or allied health-care fields such as PsycINFO and CINAHL so may have missed some psychophysical articles.

Future work

Our review identifies a broad and markedly heterogeneous range of outcome domains and measurement instruments used in nystagmus research. These findings highlight the overdue need for consensus on the ideal outcome measures for patients with nystagmus in interventional studies.

Given the variability observed, this precludes the definition of a definitive COS based on the current evidence alone. Instead, our findings should be considered as a catalogue of candidate domains to inform future consensus development (online supplemental appendix 2).

We propose that consensus would be best facilitated through a Delphi Process involving key nystagmus stakeholders as demonstrated by similar COMET and OMERACT initiatives.^{36 37} The development of this COS requires a formal, multi-stakeholder consensus process incorporating the perspectives of patients, carers, clinicians and researchers.

Furthermore, given the symptomatic difference between infantile motor nystagmus, acquired nystagmus and nystagmus associated with specific conditions such as albinism and retinal dystrophies, future work may need to incorporate both universal core domains and condition-specific domains, which is beyond the scope of work of this review.

The findings of this review, therefore, provide an essential foundation for future consensus-based initiatives aimed at establishing standardised outcome frameworks for improving the design, reporting and comparability of nystagmus clinical trials.

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