

# INPLASY

## Measuring visual and quality of life outcomes in nystagmus; a scoping review protocol

INPLASY202450002

doi: 10.37766/inplasy2024.5.0002

Received: 01 May 2024

Published: 01 May 2024

### Corresponding author:

Helena Lee

helena.lee@soton.co.uk

### Author Affiliation:

University of Southampton.

Clancy, N; Vennik, J, Self JE; Lee, H.

### ADMINISTRATIVE INFORMATION

**Support** - None.

**Review Stage at time of this submission** - Preliminary searches.

**Conflicts of interest** - None declared.

**INPLASY registration number:** INPLASY202450002

**Amendments** - This protocol was registered with the International Platform of Registered Systematic Review and Meta-Analysis Protocols (INPLASY) on 01 May 2024 and was last updated on 01 May 2024.

### INTRODUCTION

**Review question / Objective** This scoping review aims to characterise all currently available experimental or established methods, including instruments, by which either visual function or quality of life is measured in patients with nystagmus.

**Population:** All patients with nystagmus regardless of underlying aetiology. There is no set age limit provided there was compliance with investigations.

**Concept:** Domains of Visual Function (e.g. binocular visual acuity) or Quality of Life in Nystagmus. Specific methods (e.g. Snellen Chart) by which these domains are measured.

**Context:** Any measurement, change or therapeutic intervention posed to affect the visual function or quality of life in patients with nystagmus.

**Background** Nystagmus is characterised by involuntary oscillations of the eyes, involving a slow component, that disrupts steady fixation (1). It is typically classified into physiological and pathological, with the latter being further subdivided into early-onset (childhood) nystagmus and acquired nystagmus.

Early-onset (childhood) nystagmus typically presents between 4 to 6 months. It is often idiopathic though may be secondary to other ocular conditions including those causing sensory deprivation e.g. albinism and retinal disorder (2). Early-onset nystagmus typically doesn't present with oscillopsia, however, can affect visual function. Patients often have a 'null zone' where oscillations are minimised and foveation periods facilitate their best visual acuity (3).

Acquired nystagmus is typically characterised into peripheral (vestibular) and central (central nervous system) causes. These can be transient or persistent depending on the underlying pathology.

Most patients report oscillopsia, the perception of vision ‘jumping’ during nystagmus oscillations, which can significantly affect a patient’s quality of life (4).

In addition to an effect on visual acuity, patients may have difficulties with letter crowding, additional time needed to see (slow-to-see phenomenon), and variable vision especially in periodic alternating nystagmus (5). Further patients with early-onset nystagmus may develop torticollis due to an anomalous null zone, strabismus, and amblyopia (6).

#### References

1. Abadi RV. Mechanisms underlying nystagmus. *JRSM*. 2002 May 1;95(5):231–4. doi:10.1258/jrsm.95.5.231
2. Bertsch M, Floyd M, Kehoe T, Pfeifer W, Drack AV. The Clinical Evaluation of infantile nystagmus: What to do First and why. *Ophthalmic Genetics*. 2017 Jan 2;38(1):22–33. doi:10.1080/13816810.2016.1266667
3. Dunn MJ, Wiggins D, Woodhouse JM, Margrain TH, Harris CM, Erichsen JT. The effect of gaze angle on visual acuity in infantile nystagmus. *Investigative Ophthalmology & Visual Science*. 2017 Jan 27;58(1):642. doi:10.1167/iovs.16-20370
4. Nystagmus [Internet]. 2022 [cited 2024 Apr 26]. Available from: <https://www.rnib.org.uk/your-eyes/eye-conditions-az/nystagmus/>
5. Almagren B, Dunn MJ. Measurement of visual function in infantile nystagmus: A systematic review. *British Journal of Ophthalmology*. 2023 Dec 6; doi:10.1136/bjo-2023-324254
6. Self JE, Dunn MJ, Erichsen JT, Gottlob I, Griffiths HJ, Harris C, et al. Management of nystagmus in children: A review of the literature and current practice in UK specialist services. *Eye*. 2020 Jan 9;34(9):1515–34. doi:10.1038/s41433-019-0741-3.

**Rationale** Given the varied effect that nystagmus can have on a person’s vision, quality of life and its resultant complications, it is unclear which patient outcomes should be prioritised when developing therapies for patients with nystagmus. Additionally, Almagren et al. previously highlighted the need for alternative measures to visual acuity in nystagmus due to these confounders (5). Therefore, we aim to review the published literature to ascertain which outcomes are currently assessed, the methods by which they are measured and develop a core outcome set. Given the varied effect that nystagmus can have on a person’s vision, quality of life and its resultant complications, it is unclear which patient outcomes should be prioritised when developing therapies for patients with nystagmus.

We aim to review the published literature to ascertain which outcomes are currently assessed and the methods by which they are measured.

## METHODS

**Strategy of data synthesis** A preliminary data search of relevant articles through Scopus and Google Scholar informed the development of the search query. The term “nystagmus” will be limited to the article title given the preliminary data search and resultant breadth of the published literature.

Given the potential extent of visual and quality of life outcomes, we utilised 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 to ensure a thorough analysis of the known literature. Date of article publication will not be restricted. The grey literature will be assessed through reviewing systematic reviews, checking reference lists and inclusion of conference proceedings.

All papers will be exported into Rayyan Systematic Review Software for removal of duplicates and to facilitate a traceable record between reviewers.

**Eligibility criteria** The following types of studies will be included: case reports, case series, conference papers/abstracts, letters to the editor and original research papers (cohort studies, case control and randomised control trials).

Exclusion criteria will include animal studies, book chapter, systematic reviews and case series that do not explicitly define outcomes within their methodology.

Studies will be restricted to the English language.

#### Source of evidence screening and selection

Title and abstract screen will be performed by one researcher with any uncertainty clarified by a second researcher.

Full text screen and data extraction of all studies meeting the inclusion criteria will be performed by two independent researchers.

Disagreements between researchers will be primarily resolved through discussion, however, a third reviewer is available for consultation.

---

**Data management** Data Extraction for each paper will result in the following:

1. Bibliographical information
2. Scope (use setting, measurement/change/intervention)
3. Domain(s) of visual function or quality of life (e.g. monocular visual acuity) and a working definition of the domain.
4. Outcome measurement instrument(s) utilised for each domain.

The outcome measures and instruments generated by the scoping review will be summarised and a candidate list will be generated.

**Language restriction** English.

**Country(ies) involved** United Kingdom.

**Keywords** Nystagmus; vision; visual function; quality of life; core outcome set.

**Contributions of each author**

Author 1 - Noah Clancy.

Email: [n.clancy@soton.co.uk](mailto:n.clancy@soton.co.uk)

Author 2 - Jane Vennik.

Email: [j.vennik@soton.co.uk](mailto:j.vennik@soton.co.uk)

Author 3 - Jay Self.

Email: [jes3@soton.co.uk](mailto:jes3@soton.co.uk)

Author 4 - Helena Lee.

Email: [helena.lee@soton.co.uk](mailto:helena.lee@soton.co.uk)