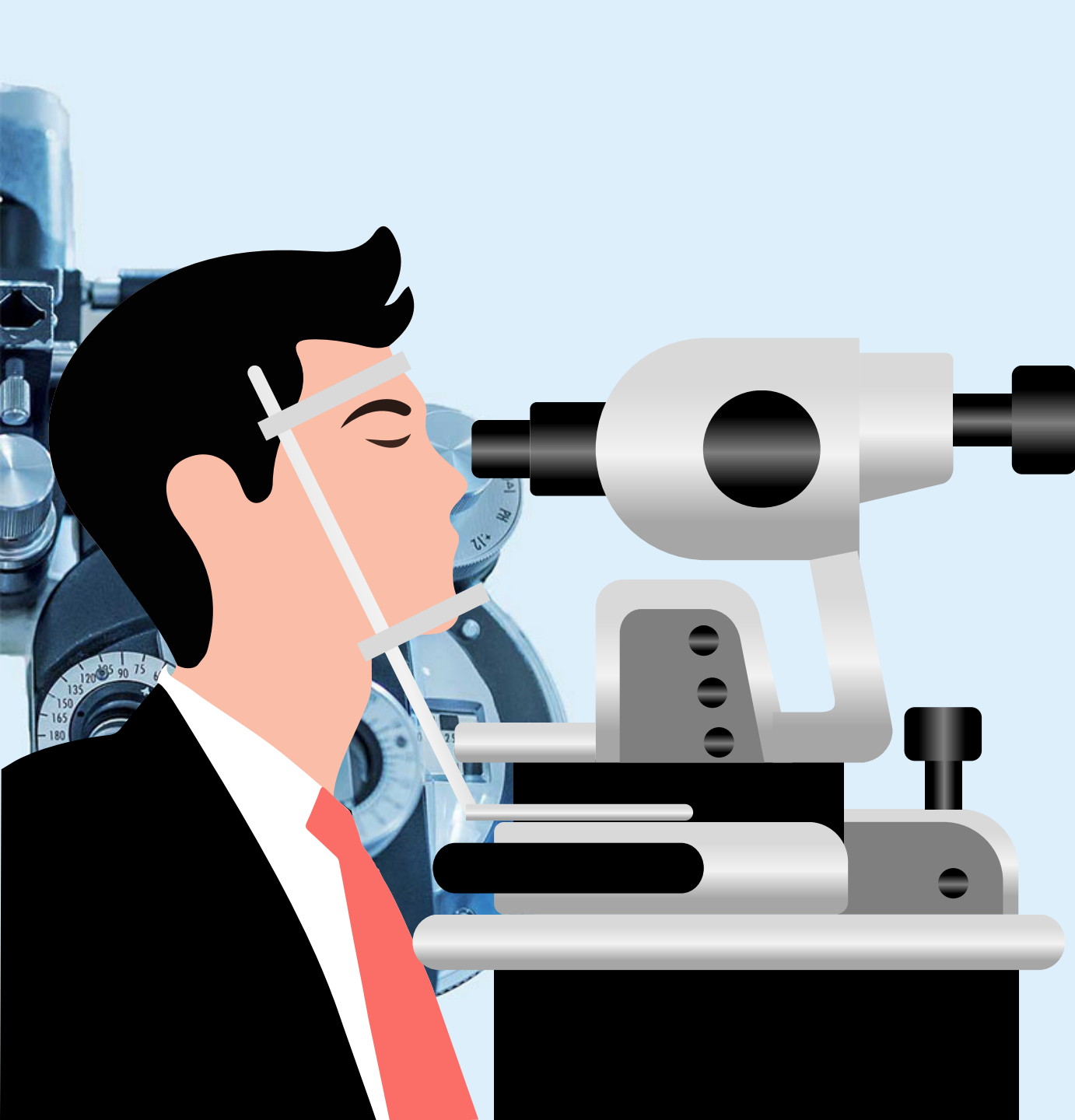


Nystagmus

Gazing back:

To what extent does the lived experience of individuals with nystagmus reflect the medical definition and diagnosis?

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Doctoral Student: University of Chester
Lecturer: UCM



Outline



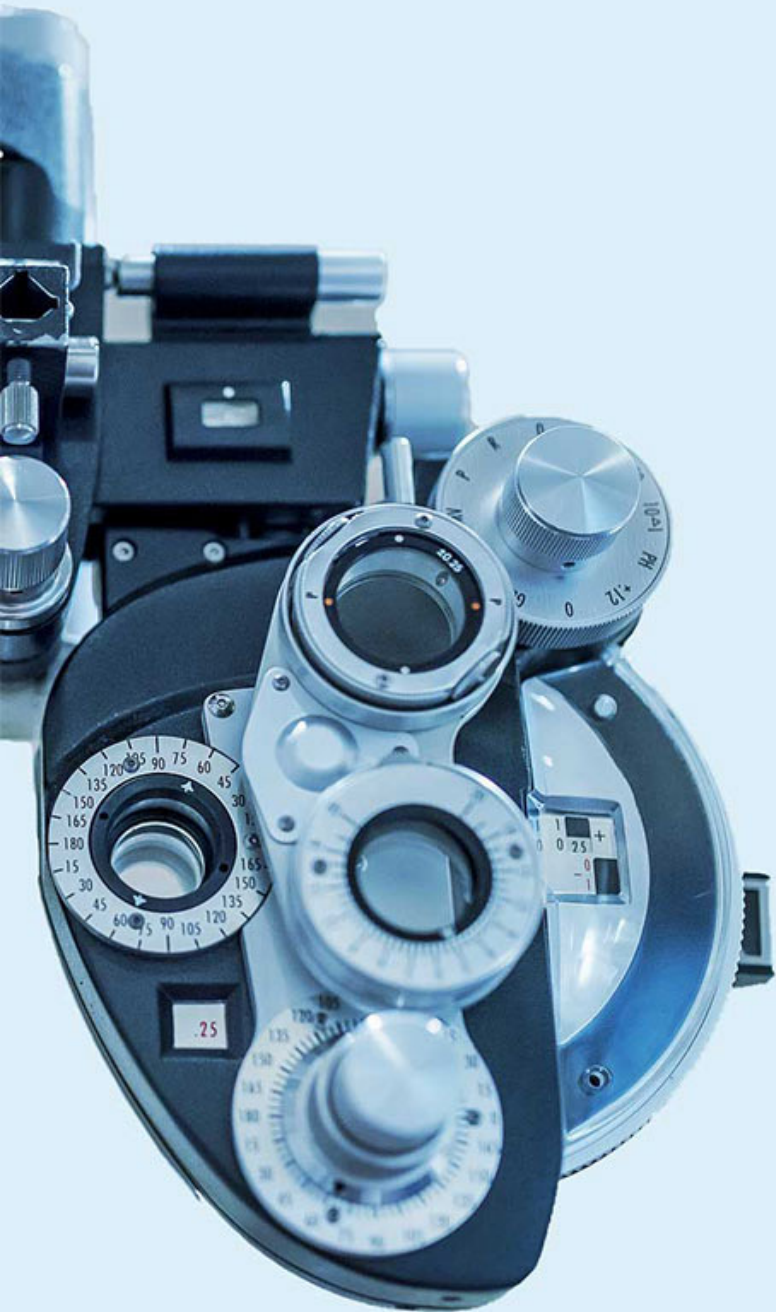
**Overview of
condition**



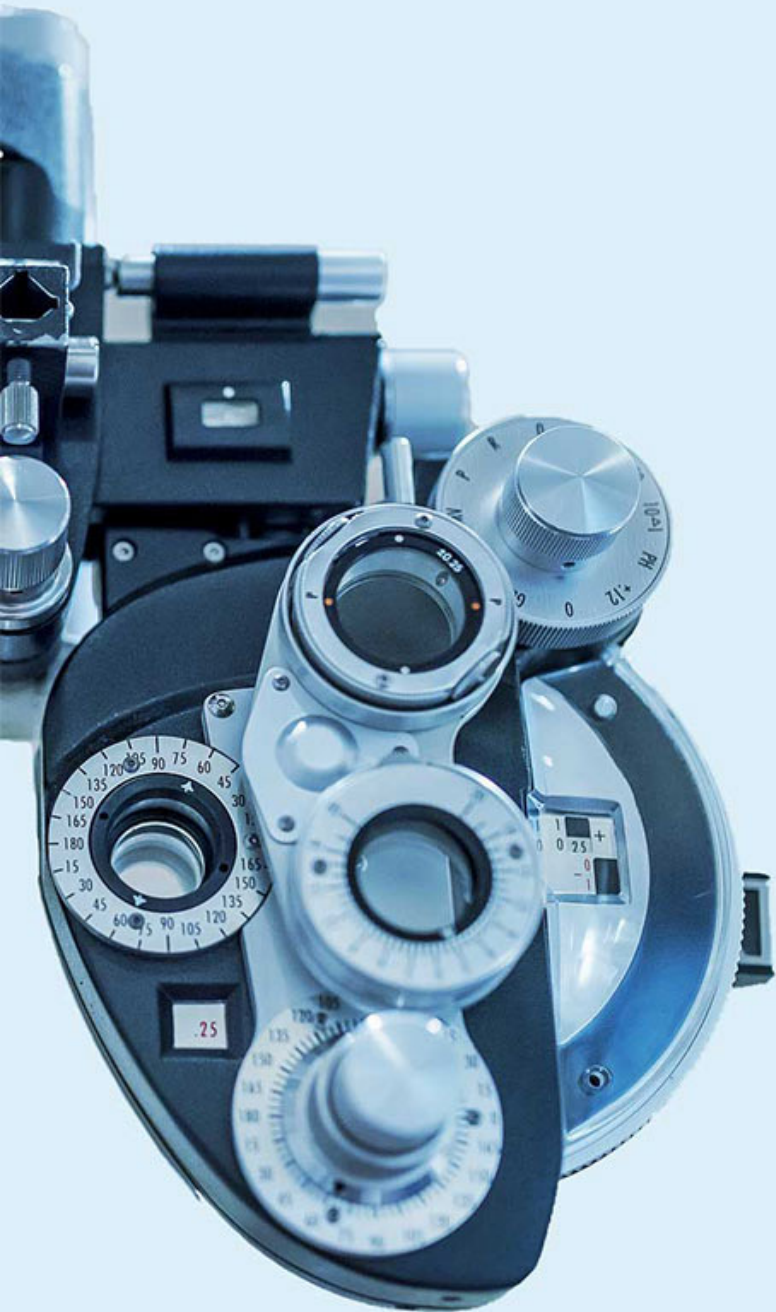
Current literature



**My Research
Methodology/Methods**



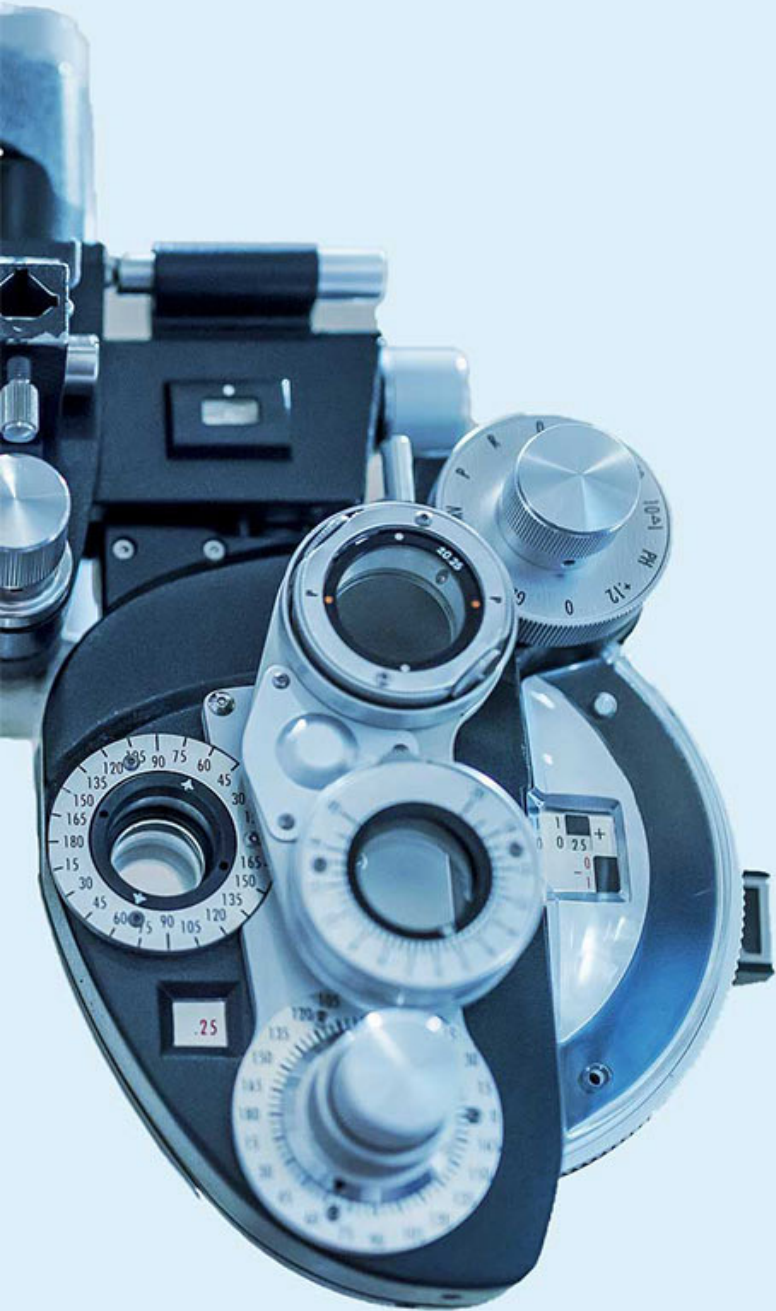
**What do you
know about
Nystagmus?**

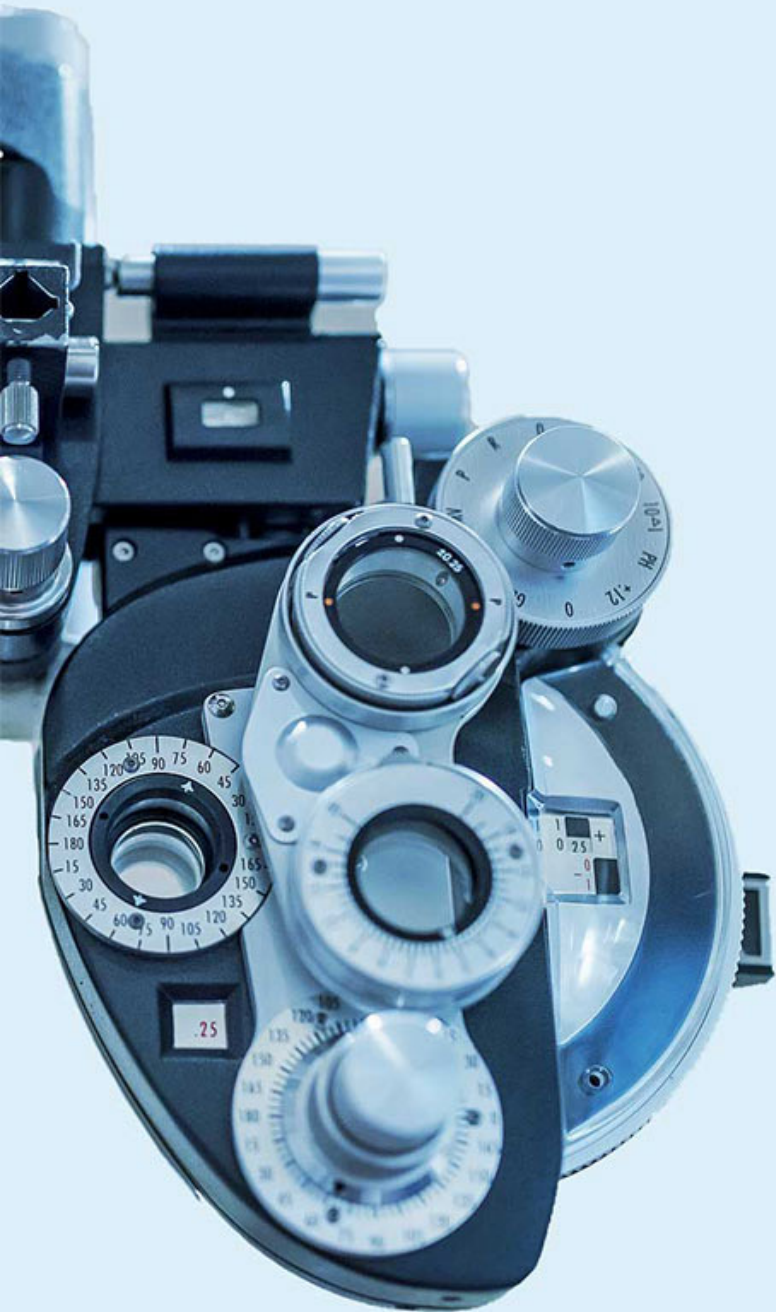


What is Nystagmus?

- Eye condition which causes involuntary eye movement (in any direction or combination)
- As many as 47 types of nystagmus have been reported in literature (Dunn, 2016)

Horizontal Nystagmus





- **At least 1 in 1,000 babies are born with nystagmus**

Many more people will develop nystagmus as adults

(Nystagmus Network, 2022)



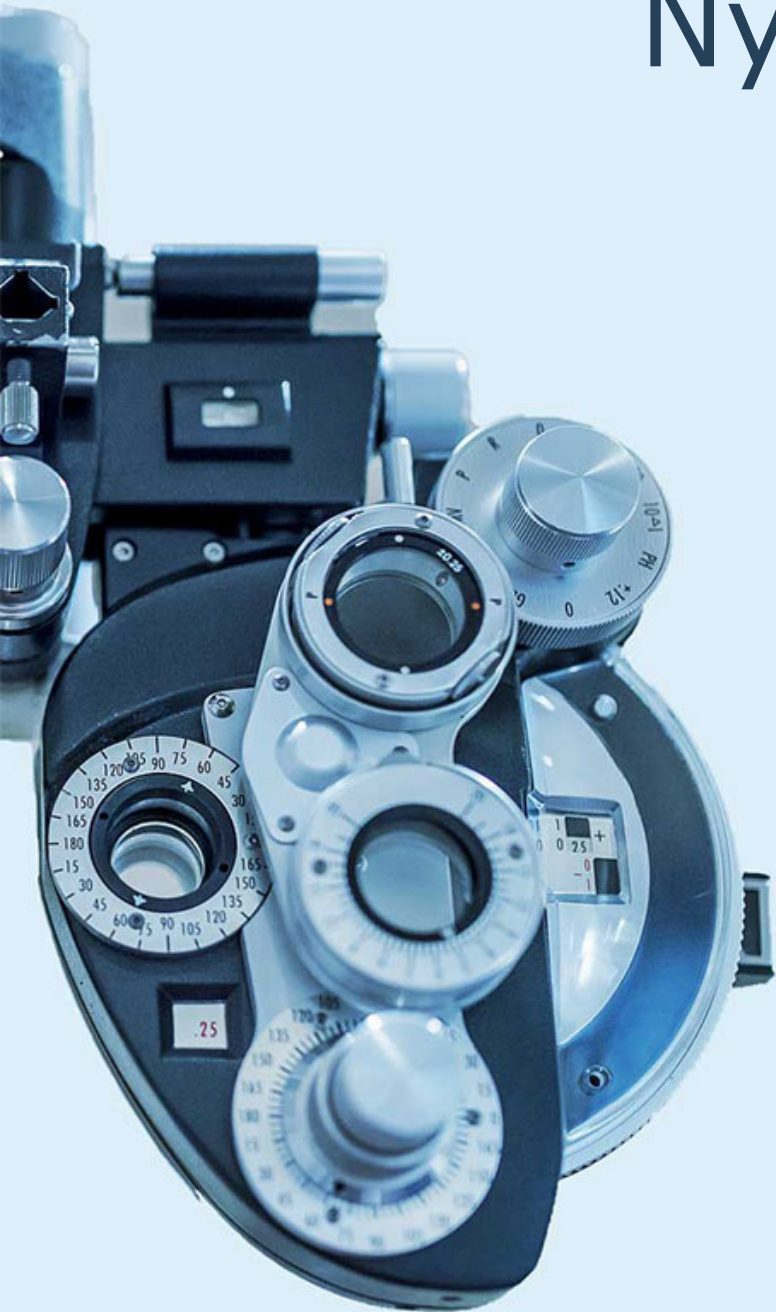
Congenital nystagmus, although often called this, is thought not to be hereditary but rather acquired after birth (or within first few months) and is now often referred to as Infantile Nystagmus Syndrome (INS)

It may present on its own or alongside other conditions



(Khanna, & Dell'Osso, 2006)) (Zahidi, Woodhouse, Erichsen, & Dunn, 2017).

Nystagmus, by George, aged 11



- My eyes sometimes move without me wanting them to
- Sometimes I find it difficult to see things
- I can only see about 3 metres clearly
- It hurts my eyes if I have to look at long distances

Nystagmus

Develops later
in life

**Acquired
nystagmus**

May develop with stroke,
multiple sclerosis, head
injury or from taking
certain prescribed or
recreational drugs

Infantile – with
identifiable
pathology

Early Onset

**Infantile -
Idiopathic**

Current Literature and Research

- From initial searches it appeared that the literature is predominantly clinical and quantitative in nature
- Limited research exists surrounding the lived experience, social and psychological aspects of the condition
- Limited studies in the area of lived experience
- Singh (2015) reiterates this in his qualitative review 'A Life with Nystagmus' noting the missing areas needed to be filled with research, particularly in the area of quality of life.

Current Literature and Research – Living with nystagmus: a qualitative study

(McLean et al., 2012).

- **Methods:** Semistructured interviews were conducted at the University of Leicester, UK with participants with acquired and infantile nystagmus. In total 21
- Interviews revealed universally negative experiences of living with nystagmus that are previously unreported
- **Results:** Analysis identified six domains that were adversely affected by nystagmus; visual function, restriction of movement, standing out/not fitting in, feelings about the inner self, negativity about the future and relationships

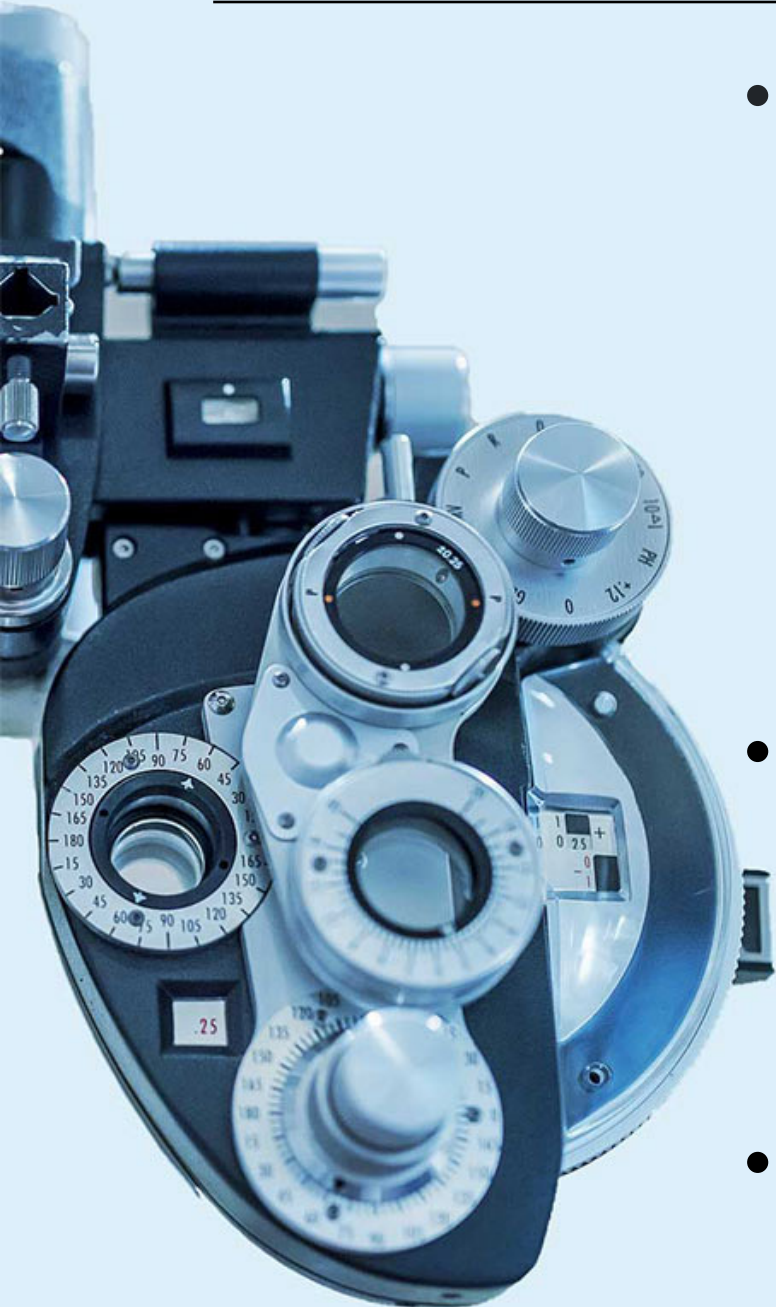
Current Literature and Research

- Rennie et al. (2022) concurs with previous authors and the general consensus of this thesis, that, there is limited literature that looks at the understanding and public or social elements of nystagmus
- Rennie et al. (2022) examined both public understanding of how nystagmus affects people who have it and the perceptions of public understanding by those with the condition and their carers
- **Conclusion:** This study highlights the lack of public awareness regarding nystagmus and suggests opportunities to increase the awareness of nystagmus

Current Literature and Research

- Studies such as Penix (2015) encouragingly point toward the need for quality of life and the patient experience to be examined
- Noting that, the existing research has looked very little at vision-specific and health in relation to life quality for individuals
- In addition, research papers that are in existence look at a range of eye conditions, rather than specifically nystagmus
- As nystagmus is complex, the lack of a condition specific research is clear and in particular how the patient lives with the diagnosis

Research Methodology: Biographical Research Methods



- A specific type of qualitative research “which uses stories of individuals and other ‘personal materials’ to understand the individual life within its social context” (Roberts 2002: 3).
- Emphasises the importance of subjective experience within historical & social contexts
- The voice of the patient rather than the medical world.

Did you know?

Richard Osman TV
presenter and
author has
nystagmus



- Dunn, M. (2016). Clinical assessment of nystagmus. *Optometry Today*, 56(7), 80-85.
- Khanna, S., & Dell'Osso, L. F. (2006). The diagnosis and treatment of infantile nystagmus syndrome (INS). *TheScientificWorldJOURNAL*, 6, 1385-1397
- McLean, R. J., Windridge, K. C., & Gottlob, I. (2012). Living with nystagmus: a qualitative study. *British journal of ophthalmology*, 96(7), 981-986.
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<https://www.dovepress.com/getfile.php?fileID=26643>
- Rennie, K., Alagendran, R., Lee, H., Griffiths, H., & Self, J. (2022). Impact of the COVID-19 pandemic on individuals with nystagmus and an exploration of public assumptions about the condition: an electronic questionnaire study. *BMC ophthalmology*, 22(1), 1-8.
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- Zahidi, A. A., Woodhouse, J. M., Erichsen, J. T., & Dunn, M. J. (2017). Infantile nystagmus: an optometrist's perspective. *Clinical optometry*, 9, 123.

