

# **A MULTI-METHODS STUDY OF THE IMPACT OF NYSTAGMUS ON THE LIVED EXPERIENCE OF ADULTS WITH THE CONDITION IN AN ISLAND COMMUNITY**

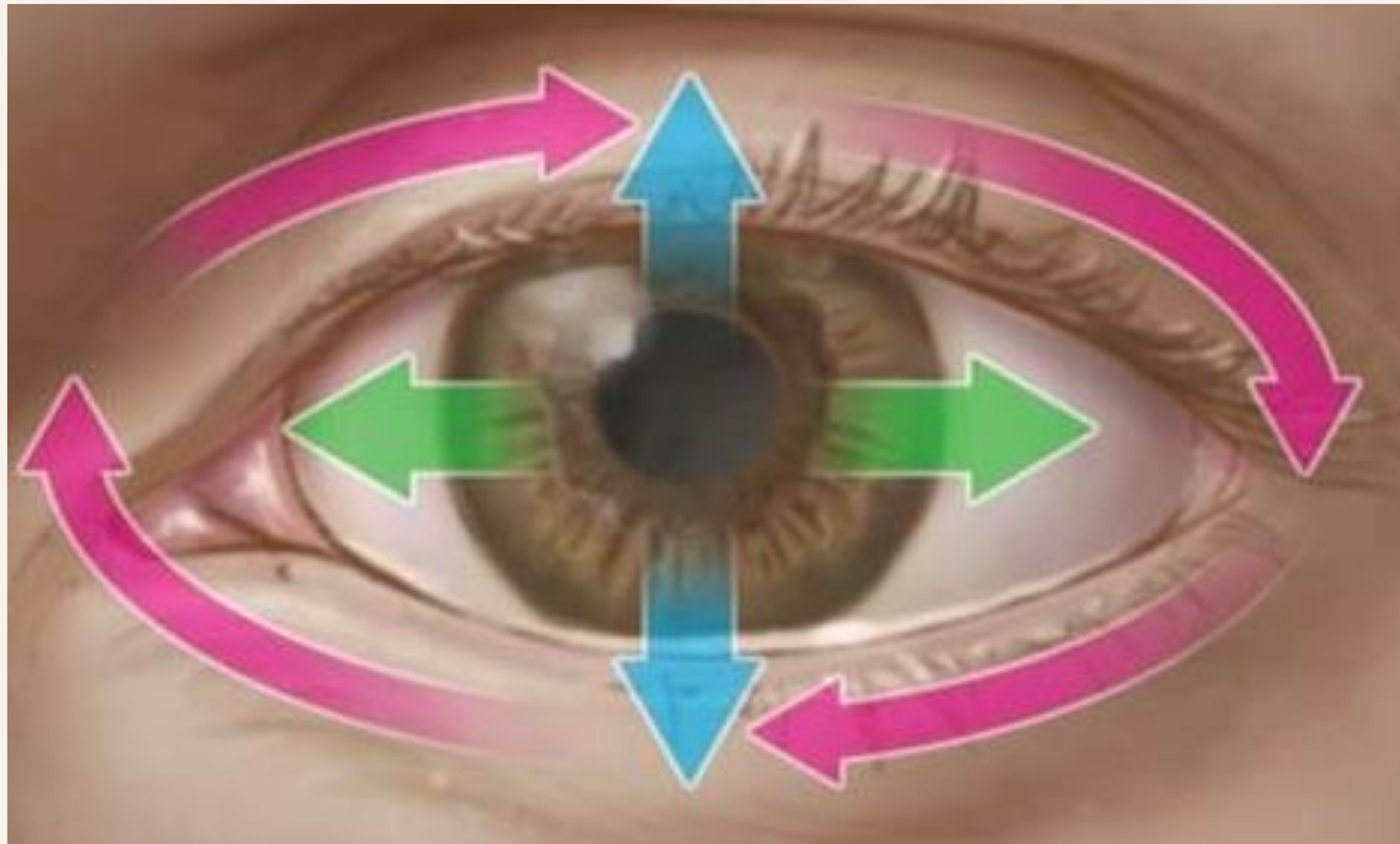
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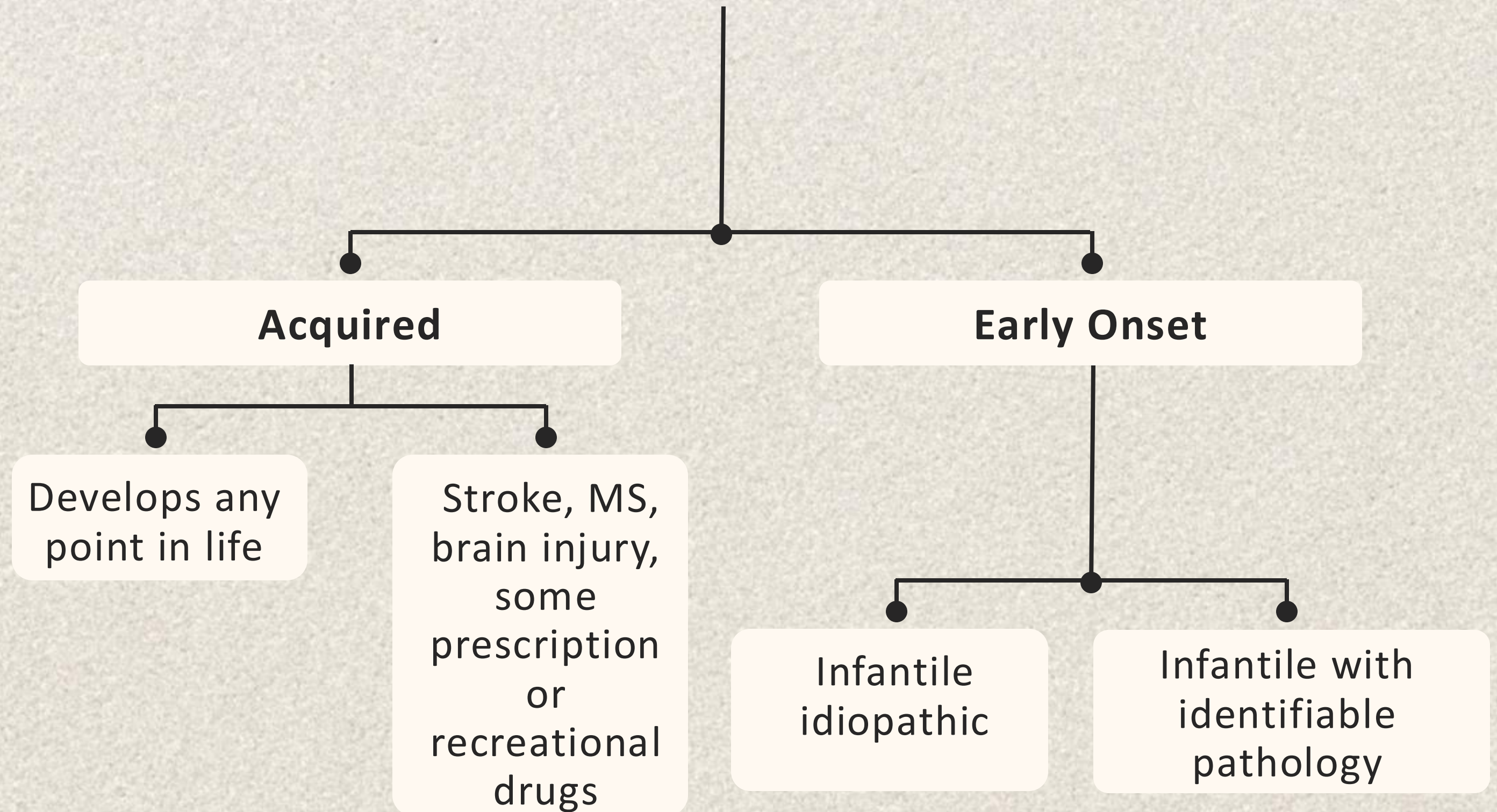
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- **Nystagmus is characterised by involuntary eye movement, these movements can present in many variations (patterns).**
- **The condition can develop in infancy or be acquired through other conditions, later in life.(Leigh & Zee, 2015) (Sarvananthan et al., 2009).**




# NYSTAGMUS



*Adapted from Dunn (2016).*

# Methodology and Methods


**What is the impact on the lives of adults living with nystagmus in an island community?**



**Theoretically this study draws on a symbolic interactionist approach, which focuses on how individuals construct the meaning around the social world and objects and experiences within it (Weber & Henderson, 2012). Favouring observation and in-person interactions to help to understand how society works' (Fuller, 2015)**



**Utilised a biographical methodology, theoretically this is a complex area rooted in the traditions of sociology and the Chicago School. Becker et al (2023)**

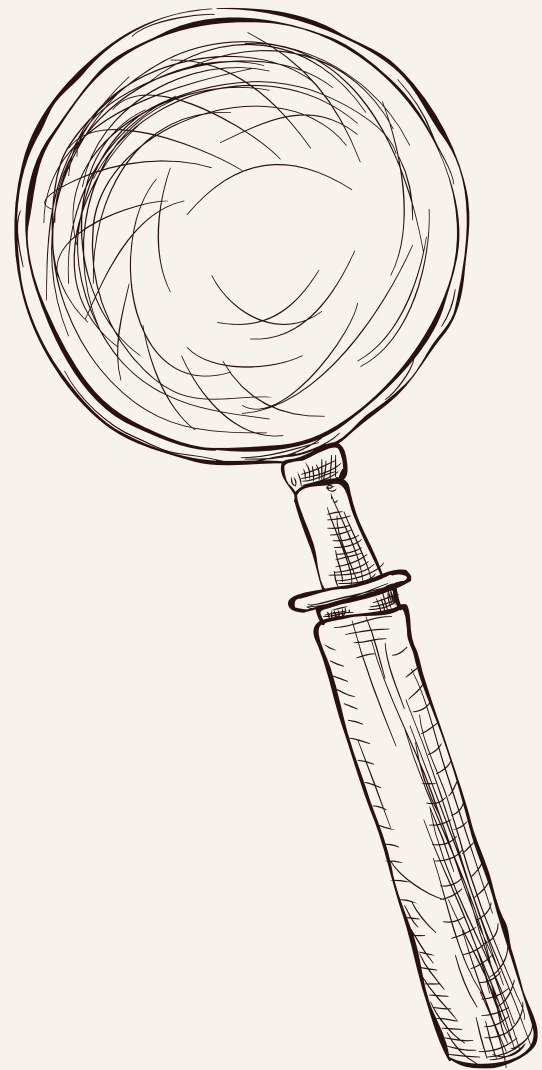


**This study draws on qualitative biographical research, through the use of semi-structured interview**

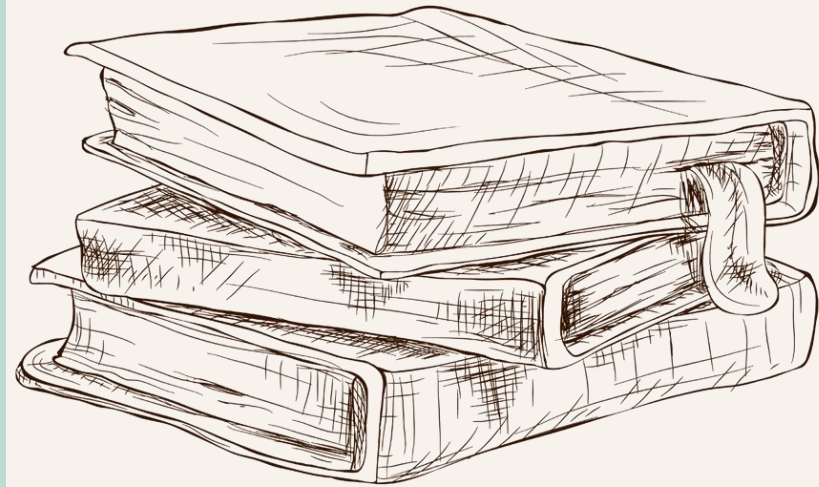
# Positionality and Reflexivity

- **Willson, James & Williams (2022) define positionality as the researcher's acknowledgment of their assumptions related to the research topic and participants.**
- **Reflexivity encourages researchers to question and address these assumptions.**
- **Holmes (2020) discusses the insider-outsider debate, highlighting that insiders may better understand cultural experiences.**
- **Being an insider enhances the researcher's empathy and connection with participants.**
- **Participants noted that I was often the first person they met with nystagmus.**

# Sample



- All participants were over 18 and lived on Isle of Man or clinicians
- Non-probability purposive sampling was used
- A total of 15 participants were interviewed, including 5 clinicians
- Reached 36% of the available sample population initially
- The final sample of 10 participants represented 15% of the adult population with the condition on the islands
- An estimated 1 in 1000 people have nystagmus, equating to approximately 67 adults on the Isle of Man with the condition



# Data Analysis

- **Inductive thematic analysis focused on themes to address the research question (Ayre & McCaffery, 2022)**
- **Interviews were transcribed, checked, and coded; codes were re-evaluated and condensed**
- **Broader themes were developed in line with the research question**
- **Directed quotes and excerpts from the data were highlighted to support the themes**

Interviewee 6

I feel that they don't listen. So I deliberately type everything out before I go and I put it down and they won't look, but you gotta' push them.

Interviewee

I don't think there's a good communication between Clinicians, Optoms, everybody involved really. (clinician)

Interviewee 4

when I look back, the management and the support I got was rubbish. but I only really know that cause I have comparison now and I know it a little bit more.

Frustration around treatment of condition (clinician and patient)







**Interviewee**

**14**  
People don't like being labelled I always think it's very hard if you put a label on somebody. Very difficult to take that label off.



**Interviewee 2**

**I do think the running theme is actually that not having the label with limitations [is better].**



**Rejecting the label**





### Interviewee 1

**No one ever ever told me. Until then, no doctor, no parent, no family member.**



### Interviewee 3

**So I never even knew the word until about ten years ago, the word nystagmus, I just used to say, oh I've got jumpy eyes.**

### Interviewee 4

**Mine is a congenital idiopathic nystagmus and that's all I knew. I didn't really delve too much into it.**



Lack of knowledge surrounding condition



### Interviewee 7

It doesn't phase me anymore, but it probably did when I was younger. People aren't bothered. It's just in your head. It's all in the mind.

### Interviewee 2

For me, I'm not not bothered by it, so a lot of the time I won't raise it. Yeah, I was younger. I used to [in school].

### Interviewee 6

Once you've got the nystagmus then really you're stuck with it, it's up to you to adapt your life to cope with it,

### Interviewee 3

I didn't think about it. It wasn't something I woke up every morning thinking about, I forgot about it.

### Interviewee 4

I might not see everything regardless of my nystagmus. You know, I think that's just the card I've been dealt.

The card I've been dealt (resilience)

Patwardhan (2024)

**Aligns with evidence that men and women experience illness differently and gender norms cause health difference e.g men reporting illness later**

Continuing gender-based trends

**Women were more willing to share experience of condition than men in the study**

# Discussion

Goffman notes: "The individual who presents himself...wishes them to think highly of him, or to think that he thinks highly of them, or to perceive how in fact he feels toward them...Thus, when an individual appears in the presence of others, there will usually be some reason for him to mobilize his activity so that it will convey an impression to others which it is in his interests to convey."

*(Goffman, 2023), The presentation of self in everyday life.*

- People present different versions of themselves in social interactions
- Playing different roles and putting on "performances" to control how they are perceived
- Managing the impression given to others in order to counter assumptions about visual impairment
- "Denying the reality of my impairment" is also discussed by (French, 2004, p.82)

# **Initial Implications of research**

- **Links with one of the few similar studies, but McLean et al, (2012) revealed universally negative experiences of living with nystagmus**
- **While negatives reported there was also a clear theme of resilience (Island community?)**
- **Clear that more awareness needed of nystagmus from clinician and patient perspective**
- **In turn increasing knowledge and improving the individuals experience of education, healthcare and experience of condition (links with schools)**
- **Plan to set up local support e.g Facebook groups etc**
- **Brought people together with myself who had never met other people with nystagmus**

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