Impact of the COVID-19 pandemic on individuals with nystagmus and an exploration of public assumptions about the condition: an electronic questionnaire study

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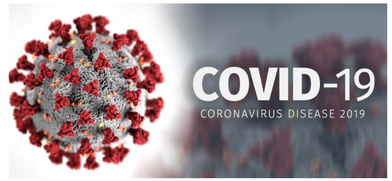
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Introduction

- Nystagmus is a disorder of eye movement characterised by an uncontrolled, repetitive, movement of the eyes
- Patients with nystagmus can have reduced visual function beyond that of visual acuity alone
- There is a lack of literature regarding the public understanding of nystagmus, and there are no published data on the impact of the COVID-19 pandemic on those with the condition

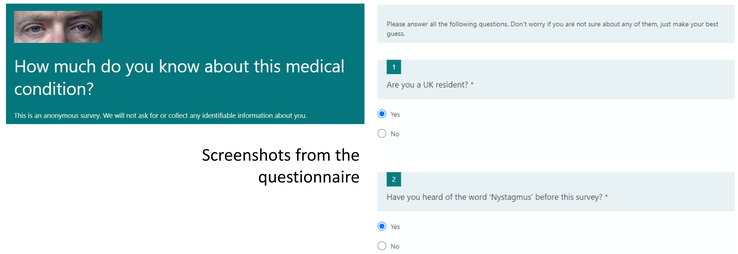
Aims

- Understand the self-reported impact of the COVID-19 pandemic on those with nystagmus
- Understand public understanding of how nystagmus affects people who have the condition
- Understand perceptions of public understanding by those with nystagmus and their carers



Methods

- Prior to designing the questionnaire, patient and public involvement work was undertaken
- The questionnaire was created on Microsoft Forms and contained a video of nystagmus to ensure that members of the public were clear about the nature of the condition.
- The link to the questionnaire was posted to social media platforms and to charity websites
- Both people with nystagmus and members of the public were recruited
- 1645 participants were recruited within the study period



Screenshots from the questionnaire

Recruitment

- Recruitment: 849 = nystagmus group, 796 = public group
- The public group was subdivided into those who did not know anyone with nystagmus (n=516) and those who did not have nystagmus but had met someone with the condition (n=280)

Results – themes from responses

- People with nystagmus consistently reported additional challenges due to their nystagmus due to the COVID-19 pandemic, for example 75.5% faced challenges with social interactions
- People with nystagmus underestimated how much the public would think that nystagmus would be an issue in their lives

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Conclusions

- People with nystagmus tended to predict that the public would not think that the condition affects their daily lifestyle as much as it actually does
- Members of the public had a greater understanding of challenges faced by individuals with nystagmus if they had met someone with nystagmus or if they had even heard of the condition. This suggests that greater public awareness of the condition could be achieved through increased exposure of the condition through media and other online methods of promotion

Future work

- Further qualitative questionnaire studies regarding nystagmus could be carried out to identify specific issues that individuals with nystagmus have faced during a lockdown and whether these are common to other disorders of vision

Nystagmus Network