

Assessing Patient Awareness and Self-Advocacy in Glaucoma Care: An Audit of Compliance with NICE Guidelines and International Glaucoma Association Policies

H. Qadri, J. Rai, A. Kadyan, Malik A
University Hospitals Birmingham NHS Trust

1 Background

- Over 700,000 people suffer from Glaucoma in the UK ¹
- In May 2022 there was a backlog of 633,000 ophthalmology patients ²
- A study conducted by the British Ophthalmological Surveillance Unit found that delays in glaucoma appointments can lead to sight loss ³
- These concerning figures highlight the need for an improvement in timely glaucoma services across the nation
- NICE Guideline NG81** emphasises the importance of patient awareness in regards to their diagnosis, treatment and follow up appointments ⁴
- Royal National Institute of Blind People** (RNIB) launched the Ask & Tell initiative which incorporates NG81 and encourages patients to advocate for themselves when experiencing delays in glaucoma services ⁵
- Patient self-advocacy could be a driving factor for change within the NHS and allow us to see an improvement in glaucoma services
- With glaucoma being the leading cause of irreversible blindness it is crucial that we tackle these issues from every aspect ⁶

2 Our Aims

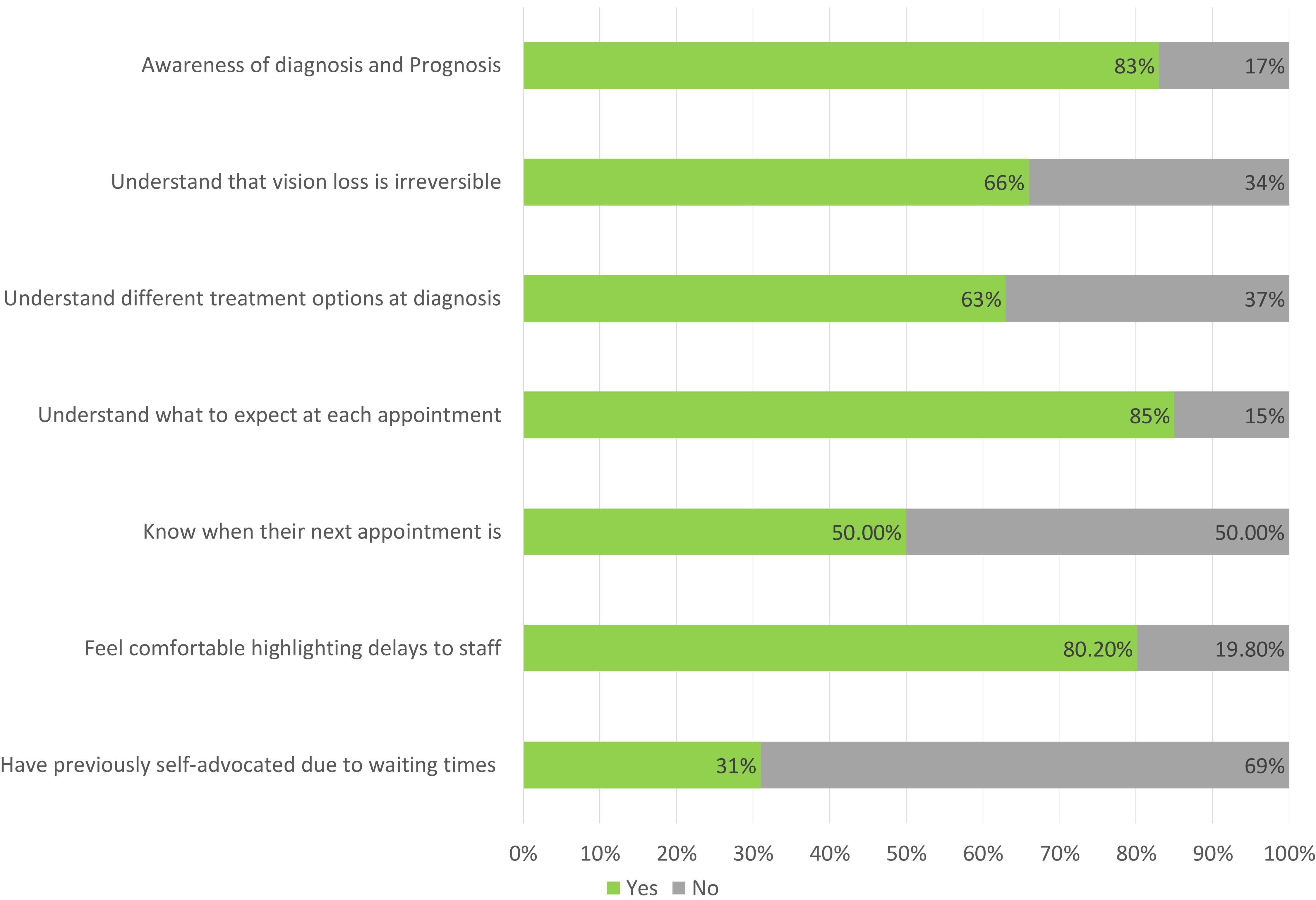
- Assess **adherence** to **NG81** in regards to whether patients had **received the necessary information** regarding their glaucoma diagnosis
- To determine the **proportion of glaucoma patients** who felt **comfortable advocating** for themselves regarding appointment delays
- To identify **preferred methods of self advocacy** and general feedback

3 Methods

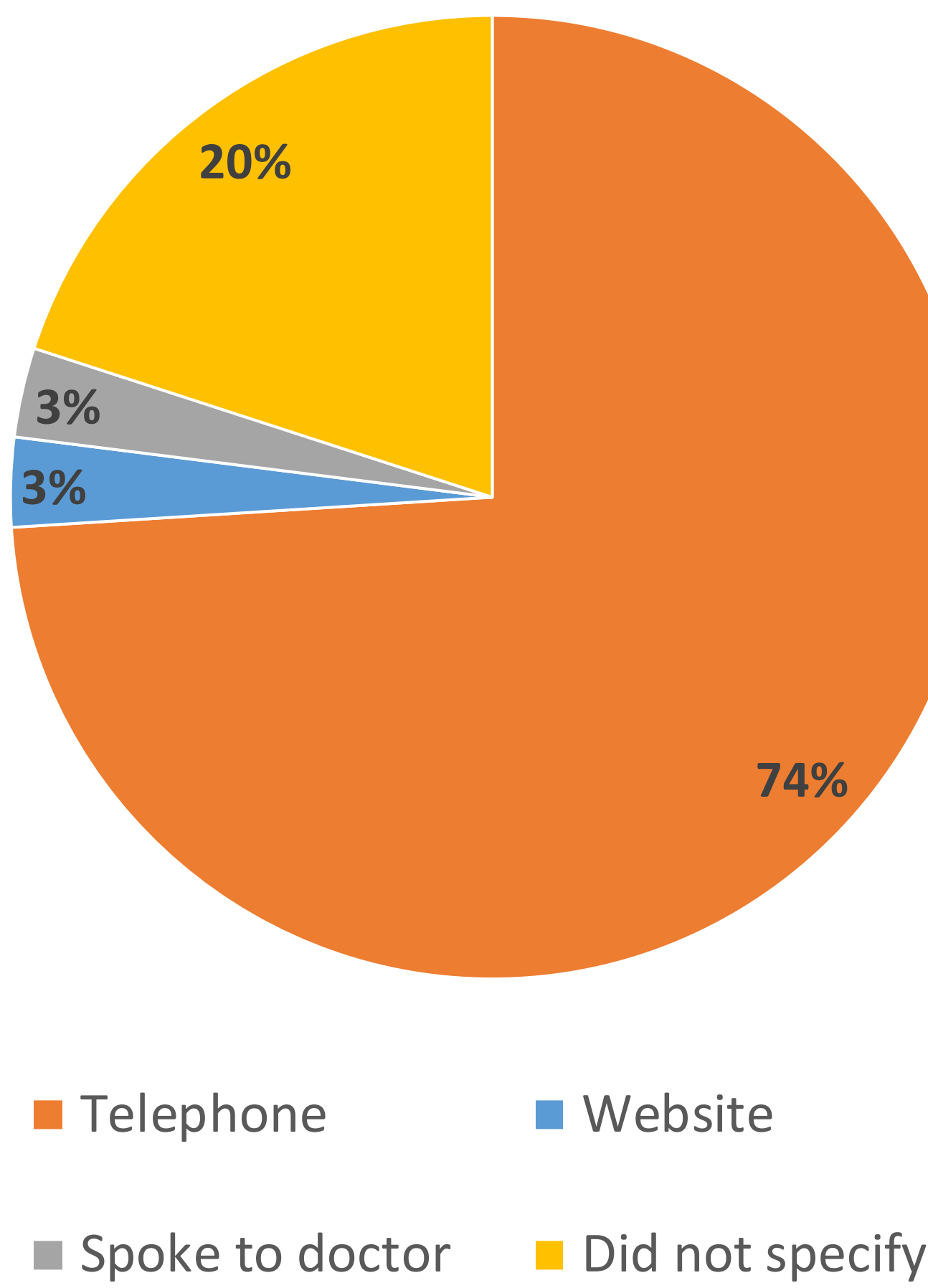
Study Type: Audit
Study Setting: Solihull Hospital – Ophthalmology Outpatient Department
Study Size: 100 patients
Study Timeframe: June – September 2024 (inclusive)
Data Collection: 10 question survey including; Yes/No questions, Likert scale (1-10) for rating importance and an open ended question for feedback
Analysis: Analysed to evaluate patient knowledge of diagnosis, treatment and prognosis; understanding of appointment scheduling; confidence raising concerns in relation to appointment delays, and preferences for communication

4 Results

Patient Awareness & Self Advocacy



Methods of Self Advocacy



5 Discussion

- This audit highlights that the majority of patients had awareness regarding their glaucoma diagnosis and prognosis.
- Only 66% of patients understood that sight loss from glaucoma is irreversible, which is concerning as 34% of patients do not understand the severity of their condition.
- Most patients understand what each appointment entails, however they often leave the clinic without full knowledge of when their next appointment should be.
- Open ended feedback from patients expressed their dissatisfaction with the lengthy waiting times between each appointment. They also stated that they would like reasons for why delays occur as well as more notice of delays.

Limitations:

- Small sample size reduces external validity of findings
- This audit only focused on one subspeciality in one hospital
- Independent questionnaire means some patients may not fully understand the question leading to inaccurate data

6 Conclusion & Recommendations

- Although most patients had sufficient overall awareness of their glaucoma, there is a need for improved understanding of severity of the disease and potential for irreversible vision loss.
- Many patients felt uncomfortable addressing appointment delays, highlighting the need to empower patients to self advocate.
- The majority had a preference for telephone communication, which provides an opportunity for clinics to streamline their patient outreach and support efforts.
- Targeting gaps in patient knowledge could consequently lead to improved self advocacy. Future developments need to target patient education in particular focusing on increasing awareness of the risks of glaucoma disease progression.
- Interventions include distribution of information leaflets throughout the clinics, informing patients of the importance of self advocacy and the dangers of delayed appointments.
- A subsequent re-audit will be carried out to evaluate the effectiveness of these interventions.

References: 1.Royal National Institute for Blind People. New report details the impact of the pandemic on Britain's vision. [internet]. 2022 [cited 2024 September 27]. Available from: <https://glaucoma.uk/blog-category-blog/new-report-details-the-impact-of-the-pandemic-on-britains-vision/>. 2. Specsavers. The state of the UK's Eye Health 2022. [internet]. 2022 [cited 2024 September 27]. Available from: <https://content.specsavers.com/state-of-the-nation/The%20state%20of%20the%20UK%E2%80%99s%20Eye%20Health%202022.pdf> 3.Foot B, MacEwen C. Surveillance of sight loss due to delay in ophthalmic treatment or review: frequency, cause and outcome. Eye 31, 771-775 [internet]. 2017 [cited 2024 September 27]. Available from: <https://www.nature.com/articles/eye20171>. 4.National Institute for Health and Care Excellence. Glaucoma: diagnosis and management. NICE guidelines [NG81]. [internet]. 2017 [cited 2024 September 27]. Available from: <https://www.nice.org.uk/guidance/ng81/chapter/Recommendations#diagnosis> 5.Royal National Institute for Blind People. New self-advocacy pilot launches to help prevent sight loss for eye patients. [internet]. 2017 [cited 2024 September 27]. Available from: <https://glaucoma.uk/blog-category-news/new-self-advocacy-pilot-launches-to-help-prevent-sight-loss-for-eye-patients/>. 6.Johns Hopkins Medicine. Glaucoma. [internet]. [date unknown] [cited 2024 September 27]. Available from: <https://www.hopkinsmedicine.org/health/conditions-and-diseases/glaucoma>.