



Understanding patient knowledge of systemic immunosuppressive medication prescribed for uveitis.



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Aims

- 1. Assess patient knowledge of immunosuppression
- 2. Test associations (age, education, duration)
- 3. Evaluate impact of an information sheet

Introduction

- Uveitis has been estimated to account for 10% of blindness in the working age population of the Western world (Suttorp-Schulten 1996).
- Systemic immunosuppression is sometimes needed for uveitis.
- patients who are immunosuppressed have an increased risk of becoming unwell when exposed to infection (Martinson 2024).
- There is limited research available on patient knowledge and understanding of immunosuppressive medication used for ocular conditions.

Methods

- **Design:** mixed methods
- **Sample:** consecutive eligible patients attending the Uveitis Clinic
- **Eligibility criteria:** 18 years of age or older and on systemic immunosuppression for non-infectious uveitis for at least 3 months.
- **Ethical approval** was obtained from The University of Edinburgh and The Belfast Health and Social Care Trust.
- **Questionnaire: key outcome** was the answer to “do you know what action to take if you become unwell?”
- **Intervention:** participants were then given an information sheet on their medication, from rheuminfo.com (accessed May 2026) and one week later phoned and asked: “*did you learn anything new from reading the information sheet provided?*”

Results.

All who were invited to participate, agreed. The sample (n=25) reflected the local wider uveitis service population: 40% male; 4% were 18-25 years old, 24% 26-39 years old, 44% 40-59 years old and 28% 60+ years old

100% thought they understood their systemic immunosuppression



but only 40% knew to stop when unwell



1 week later, 24/25 said they learned nothing from the information leaflet

Fisher's exact test showed no statistically significant association between any of age group, educational level, or length of time on medication and providing the correct answer to the following question 'do you know what action to take if you are unwell?'. Firth's penalised logistic regression showed that none of age group, educational level, or length of time on medication together were significantly associated with knowing to stop medication if unwell.

Conclusions.

- Many patients don't know to stop immunosuppression if unwell
- Education must be individualised and reinforced
- Leaflets alone are ineffective
- Alternative strategies could include intravitreal steroids

Discussion.

All but one said they learnt nothing new from the information sheet when phoned 1 week later.

- It is possible that a) they didn't understand the information, b) didn't read it c) didn't retain the information. The Flesch-Kincaid (FKGL) Score for all leaflets given out in this study was 6-9, described as being appropriate for ages 11-14y (Readable, 2025).

This study provides evidence that, not unexpectedly, written materials are not reliable means of improving patient understanding.

Level of education. There was no statistically significant association between level of education and knowing what to do if unwell, there were signals: all participants with an undergraduate or postgraduate degree gave appropriate free text responses for the reason why they were prescribed the immunosuppressants.

Age group. Sixty-three percent (7/11) of those aged 40-59 years answered the question on what to do if unwell correctly.

- medication adherence has been shown to consistently increase as patient age increases until age 69. (Kim *et al.*, 2019). Health literacy is significantly lower among the elderly (Baker *et al.*, 2000).

Length of time taking the medication. It could be argued that patients who were on the medication for only 3-12 months have had their medication counselling recently and therefore have better understanding. However as patients take the immunosuppressive medications for longer, they gain experience and improve their learning about side effects and the contraindications. However no trends of better knowledge with shorter or longer duration on medication were seen in this study.

- The **strength** of this study was its grounding in the real world, with a valid sample, arguing for its generalisability
- A **weakness** is the relatively small sample size, and so lack of associations could be due to a type II error.
- **Future studies:** larger sample sizes, go into more depth to explore barriers to understanding, and explore the benefits of AI to aid creation of bespoke patient education