

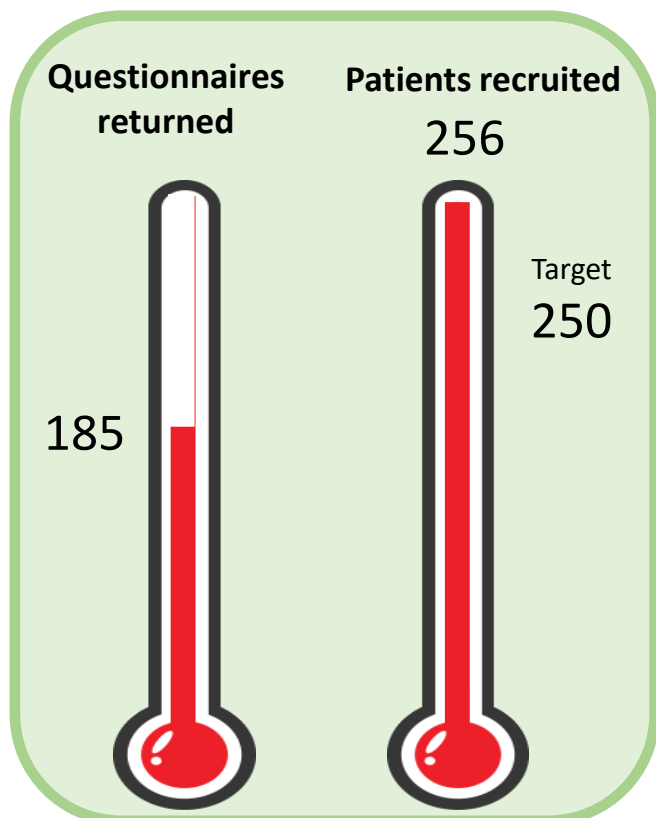
Welcome – and thank you!

Thank you for being part of the study and helping us to answer important questions about **WHAT** happens to children with uveitis, and **WHY**.

The information we are collecting will be used to help families affected by **childhood uveitis** so that we can improve outcomes.

On **page 3** we report results from the first round of questions we asked families about how uveitis has impacted their life

Study Update



Have you returned your questionnaires?

We want to make sure we hear the voices of those affected by childhood uveitis.

Please don't forget to return them – if you have lost them, email us (see contact details below) and we can send you new copies!



Pathways to disease detection

We looked at how uveitis was picked up in children

We discovered that children are more likely to be diagnosed later than average if they went to their GP's (compared to going to eye casualty or their opticians)

This shows that it's important for different medical teams to know about uveitis so we can improve the chances of picking up cases earlier. More on **page 2**

Pathways to disease detection

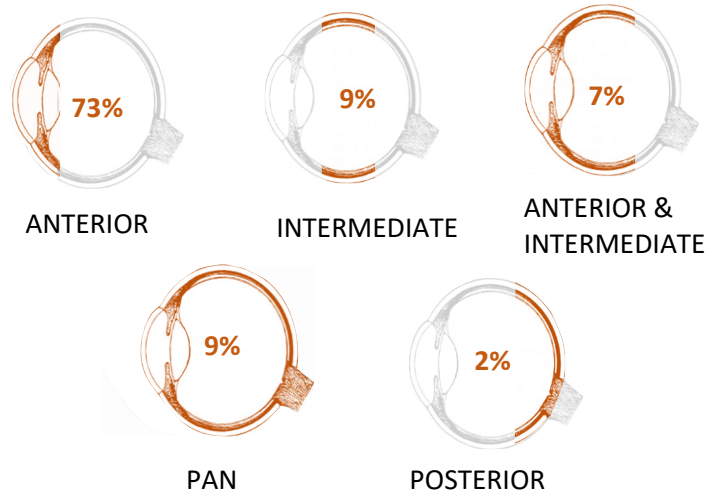
We looked at information from the first 150 children.

Most children had symptoms when their uveitis started, usually red eyes and sensitivity to light.

Anterior (front of the eye only) uveitis was the most common type of uveitis.

It usually took about 7-9 days from the start of noticing problems for uveitis to be diagnosed if children were taken to casualty or an opticians when problems started. It took longer if children were taken to their GP.

We used these findings to write an article for the British Journal of General Practice to make childhood uveitis more visible – it will be out soon!



Uveitis types within UNICORNS

JIA was the most common disease linked to uveitis (25 cases), followed by TINU (a kidney and eye disorder, 13 cases, higher than expected, which might be something to do with the COVID pandemic).

60% of the children didn't have any known illness when diagnosed with uveitis.

The uveitis had already caused changes to the structures inside the eye in a third of children at diagnosis (things like cataract and scarring of the cornea). A fifth of children already had reduced vision in at least one eye.

Median days from presentation to diagnosis

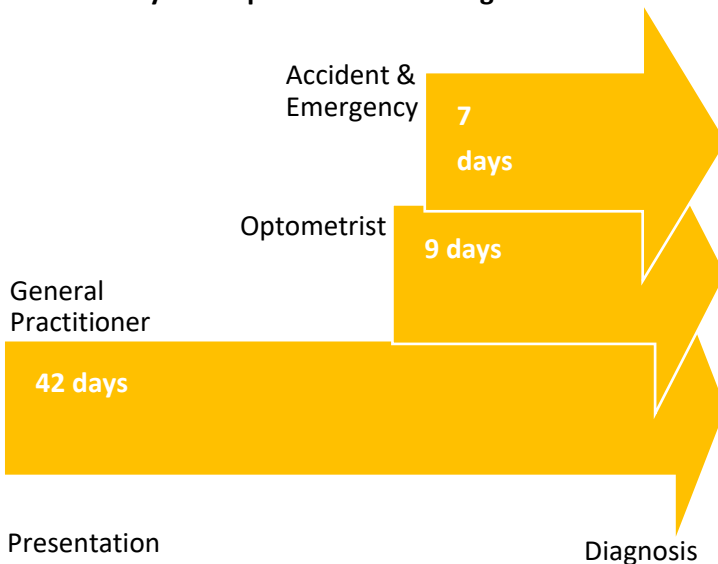


Figure 1. Median time from presentation to uveitis diagnosis

Patient Reported Outcome Measures

How is childhood uveitis affecting families around the time of diagnosis?

STRENGTH & DIFFICULTIES QUESTIONNAIRE (SDQ)

This measured how well children are coping at the time of their diagnosis – usually, about 20% of families not affected by uveitis would express concerns

- **33%** of parents with children aged 2-4 expressed concern around how well their children cope with things
- **58%** of parents with children aged 4-11 expressed concern
- **56%** of children aged 11-17 expressed concern



CHILD SLEEP HABIT QUESTIONNAIRE

This measured behaviours linked with sleep difficulties.

37% of families reported sleep related problems

GENERAL EVALUATION

This questionnaire measured how uveitis affected overall wellbeing on a scale of **0** (very well) to **100** (very poor).

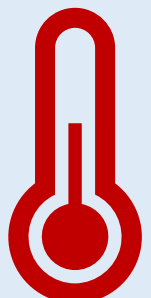
The average score was 21.

25% of families reported that uveitis had a significant negative impact (score >40)

How did things change over the first year?

On average families reported an improvement of only about **10%** from diagnosis to their 1st year after diagnosis.

These really important findings show just how much of an impact uveitis has on affected children and families across the country – thank you





CHOIR

The CHOIR study has begun!

We have been collecting samples from children who have inflammation in and around their eyes.

This is to help researchers look for signals from those tissues and see whether those signals tell them what causes disease, which treatments work best, and what happens to children with different types of disease.

These signals will be discovered by testing for different types of cells and proteins, and genetic testing. We will also look at stool ('poo') to see what kind of 'friendly bacteria' children have inside them.

We are looking forward to updating you with what we find.

STUDY DAY

Book your ticket now! To our second Childhood Uveitis Open Day event, which we will be holding on **October 14th, 2023**, with an option to attend in person or online.

The day will provide an update on current and future topics, and a chance to hear from professionals of all types as well as the real experts - other families, children and adults who have been affected.

It also gives us a chance to thank all those families who are helping other families like theirs by taking part in research, please scan the QR code below to register

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Find us on social media

If you would like to keep up to date on all our latest news, future events, research and findings, visit our website or follow us on social media

@UVEITISUNICORNS (for families)

@UVEITISUNICORN_YP (for young people)

On YouTube search for 'Childhood Uveitis'