A checklist of questions for anyone interested in clinical trials

Interested in clinical trials?

Over the next three slides you'll find a list of questions which you can use as a checklist when finding out about clinical trials. Not every question will apply to every trial, so you may choose to focus on the ones that feel most relevant and important to you.

We hope these questions support you in feeling more confident when seeking information about trials, and help you make informed decisions about whether to participate.

Initial questions to ask about a clinical trial

- Is the treatment intended to slow, stop or prevent progression of vision loss, or restore vision which has already been lost?

- What are the eligibility criteria for trial (e.g. genetic diagnosis, age, other conditions etc.)

Questions to help you know what is involved....

What does participation involve? For example;

- How and what is administered, and what procedures will be carried out?
- Will all participants receive treatment, or could they receive sham?
- How often would a participant attend clinic in relation to the trial and is this always at the main trial site? Should the participant continue with their regular eye clinic appointments whilst on the trial?
- Is there a cost for participating in the trial?
- Is there any help available with costs of travel/parking/accommodation to attend trial sites regularly?
- How long does each visit take, and is the participant likely to need time off school/college/work afterwards?
- Is there anything the trial participant can't do whilst on the trial?
- If patient is not registered as a patient at the trial site clinic, can they still access the trial?

usher Kids UK

Additional questions....

- Is there a chance the trial treatment could have the opposite effect of making vision worse?
- Can participants withdraw if they change their mind during the trial?
- Would participation in this trial affect someone's eligibility for future trials of other treatments?
- Will the age criteria be widened in future if treatment is shown to be safe and successful?
- What happens when the trial period ends? Will there be any long-term follow-ups to monitor potential side effects? If the patient has seen positive effects, can they still access the treatment?