

Involve to Engage to Involve: a journey in co-development

PPP Engagement SIG Symposium Feb 2021

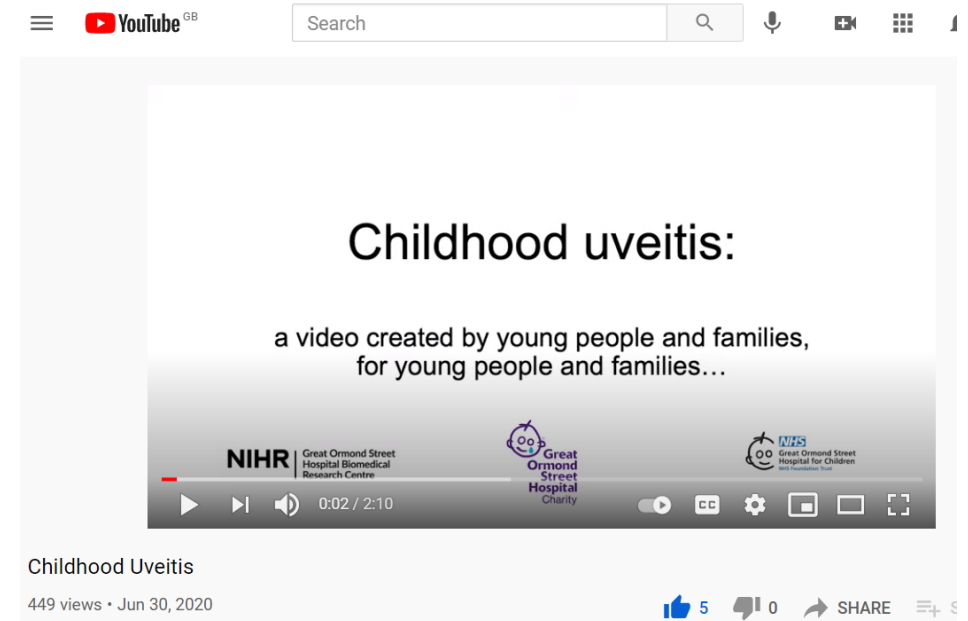
Ameenat Lola Solebo

NIHR Clinician Scientist / Paediatric Ophthalmologist

Involve to engage to involve:

Co-developed
patient information videos

rare potentially blinding eye disorder
often associated with other disorders

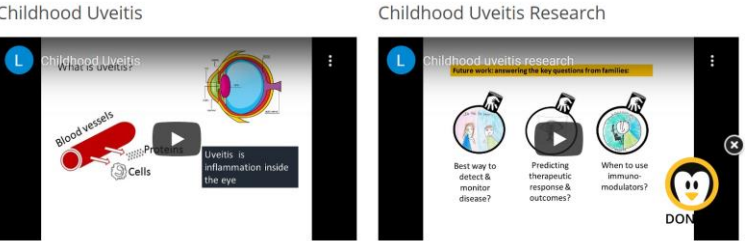


Involve to engage to involve:

The screenshot shows the NHS Great Ormond Street Hospital for Children website. The header includes the NHS logo and navigation links: About us, News, Working and learning, and Contact us. Below the header is a search bar and tabs for 'Our hospital site' and 'Our charity site'. A main navigation bar contains links: Home, Your hospital visit, Wards and departments, Conditions and treatments, Our people, and Our research. The breadcrumb trail reads: Home > News > Fresh perspectives from children and young people. The article title is 'Fresh perspectives from children and young people' dated 29 Jul 2020, 4:35 p.m. The video player shows a thumbnail with the text 'What is uveitis?' and a diagram of an eye. The diagram labels 'Blood vessels', 'Proteins', and 'Cells' with arrows pointing to the eye. A text box states: 'Uveitis is inflammation inside the eye'. A 'Copy link' button is visible in the top right corner of the video player.

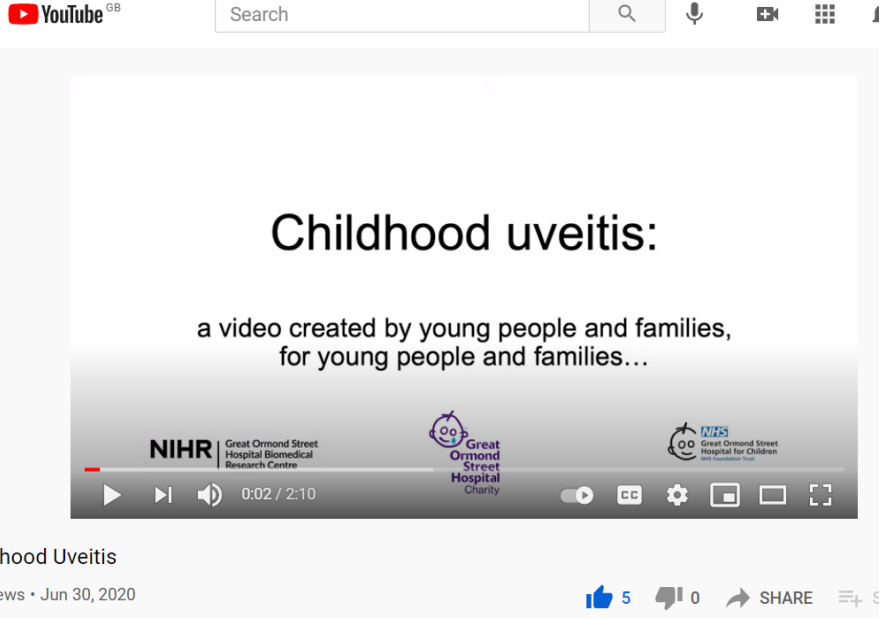
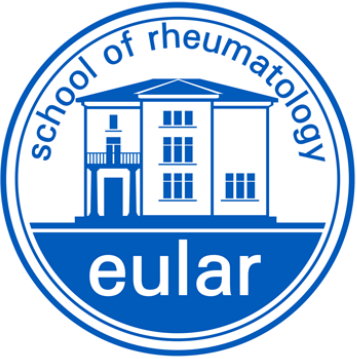
The screenshot shows a YouTube video player for the video 'Childhood Uveitis'. The video title is 'Childhood uveitis:' followed by the subtitle 'a video created by young people and families, for young people and families...'. The video player interface includes a search bar, a play button, and a progress bar showing 0:02 / 2:10. The video player also displays the NIHR logo and the Great Ormond Street Hospital Biomedical Research Centre logo. The video has 449 views and was uploaded on Jun 30, 2020. The video player interface includes a play button, a progress bar, and a volume icon. The video player also displays the NIHR logo and the Great Ormond Street Hospital Biomedical Research Centre logo. The video has 449 views and was uploaded on Jun 30, 2020. The video player interface includes a play button, a progress bar, and a volume icon. The video player also displays the NIHR logo and the Great Ormond Street Hospital Biomedical Research Centre logo.

Involve to engage to involve:



A Little Box Of Hope

Being told that your child has a long-term health condition can be scary or daunting, and can leave you feeling isolated and alone. We have developed A Little Box Of Hope to show that children with juvenile arthritis, and their families, are not alone. Each Little Box Of Hope is packed with information, support and practical items that may be of help – all to help parents and their children through the first daunting weeks and months following a diagnosis, and to reassure them that they are not alone.



Involve to engage to involve:

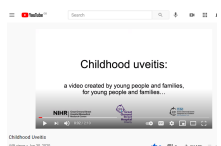
Journey in PPIE



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for Health Research



NIHR | Great Ormond Street
Hospital Biomedical
Research Centre



March '15

Aug '16

May '17

Aug '17

Dec '17 – March '18

Sept '18

March '19

Sept '19

June '20

Young persons advisory group

Visual disability is a sentinel child health event

15 February 2021

Researchers at the UCL Institute of Child Health (UCL GOS ICH), working through a national collaborative study group, have undertaken the first ever national population based epidemiological study of full spectrum of all-cause childhood visual impairment (VI).



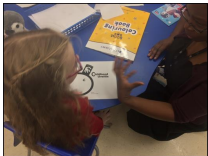

UCL Great Ormond Street Institute of Child Health

Further information

- About Us
- Athena SWAN
- Strategic Partners
- Support Us

Contact

- People
- Contact Us



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Involve to engage to involve:

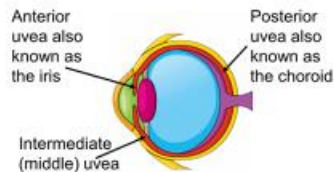
A bit about uveitis: (co-designed content!)

NHS
National Institute for
Health Research



What is uveitis?

The uvea (latin for 'grape') is the middle 'lining' of the eye, and the red layer in this diagram. It holds much of the blood supply for the eye.



?aetiology

?surveillance at risk

populations

?disease classification

?disease metrics

?long term outcome /
determinants



Visual disability is a sentinel child health event



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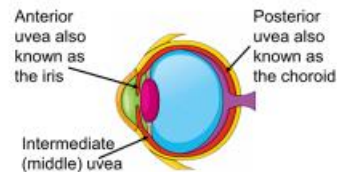


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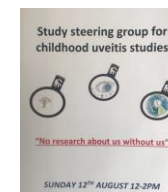
Clinical need
Research need
Platform for impactful
methodologies



Visual disability is a serious child health event



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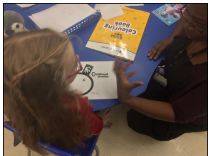
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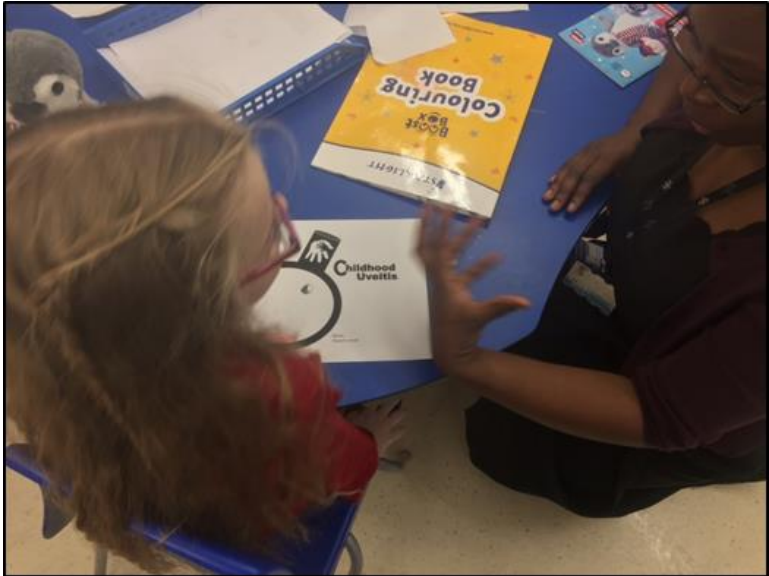


PPI/E informed by PPI



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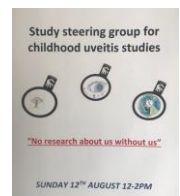
Involve to engage to involve:



**Funded by NIHR Enabling involvement fund*



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1. Find your collaborative partner(s)



2. Invest in developing leadership and collaborative relationships



3. Make time for learning - and share it



4. Go where the energy is (under the radar)



3. Embed collaborative activity (authorise it, make it legitimate)

The King's Fund

Ideas that change health care

Patients as partners

Building collaborative relationships among professionals, patients, carers and communities

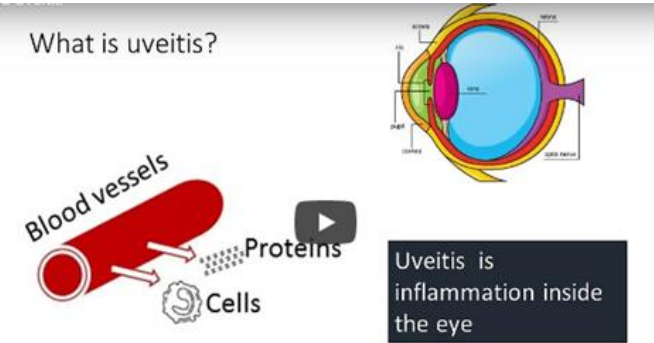
Becky Seale

Study steering group for childhood uveitis studies

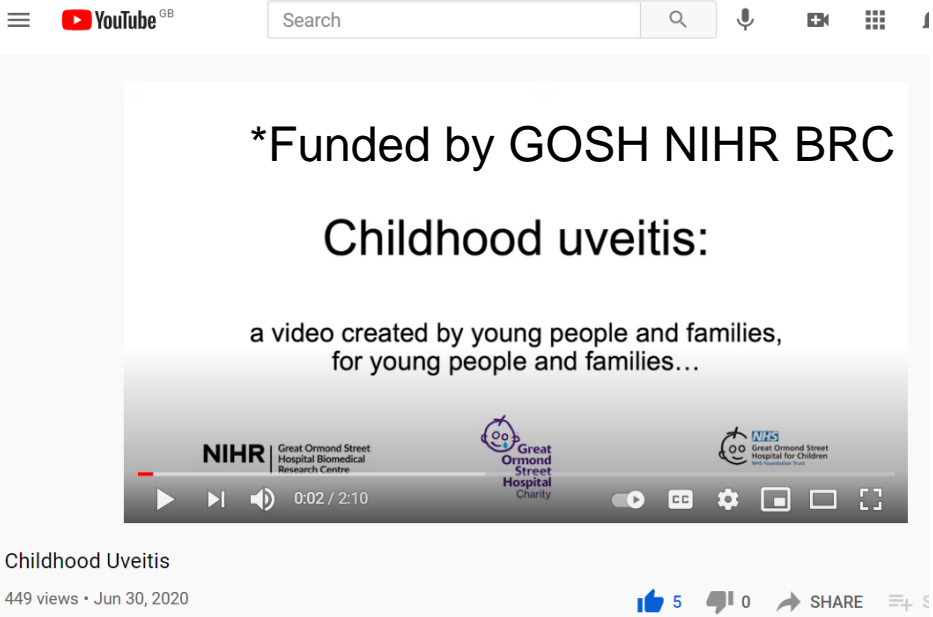


"No research about us without us"

Involve to engage to involve:



- *Co-production of images / storyboard
- *Co-production of script
- *Narrated by children / families



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Involve to engage to involve:



UNICORNS

UNICORNS: Uveitis in childhood prospective national cohort study

We need your help to answer important questions about what happens to children with uveitis, and why.

Childhood uveitis (inflammation inside the eye) is a rare disorder. UNICORNS is the first national, prospective study which will look at what happens to children after they are diagnosed with uveitis.

Through UNICORNS, we will collect information which will be used to advise affected families, balance treatment decisions to help improve outcomes, and plan further research.

What is the aim of the study?

We want to collect information about children with uveitis in the UK so that we can better understand the disease.

Why is the study being done?

There are still some unanswered questions about why children get uveitis and why some children with uveitis are more severely affected than others. By analysing data on a large number of children, we hope to provide information that will help doctors and parents make decisions about the most effective treatments.

Which children will be included in the study?

Any child or young person who has been newly diagnosed with uveitis in the UK since 1st March 2020.

What will happen to children who decide to take part?

Children and families will be asked to complete questionnaires about how the uveitis is affecting them. They will do this when they enter the study, and then every year.

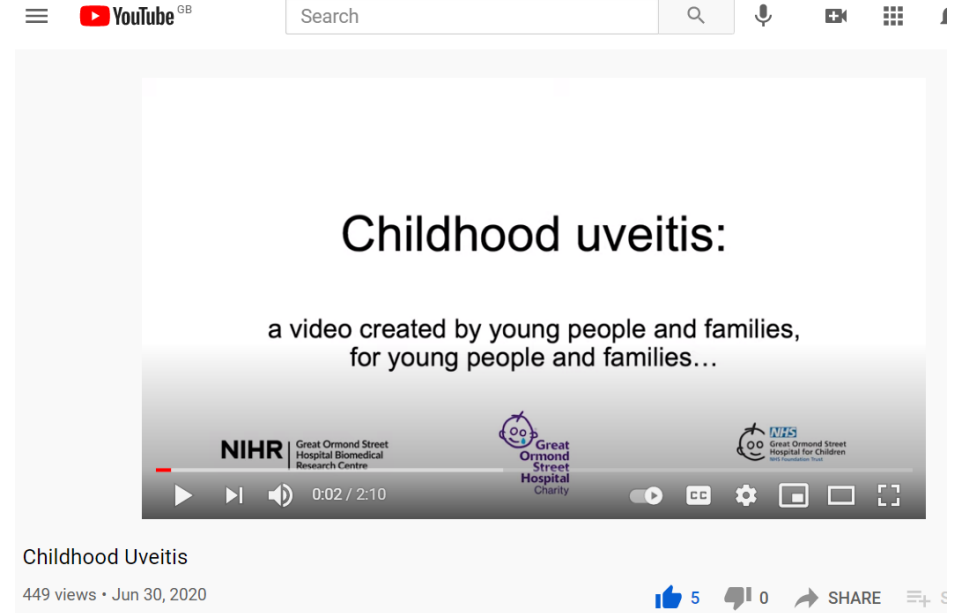
We will also ask the child's clinical team to share information, about their eyes and their health, with us. So far 26 eye centres across the UK have agreed to share their data: we hope that every centre will join us.

This study will not affect the treatment given to children or young people.

Families will be free to stop taking part at any time during the research without giving a reason.

Who is organising and funding the research?

The study is organised by Lola Solebo, and funded by the National Institute of Health Research.



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Take home points:



Involve to engage to involve:

The videos:

https://www.youtube.com/watch?v=1vBzqS_HD_E&t=0s



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