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:

Fresh perspectives from children and young people
27 July 2020 - 6:23 p.m.

What is uveitis?

Blood vessels

Proteins

Cells

Uveitis is inflammation inside the eye

Childhood uveitis:
a video created by young people and families, for young people and families...

June '20
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 share the stories of children with juvenile arthritis and their families, and not alone. Each little box of hope is packed with information, support and practical items that may just help - all to help parents and their children through the first few months and months following a diagnosis and to reassure them that they are not alone.

Childhood Uveitis:

a video created by young people and families, for young people and families...
Involve to engage to involve:

Journey in PPIE
Young persons advisory group

Visual disability is a sentinel child health event
15 February 2021

Researchers at the UCL Institute of Child Health (UCL Great Ormond Street Institute of Child Health) have undertaken the first ever national collaborative study of all causes of childhood visual impairment (VI).

Further information
- Jaki Lk
- Arabia Sani
- Strategic Partners
- Contact us

Context
- People
- Contact us

UCL Great Ormond Street Institute of Child Health

15 February 2021

June '20
March '15
Aug '16
May '17
Aug '17
Dec '17 – March '18
Sept '18
March '19
Sept '19
June '20

GenerationR
young people improving research
2013 Meeting Report

NIHR
National Institute for Health Research

NIHR
Great Ormond Street Hospital Biomedical Research Centre
Involve to engage to involve:

- aetiology
- surveillance at risk populations
- disease classification
- disease metrics
- long term outcome / determinants
Involve to engage to involve:

Clinical need
Research need
Platform for impactful methodologies

A bit about uveitis (co-designed content!)

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.

Anterior uvea also known as the iris

Posterior uvea also known as the choroid

Intermediate (middle) uvea

March ’15  Aug ’16  May ’17  Aug ’17  Dec ’17 – March ’18  Sept ’18  March ’19  Sept ’19  June ’20
Involve to engage to involve:

PPI/E informed by PPI
Involve to engage to involve:

*Funded by NIHR Enabling involvement fund
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)

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

*Funded by GOSH NIHR BRC
Childhood uveitis:
a video created by young people and families, for young people and families...

NIHR

Your health is our priority
NIHR
National Institute for Health Research

March '15  Aug '16  May '17  Aug '17  Dec '17 – March '18  Sept '18  March '19  Sept '19  June '20
Involve to engage to involve:
Involve to engage to involve:

Take home points:

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)
5. Embed collaborative activity (authorise it, make it legitimate)
Involve to engage to involve:

The videos:

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