RAISING AWARENESS: THE TEDDY KIDS' WAY

From being heard to having influence

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Why involve children and young people?

01
RIGHTS

Children have a right to express their views in matters affecting them — and to have those views given due weight.

02
BETTER RESEARCH

Children and families bring experience and perspectives that researchers do not have.

03
BETTER PARTICIPATION

They can tell us whether research is understandable, acceptable, feasible and relevant.

UN Convention on the Rights of the Child, Article 12

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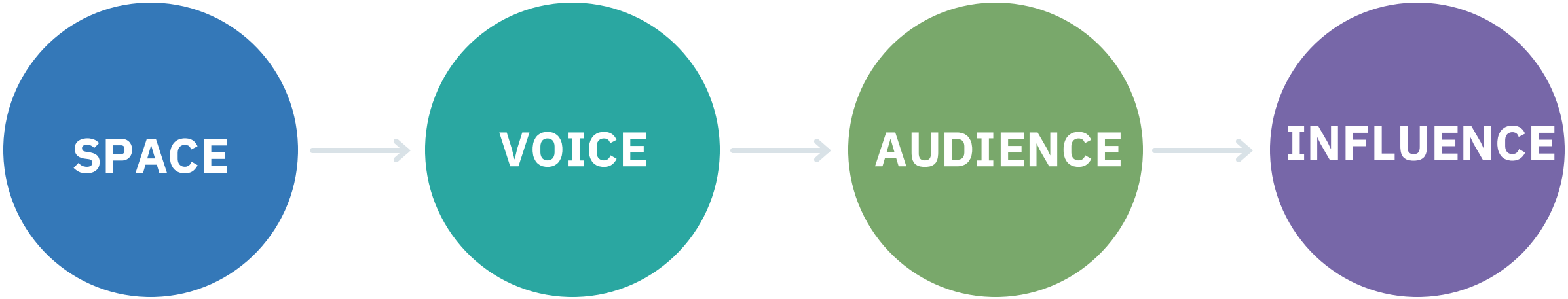
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From “giving children a voice” to giving them influence: The Lundy Model – Article 12 in practice



Lundy, L. 2007. “Voice’ is Not Enough: Conceptualising Article 12 of the United Nations Convention on the Rights of the Child.” *British Educational Research Journal* 33 (6): 927–942. https://doi.org/10.1080/01411920701657033.

From “giving children a voice” to giving them influence



Children and young people must be given safe, inclusive opportunities to form and express their views

Children and young people must be facilitated to express their views

The views must be listened to

The views must be acted upon, as appropriate

Does PPIE actually change research?

RELEVANCE

Research questions and outcomes can become more meaningful to patients and families.

PARTICIPANT-CENTRED DESIGN

Information, recruitment, procedures and study materials can become more appropriate and understandable.

DELIVERY & IMPACT

PPIE can contribute to recruitment, interpretation and dissemination.

Brett J, Staniszewska S, Mockford C, Herron-Marx S, Hughes J, Tysall C, Suleman R. Mapping the impact of patient and public involvement on health and social care research: a systematic review. Health Expect. 2014 Oct;17(5):637-50.
Brady LM, Miller J, McFarlane-Rose E, Noor J, Noor R, Dahlmann-Noor A. "We know that our voices are valued, and that people are actually going to listen": co-producing an evaluation of a young people's research advisory group. Res Involv Engagem. 2023 Mar 20;9(1):11.

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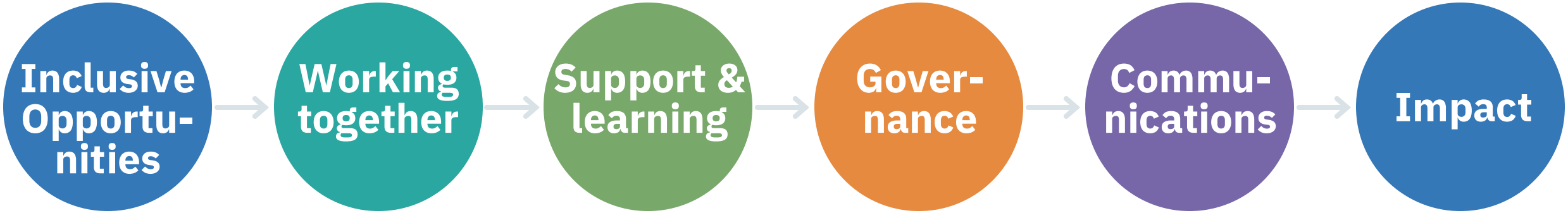
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From good intentions to reproducible process

UK STANDARDS FOR PUBLIC INVOLVEMENT



PLAN → DO → RECORD → REFLECT → SHOW WHAT CHANGED

PIRIT: a practical way to plan and track PPIE activities and their impact.

Newman A, MB, SK, PS and NA. Public Involvement In Research Impact Toolkit (PIRIT) . Cardiff University Wales, UK: Cardiff University 2023. Available at: https://www.cardiff.ac.uk/marie-curie-research-centre/patient-and-public-involvement/public-involvement-in-research-impact-toolkit-pirit [Accessed August 17, 2026].

PPIE should accompany the whole research cycle

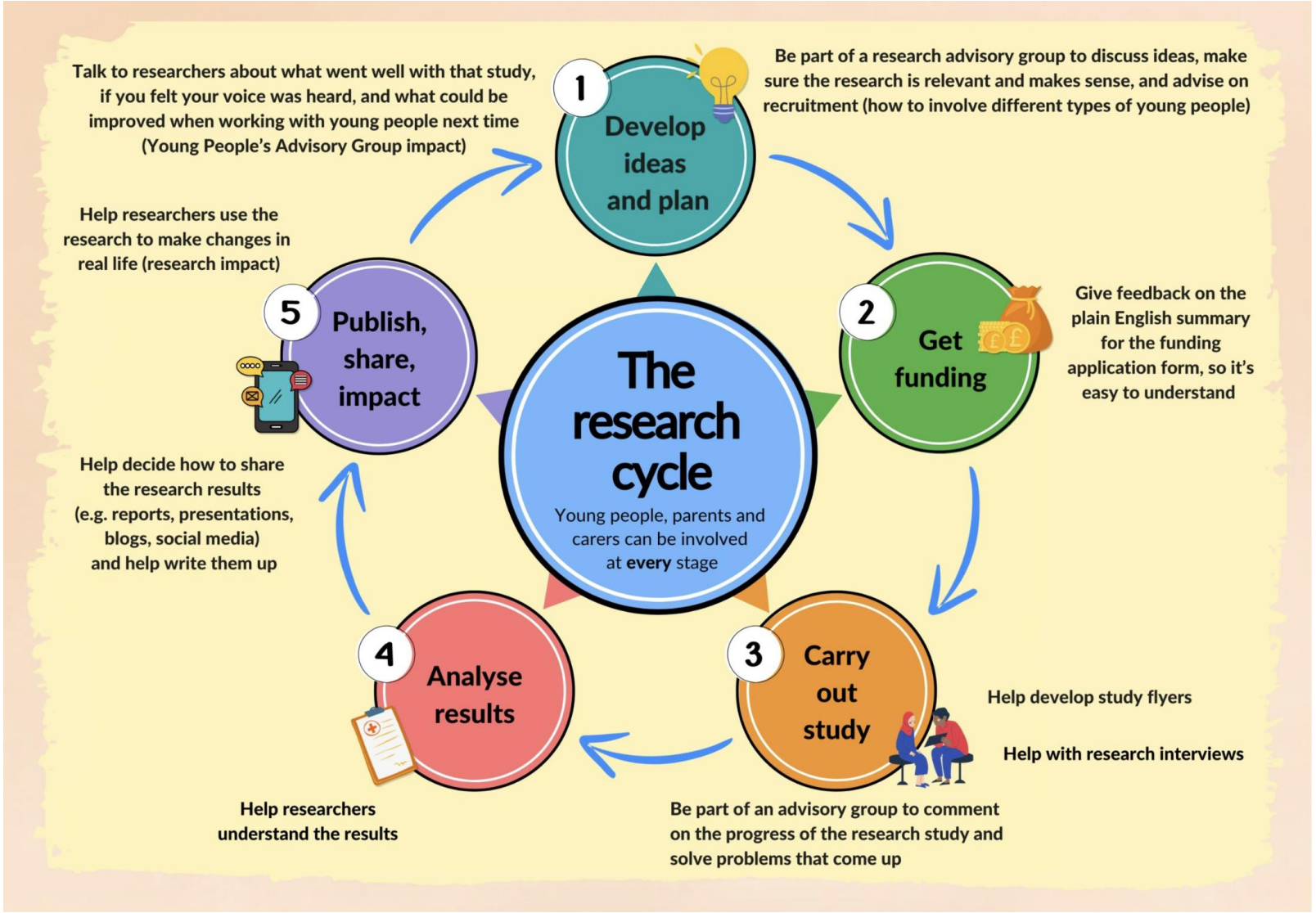


Image courtesy of NIHR GenR YPAG Bristol

MODERATO: PPIE from the beginning

2018

C4C funding application

Family focus group
Spanish patient organisation input
eYPAGnet
GOSH YPAG advice on PPIE

2018–19

EMA Paediatric Investigation Plan

PPI evidence + young-person involvement

2024

International PPI:
TEDDY
Eye-YPAG
iCAN Bari

Development and review of cartoons as participant information material
Study design
Study logo
Study visit diary

Children influencing the intervention

“Please don't make the drops sting.”

CHILDREN & PARENTS SAID

Stinging mattered
Nightly treatment was acceptable, but less frequent treatment was preferred
Timing mattered

THE RESEARCH TEAM

Recommendations were taken forward in discussion with the manufacturer, including development of a preservative-free formulation and exploration of dosing frequency.

TEDDY: protocol, information and enrolment

What is the plan, and what can we do so that families take part?

- **KIDS Bari** – paed. communication expertise: M Cavallo
- What would make children and parents want to take part? - ideas for age-appropriate communication and participant information
- Impact: storyboard for cartoon-based MODERATO participant information material developed by Gianfranco Bonadies, creative illustrator, Bari

VOICE

↓

AUDIENCE

↓

INFLUENCE

eyeYPAG: making the trial understandable

What does this trial look like through a child's eyes?

- Visits should not be too long
- Children need breaks
- Explain what each test is for
- Use natural language rather than research jargon
- Think about age, representation and accessibility

VOICE

↓

AUDIENCE

↓

INFLUENCE

eyeYPAG: making the trial understandable

How can we make the information material better?

- Make dialogues more realistic and less technical
- Ethnic diversity of characters
- Make clinical scenarios more realistic
- Consider online animation
- Clarify what happens to the child during the trial

VOICE

↓

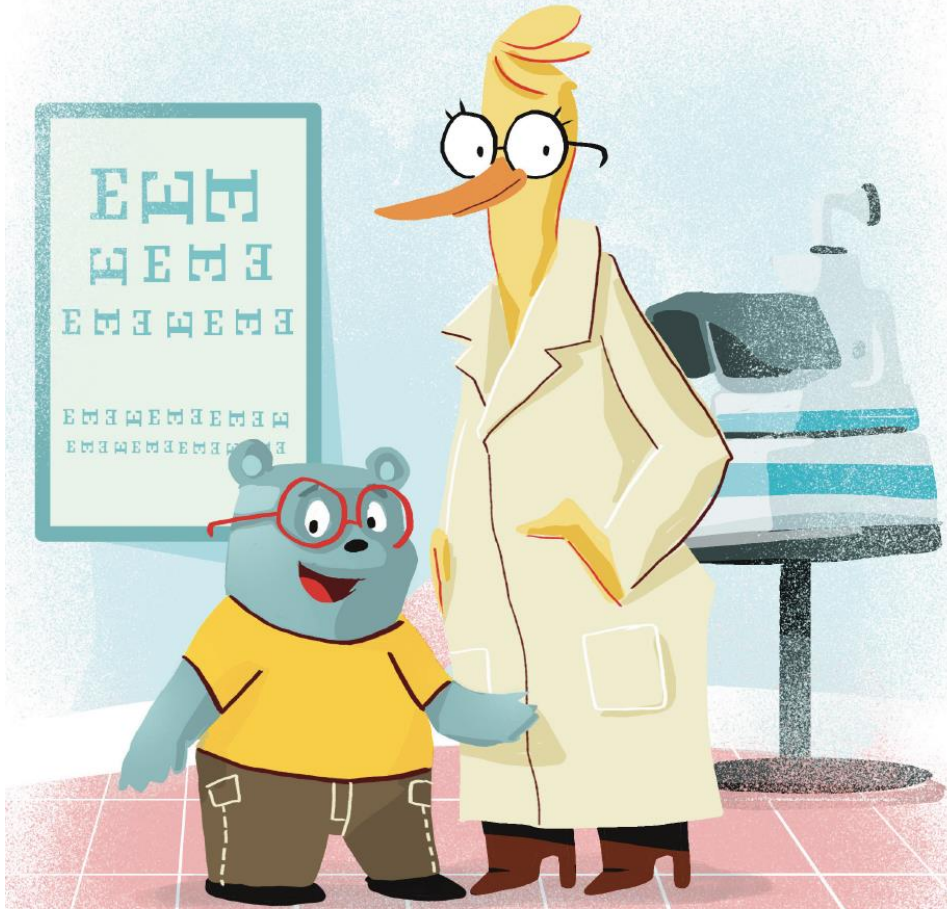
AUDIENCE

↓

INFLUENCE

3-5 years

A special visit for Charlie



MODERATO

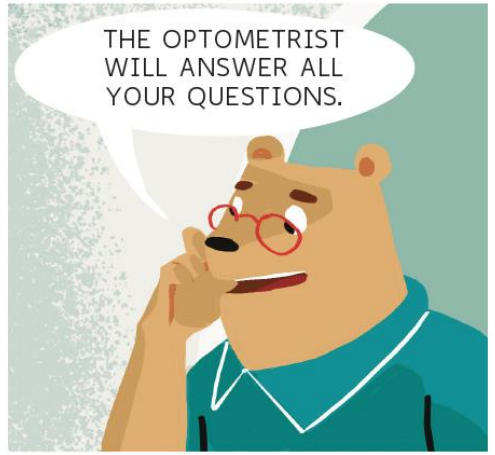
Informative booklet for children 3-5 years old

UK version









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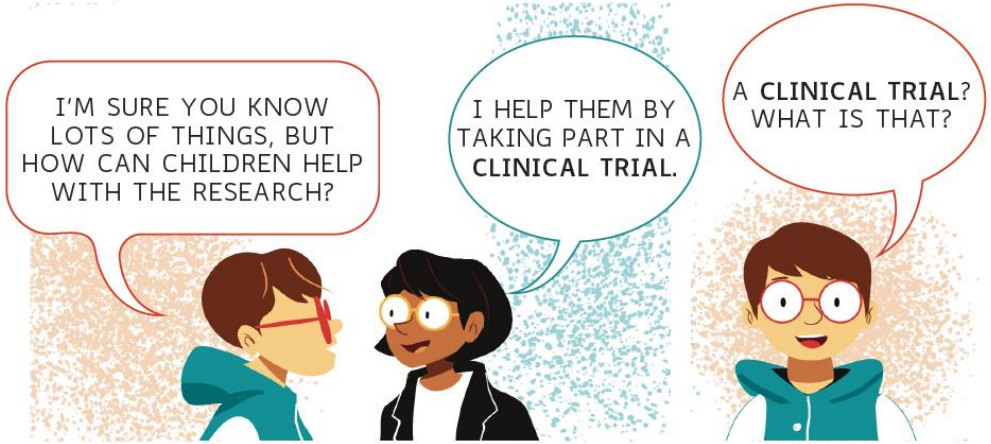
6-11 years

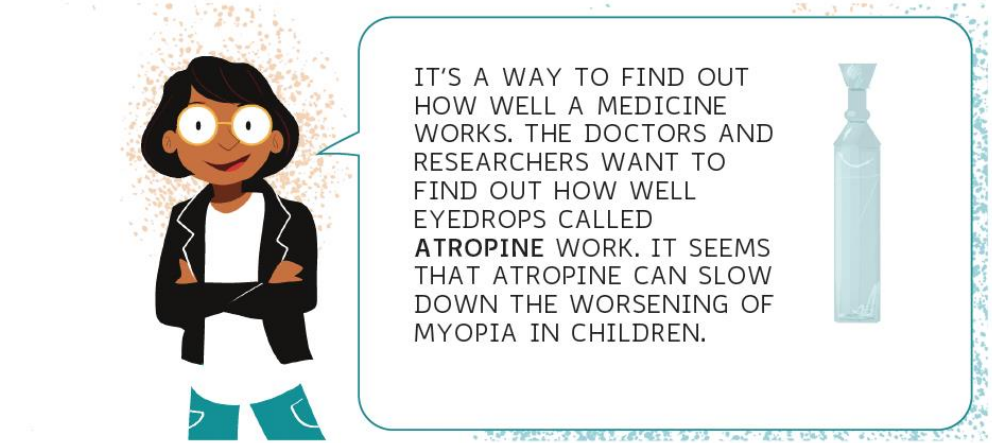
Friends for lenses



MODERATO

clinical trial - booklet for children 6 - 11 years old







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MODERATO clinical trial



STUDY ON ATROPINE TO PREVENT WORSENING OF MYOPIA IN CHILDREN AND YOUNG PEOPLE

MODERATO_Booklet_12-15_ENG_UK_V.1.0_15.08.2024

12-15 years

Study Visits

All visits will happen at the clinic. In total you will come to the clinic six or seven times for check-ups. During the study period, you will talk to the study doctor over the phone 3 times, who will also monitor your health remotely.

During the first hospital visit you will be screened to see if you meet the requirements to participate in the study. You will be asked questions about yourself, your medical condition(s) and your medical history, other medicines you take and recent treatments.

You will fill out 2 questionnaires about your vision and 1 questionnaire about eyedrops acceptability. If you are a girl, you will take a pregnancy test.

If the results meet the requirements some eye tests will be done, and your glasses prescription will be checked. You will be randomly assigned to one of the groups and given a code that will identify you. The drops will be given to you for the first time and the study doctor will give you the eyedrop vials and the instructions to use them at home until the next visit.

Depending on the number of the study visit the following will be done:

A – Screening to see if you meet the requirements to participate in the study

B – Medical history review including any current medications or recent procedures

C – Questionnaires 1 and 2 about your vision

D – Questionnaire 3 about eyedrops acceptability

E – pregnancy test if you are a girl (atropine may harm an unborn baby)

F – Glasses prescription check

G – Eye tests

H – Eyedrops provided

	A	B	C	D	E	F	G	H
VISIT 1 – Day 1	✓	✓	✓		✓	✓	✓	✓
📞								
VISIT 2 – After 3 months		✓		✓	✓	✓	✓	✓
VISIT 3 – After 6 months		✓	✓	✓	✓	✓	✓	✓
VISIT 3 B								
📞								
VISIT 4 – After 12 months		✓	✓	✓	✓	✓	✓	✓
📞								
VISIT 5 – After 18 months		✓		✓	✓	✓	✓	✓
VISIT 6 – After 24 months		✓	✓	✓	✓	✓	✓	

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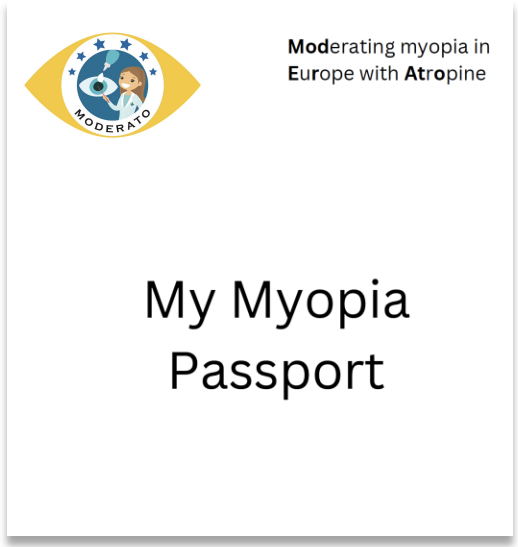
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iCAN Bari: children became co-creators



A young-person design won the competition and became the trial identity.



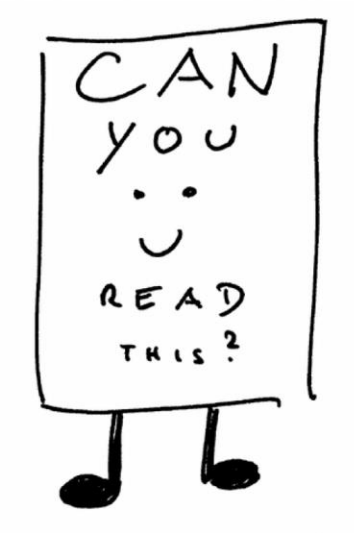
A child-friendly study visit diary showing the assessments and procedures

This is what “influence” looks like.

From “What will happen to me?” to “I understand.”

Distance vision

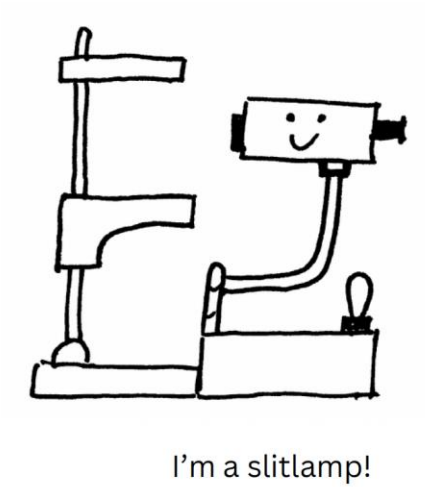
This measures the smallest letter or shape you can see from **3 or 6 metres** away.



Visit 1
Visit 2
Visit 3
Visit 4
Visit 5

Eye health: front of the eye

With the slitlamp, we check the front part of your eyes.



I’m a slitlamp!

- **LOOK** What will I see?
- **EXPLAIN** What is this test for?
- **PREPARE** Will it hurt? How long?
- **CHECK** What happens next?

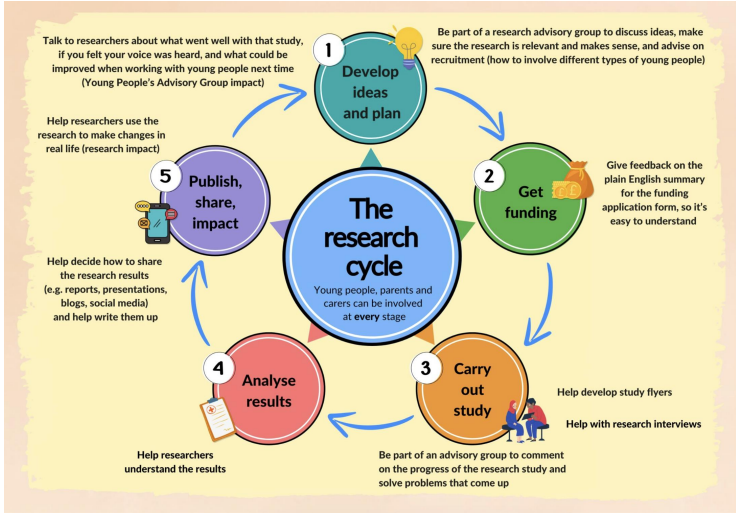
The output is not just a PPIE activity. It becomes part of the participant experience.

No PPIE since regulatory approvals

BARI • JULY 2024 → **NO SUSTAINED MODERATO PPIE** → **TRIAL RUNNING** → **2026 • WE RECOGNISED THE GAP**

WHAT WE MISSED: Opportunities to ask CYP about the experience of taking part while the trial in set-up and recruiting.

THE QUESTION NOW How do we bring CYP back into the research cycle?



Re-entering the research cycle

3 — CARRY OUT THE STUDY

- International CYP/ Parent Advisory Group
- Participant experience
- Retention and burden
- Communications
- Practical problems
- CYP/ parent representatives at selected TMG meetings

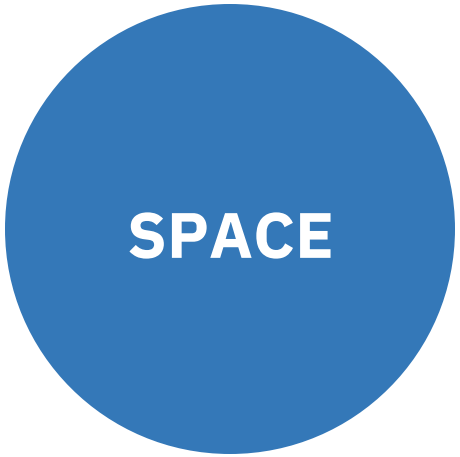
4 — ANALYSE RESULTS

- Bring emerging findings back to CYP and parents
- Interpretation.

5 — PUBLISH, SHARE & IMPACT

- Plain-language results
- Child-friendly outputs
- Dissemination
- Priorities for future research

What would meaningful involvement look like now?



Regular, accessible opportunities



Information, preparation and support



Researchers with decision-making power listen



Record what changed and tell CYP what happened

CYP/PARENT ADVISORY GROUP ↔ TRIAL MANAGEMENT GROUP ↔ RESEARCH TEAM ↔ ACTIVITY TRACKING

We don't yet have the perfect model.
We will develop it with CYP.

eye-YPAG meeting — 26 August 2026

1. **CYP want to contribute beyond recruitment**

   Analysis, interpretation and reporting were seen as important opportunities for youth perspectives.

2. **Youth voice needs a route into decisions**

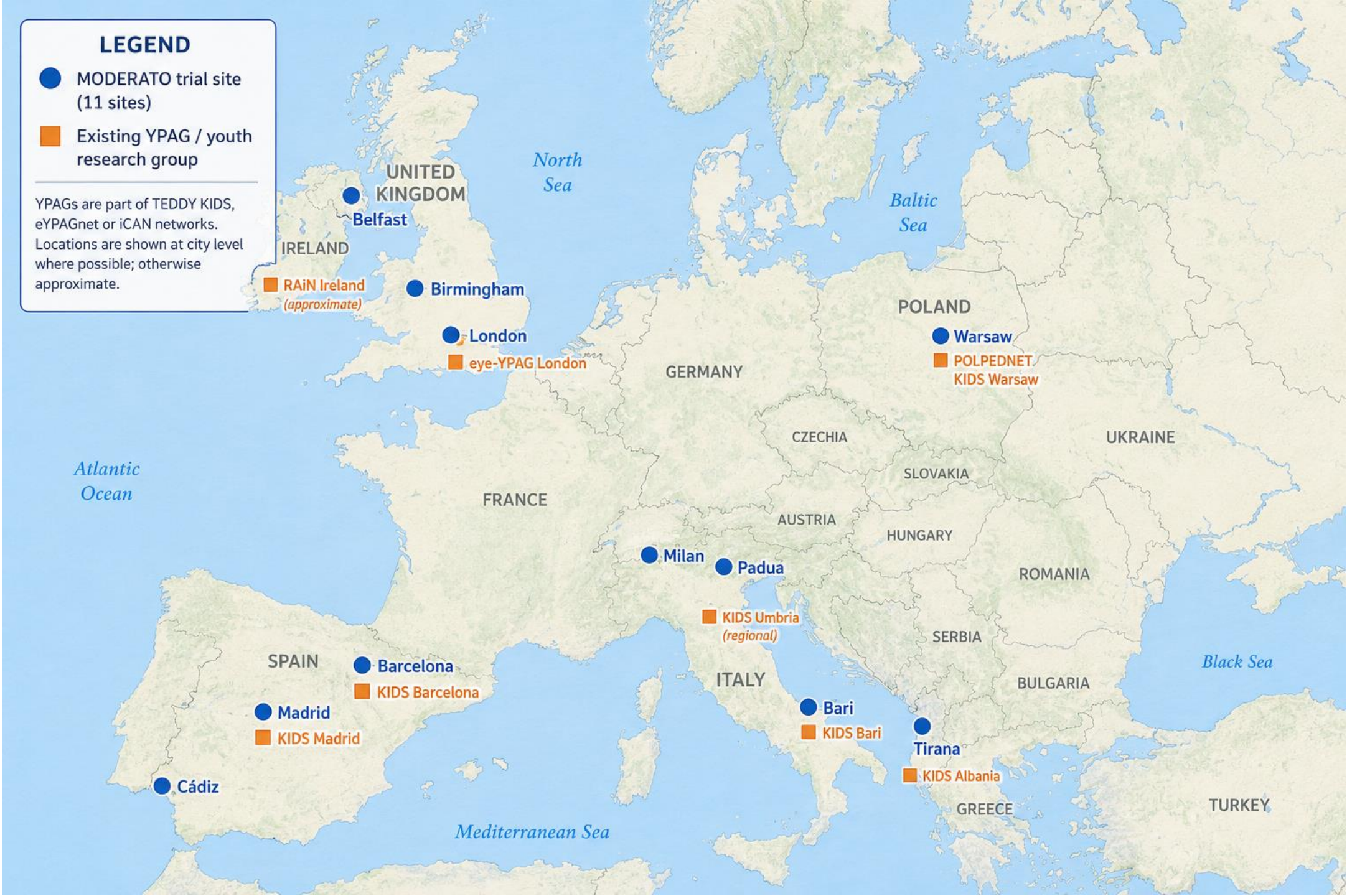
   The group welcomed the idea of an eye-YPAG representative joining selected Trial Management Group meetings.

3. **Involvement needs a clear framework**

   CYP highlighted the need to agree when, how and to what extent young people should be asked for input.

4. **We can broaden the conversation**

   eye-YPAG proposed working with other TEDDY/iCAN groups — and helping groups without myopia experience understand the condition.


LEGEND
MODERATO trial site (11 sites)
Existing YPAG / youth research group
YPAGs are part of TEDDY KIDS, eYPAGnet or iCAN networks. Locations are shown at city level where possible; otherwise approximate.
North Sea
Baltic Sea
Atlantic Ocean
Mediterranean Sea
Black Sea
UNITED KINGDOM
Belfast
IRELAND
RAiN Ireland (approximate)
Birmingham
London
eye-YPAG London
GERMANY
POLAND
Warsaw
POLPEDNET
KIDS Warsaw
CZECHIA
SLOVAKIA
UKRAINE
FRANCE
AUSTRIA
HUNGARY
ROMANIA
Milan
Padua
KIDS Umbria (regional)
SERBIA
BULGARIA
SPAIN
Barcelona
KIDS Barcelona
ITALY
Madrid
KIDS Madrid
Bari
KIDS Bari
Tirana
KIDS Albania
Cádiz
GREECE
TURKEY

From advice to partnership: what we will do next

EYE-YPAG

Review the proposed myopia / trial training material

→

OTHER YPAG/ TEDDY/ KIDSs groups

Share the material and invite local youth perspectives

→

TMG

Bring CYP/parent representatives into selected meetings

→

ANALYSIS + REPORTING

Bring emerging findings back to CYP and protect the youth voice into publication

Children should not just be asked.

They should be heard.

And they should be able to see what changed.

RIGHTS → VOICE → INFLUENCE → IMPACT

