

# Children, Young People and Parents as Active Partners in Research

Dr Pamela Dicks

Manager and PPI lead of NRS Children's Research Network  
eYPAGnet co-lead



Patient and Public Involvement Event  
City Quay Dundee  
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# Children's Research Network

To promote and facilitate high quality research in children's healthcare in Scotland that:

- increases the availability, safety and efficacy of **new medicines**,
- builds **evidence** for the best prescribing practice and for the repurposing of existing medicines, and to
- gain new understanding of **biological mechanisms** of health and disease.

Active involvement **in PPI since 2008** setting up one of the first YPAG's in UK and founded eYPAGnet in 2017

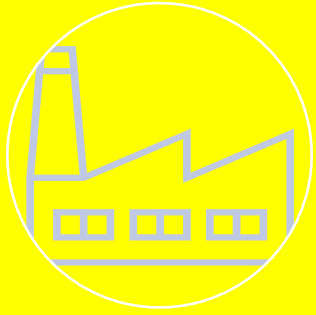
One of many disease specific research networks such as Diabetes, Cancer, Mental Health, MSK, Stroke, Dementia and NPD, Cardiovascular and Primary Care.



**NHS**  
SCOTLAND  
NHS RESEARCH SCOTLAND

CHILDREN

# What is **GOOD** research



Sponsor  
Industry



Doctor  
Researcher



Parent

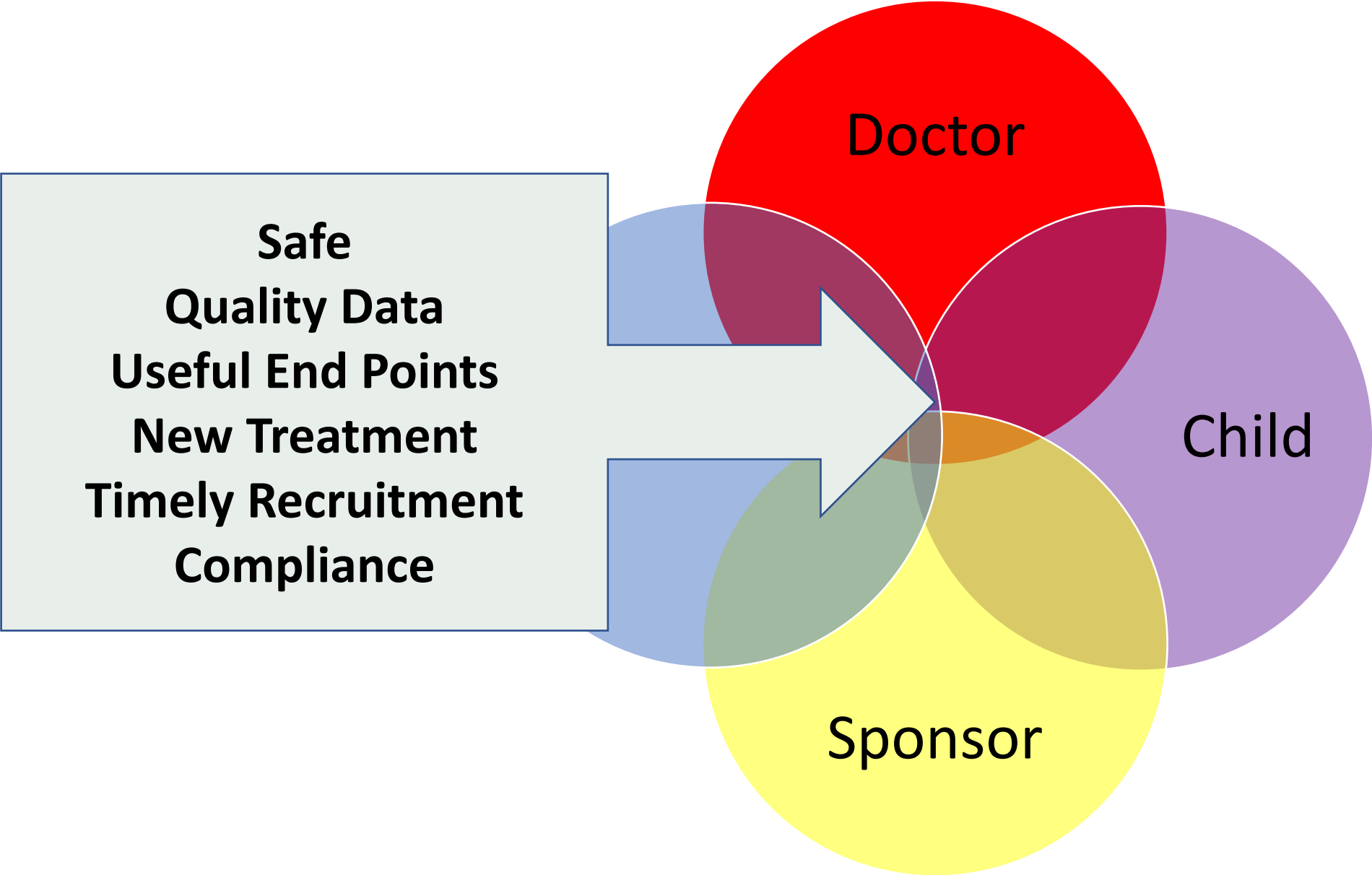


Child



Baby

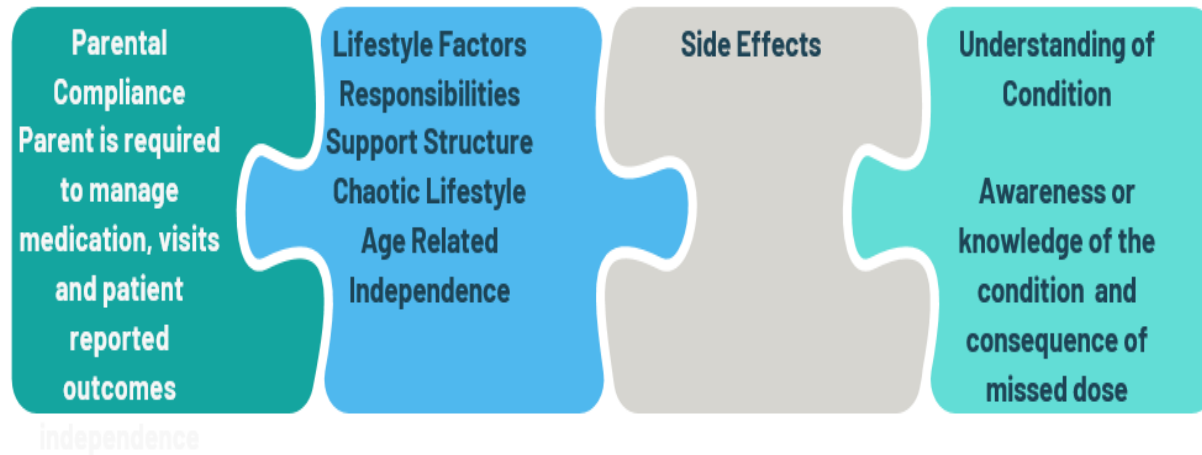




# Why is both Patient and Parent Involvement Essential in Research Design

## Protocol Adherence in Children

Factors that result in low adherence and persistence are multiple and complex



# Young Persons Advocacy Group

- Group of children and young people that advocate for children involved in research.
- With **different experiences** of chronic and acute conditions and/or accessing healthcare.
- Meeting together regularly, **working in groups** and **providing advice** from a young person's perspective on a full range of activities including clinical trial design, recruitment methods and patient materials.
- **Receiving training** on research methods, clinical research, consent and assent, clinical trial design and governance.
- Meeting regularly therefore **responsive to requests**
- Provide **young persons perspective different**
- Increase **health literacy** of documentation



# Disease Specific Focus Groups

- Patients and/or parent groups
- Disease and condition specific focus groups brought together for the **purpose of a project**
- Working with a facilitator to develop workshops to ensure **meaningful involvement** and that patient views are gathered
- **Lived experience** of physical and emotional symptoms and impact on family
- **Receiving training** on research methods being used, clinical research design
- Highly motivated



By permission of Stacey Hutchison, mum of Frankie

# Core Values

Patients, Parents and Young  
Persons Involvement is  
**meaningful** to ALL  
stakeholders

Involvement leads to change  
and is **not tokenistic**

**Impactful**

**Respectful of the needs** of  
the patients, parents and  
young people



# Core Values

## **Ethical Involvement and Engagement** of Patients, Parents and Young People within YPAGs:

- Ensure patients are informed of actions implemented
- Reimbursement - fair market value
- Inclusive
- Supportive

# Case Study -YPAG Involvement in Innovations

## Funding Award

The Scottish Gov fund a small business research initiative (SBRI) - had a competitive funding call for companies to develop a digital solution to increase the availability of psychological care for children with significant gastrointestinal symptoms no underlying medical disease at RACH. **2 YPAG members on board**

## Early Development

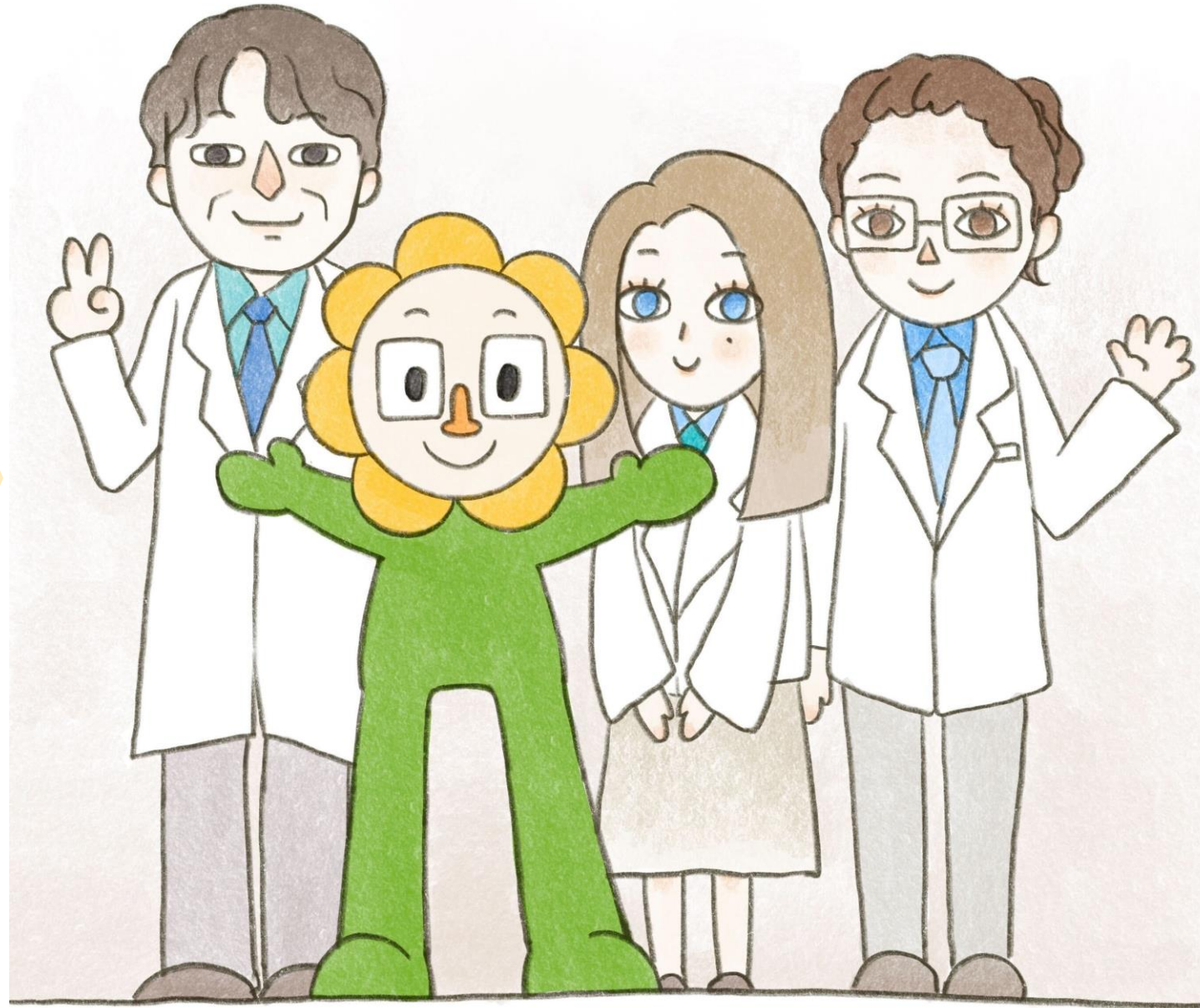
Two companies selected  
Offered PPI at each stage of development  
Parallel workshops **2 YPAG's 19 YP**  
Gathered views on product prototypes – graphics, gamification, content, user journey

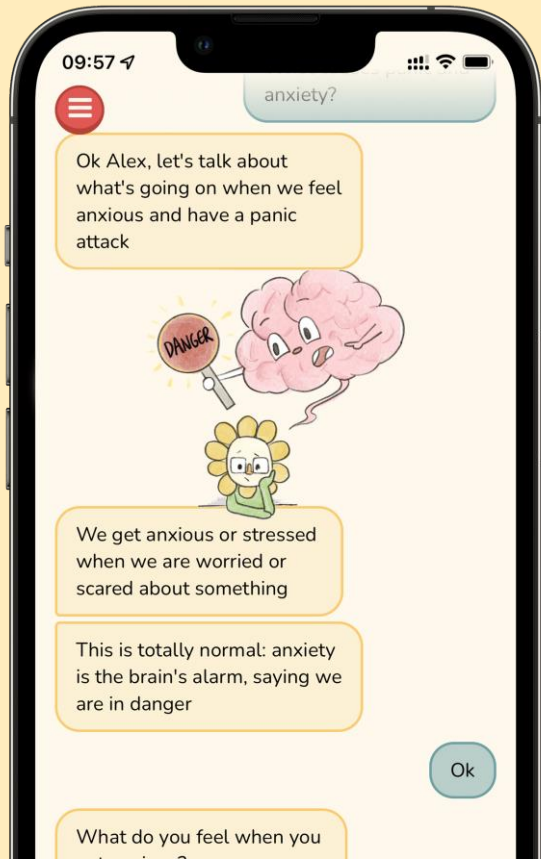
## Evaluation and advice

Second workshop – GenerationR in Birmingham  
Parallel workshops **6 YPAG's 13 YP**  
Gathered views on next stage of prototypes – graphics, gamification, content, user journey

**UBOK**

Experience of UBOK and  
CYP events



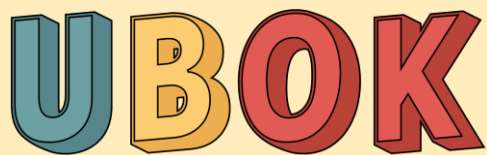


# UBOK

- App for functional constipation in children
- Engaging young people in AI driven conversations
- Focus on mild to moderate mental health issues and functional pain
- Delivering a combination of evidence-based therapeutic and clinical expertise
- Engaging young people through an app using chatbot conversations, animations and activities
- Computerised CBT programs have low completion rates
- The average app loses 77% of users after just three days. Within 30 days, 90% leave. Within three months, 95% are gone
- Mental health issues connected to physical symptoms

# Feedback from CEO VOxsio

“It is critical to work with end users when creating digital health products. We were delighted to be involved in a process that gave us access to the two groups of young people that we worked with.”

The logo for UBOK, featuring the letters U, B, O, and K in a stylized, 3D font. The 'U' is blue, 'B' is yellow, 'O' is red, and 'K' is red.

## What was the impact of the CYP events?

It has both confirmed and changed what we are doing. eg the visual design of our app was widely praised - confirming our approach. Whereas the open discussions with the young people has changed the way that the app starts up now. We learnt from the young people that they wanted the app to be much more responsive to how they feel at that moment.

## Why do you think it is important to involve YP in technology that is aimed at them or not?

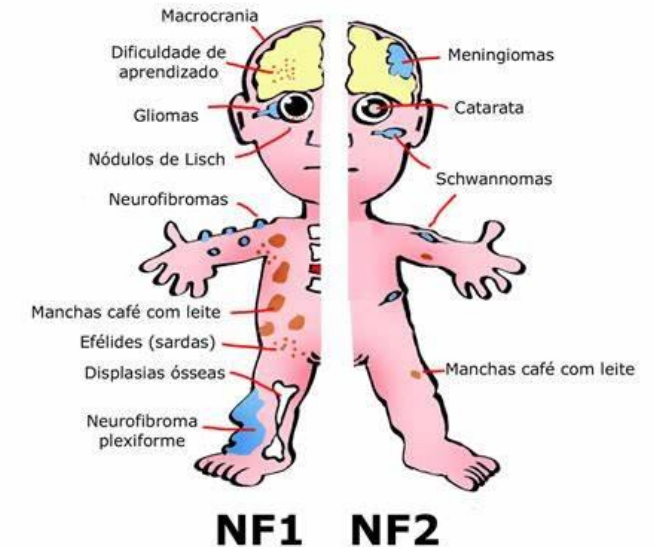
It is critical that we involve CYP. If we want to build software that changes their lives for the better then it has to be based on their needs, delivered in a way that they want and relevant to their situation.

## How can we improve this?

More user testing with young people at every point in the development process, from the initial idea right through. If possible CYP should be on the boards of these projects.

# Case study: International Study

- **Study:** Academic European Platform Trial in the rare disease Neurofibromatosis
- **Countries involved in the project:** France + UK + Spain
- **Methodology:** Focus group discussion (teenager patients + parents):  
9 families involved
- **Topics of the PPI activity:**
  1. Design acceptability
  2. Informed consent for a platform trial
  3. Schedule of assessment
  4. Acceptability of medical procedures



# Case study: multi-country advice

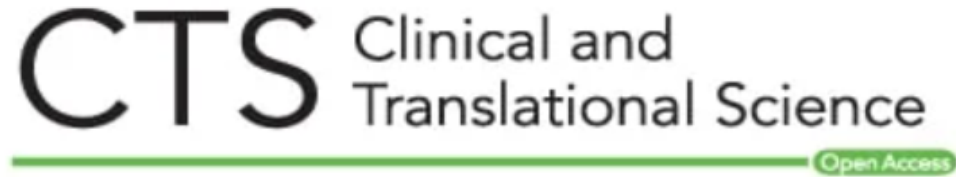
## Some outcomes

- Acceptability of the platform trial design + waiting list.

*Importance of providing to the patient the right information during the consent process: improve the health literacy of assent + consent.*



- All patients and parents indicated that they would be willing to participate the observational period, but only if the visits for this study would be the same as those during regular clinical care → **Schedule of visits adapted.**
- Families expressed a strong preference for including a patient-reported outcome measure. → **Protocol adapted**
- **Country differences** about the check-ups for the trial. Diversity of preferences in regards the places of the follow up visits: satellite sites (near to the patient's home) vs. clinical trial site.

# Case study: multi-country advice



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## Optimizing expert and patient input in pediatric trial design: Lessons learned and recommendations from a collaboration between conect4children and European Patient-Centric Clinical TRial PLatforms

Britt A. E. Dhaenens , Fenna Mahler, Hannah Batchelor, Pamela Dicks, Segolene Gaillard, Begonya Nafria, Annette Kopp-Schneider, Maria Alexandra Ribeiro, Matthias Schwab ... [See all authors](#) 

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Britt A. E. Dhaenens and Fenna Mahler should be considered co-first authors.  
Saskia N. de Wildt and Rianne Oostenbrink should be considered co-last authors.



# THANK YOU

## Contact details

[p.dicks@abdn.ac.uk](mailto:p.dicks@abdn.ac.uk)

[Pamela.dicks@nhs.scot](mailto:Pamela.dicks@nhs.scot)

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### Toolkit

The Generation R Alliance/eYPAGnet Toolkit will help you set up and run a Young Persons Advisory Group, allowing the voices of children and young people to be heard in research.

#### Understanding

- [What is Patient and Public Involvement in health research?](#)
- [Involving children and young people in health research](#)
- [What is a Young Persons Advisory Group \(YPAG\)?](#)
- [Diverse and inclusive involvement](#)

#### Getting started

- [Funding and sustainability](#)
- [Recruitment](#)
- [Safeguarding](#)
- [Payment and reward](#)

#### Delivering

- [How to run your first meeting](#)
- [Activities during and after meetings](#)
- [Training](#)
- [Presenting your research to YPAGs](#)
- [Running YPAG meetings online](#)
- [Providing feedback](#)

#### Evaluating

- [Evaluation involvement](#)
- [Shared learning](#)
- [Involving young people in evaluation](#)