PANS PANDAS UK

Experts by experience

PERSPECTIVES ON PANS

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Public Involvement Lead
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Experts by experience: What happens when patients, parents and communities become partners in research?

"You feel empowered and heard." Carrie



"I felt hopeful about what can happen when researchers and people with lived experience genuinely work together." Parent

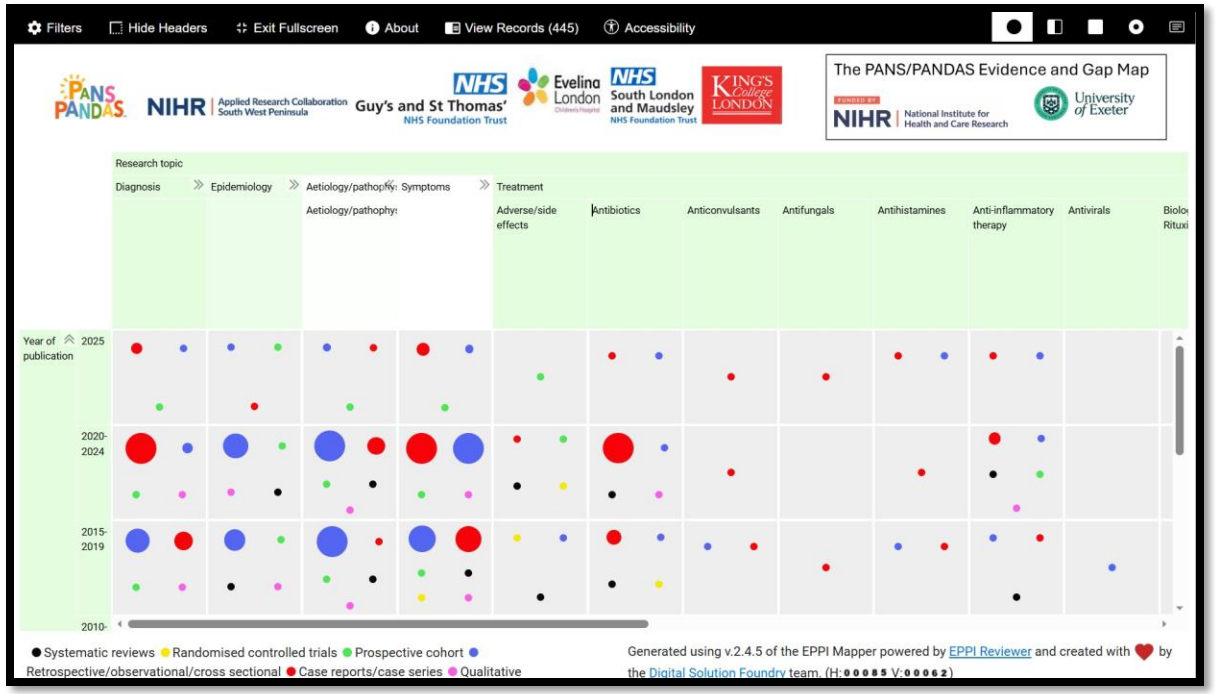
"They said we were their experts." Lorna



PANS PANDAS Unveiled

Phase 1

Evidence & gap map about the epidemiology, causes, treatment, and experiences of PANS/PANDAS



Phase 2

- **Systematic review of 3 treatments**
- **Qualitative evidence synthesis**

NIHR | National Institute for Health and Care Research

PROSPERO
International prospective register of systematic reviews

The effectiveness of immune treatments, antibiotics and psychological therapies for PANS/PANDAS: a systematic review protocol

Allison Stitt, Michael Nunns, Samantha Febrey, Pooja Sharma, Tilly Vivia Wilson, Kate Boddy, Alison Bethel, Rebecca Whear, Rebecca Abbott, Liz Shaw, Jo Thompson Coon, G.J. Melendez-Torres, Ming Lim, Katy Hindson, Ashley Liew

NIHR | National Institute for Health and Care Research

PROSPERO
International prospective register of systematic reviews

What are the views, experiences and perceptions of patients, families, and clinicians of PANS/PANDAS? Protocol for a qualitative evidence synthesis.

Tilly Vivia Wilson, Pooja Sharma, Michael Nunns, Rebecca Whear, Sam Febrey, Allison Stitt, Katy Hindson, Kate Boddy, Ming Lim, Ashley Liew, Alison Bethel, Rebecca Abbott, Jo Thompson Coon, G.J Melendez-Torres, Liz Shaw

Experts by experience: Are we talking about the same thing?

Patient and Public Involvement and Engagement - PPI / PPIE

Co-production / Involvement (Engagement)

Public **involvement** in research:

Research that is done 'with' or 'by' the public, rather than 'to', 'about' or 'for' them.

No single, accepted definition of the term **co-production**, but it

Describes a set of core values and principles applied at different stages of the research cycle	Can incorporate multiple methodologies with similar components including knowledge and power sharing, involving people in every stage of a process, rather than describing one single discrete methodology	Means people wo together in 'a partne produce and/or diss evidence synthesis

Co-production in evidence synthesis: working together in 'a partnership' to produce and/or disseminate evidence syntheses

PPIE

Public involvement

Public Partnerships

Community Engagement and Involvement

Working with the public and communities

Experts by experience partnership… in evidence synthesis?

“It felt hopeful to see researchers actively looking at what we know, what we don’t yet know,

and where research needs to go next.”

Parent

Experts by experience partnership… in evidence synthesis?

"Involving the public in systematic reviews of research is **even more important**, because systematic reviews provide short cuts to critically appraised evidence for policy decisions that affect people's lives

Original Article

Research Synthesis Methods

Received 28 July 2014, Revised 04 December 2014, Accepted 20 March 2015 Published online in Wiley Online Library

(wileyonlinelibrary.com) DOI: 10.1002/jrsm.1145

Broadening public participation in systematic reviews: a case example involving young people in two configurative reviews

Kathryn Oliver,[a]* Rebecca Rees,[b] Louca-Mai Brady,[a] Josephine Kavanagh,[b] Sandy Oliver[b] and James Thomas[b]

Res Synth Methods. 2015;6(2):206-17.

6 -10 % of reviews report PPI

Open access Original research

BMJ Open

How common is patient and public involvement (PPI)? Cross-sectional analysis of frequency of PPI reporting in health research papers and associations with methods, funding sources and other factors

Iain Lang, Angela King, Georgia Jenkins, Kate Boddy, Zohrah Khan, Kristin Liabo

Lang I, King A, Jenkins G, Boddy K, Khan Z, Liabo K. BMJ Open.2022;12(5):e063356.

When patients, parents and communities become partners… **what happens *to the research?***



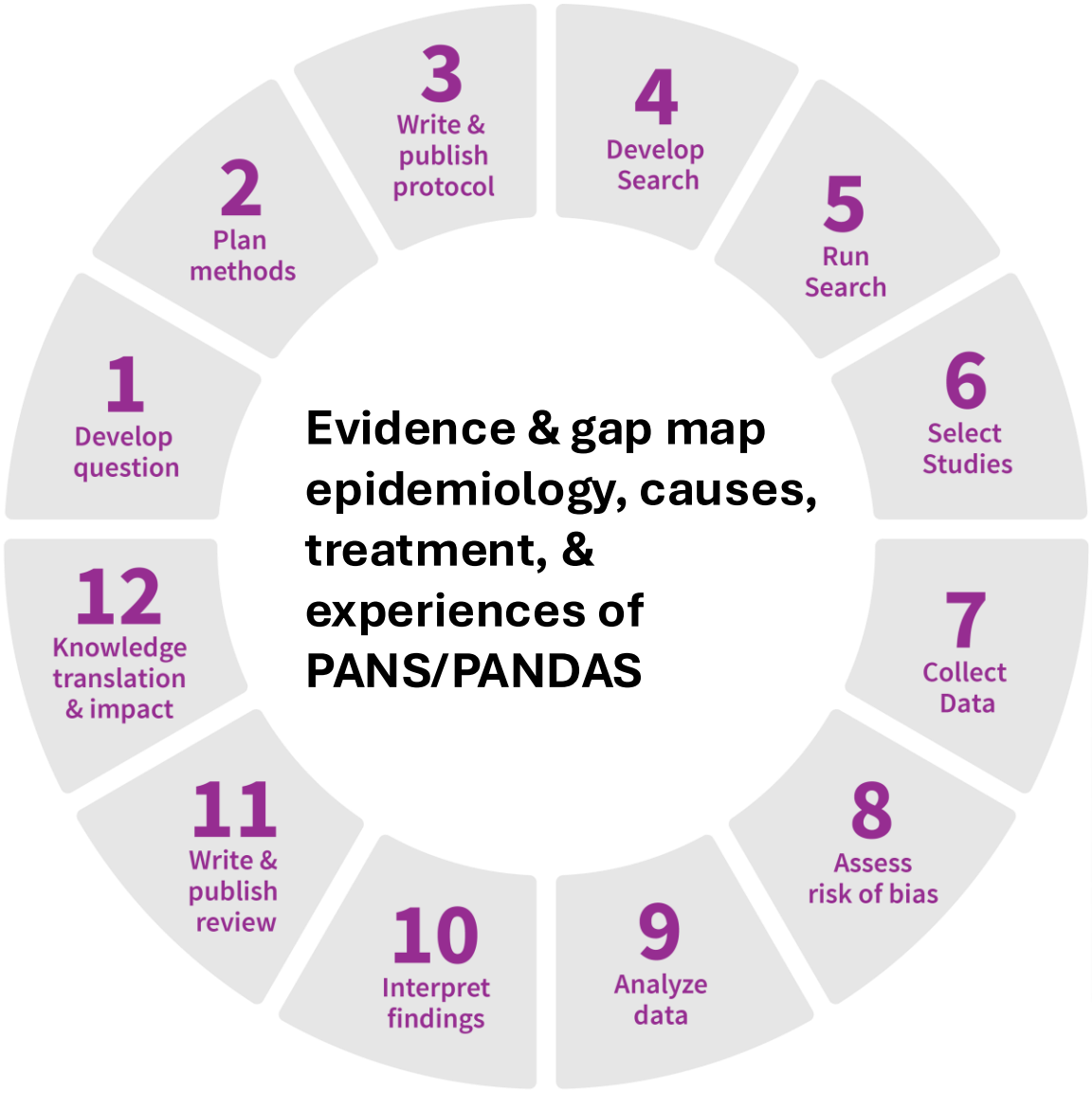








When patients, parents and communities become partners… **what happens *to the research?***



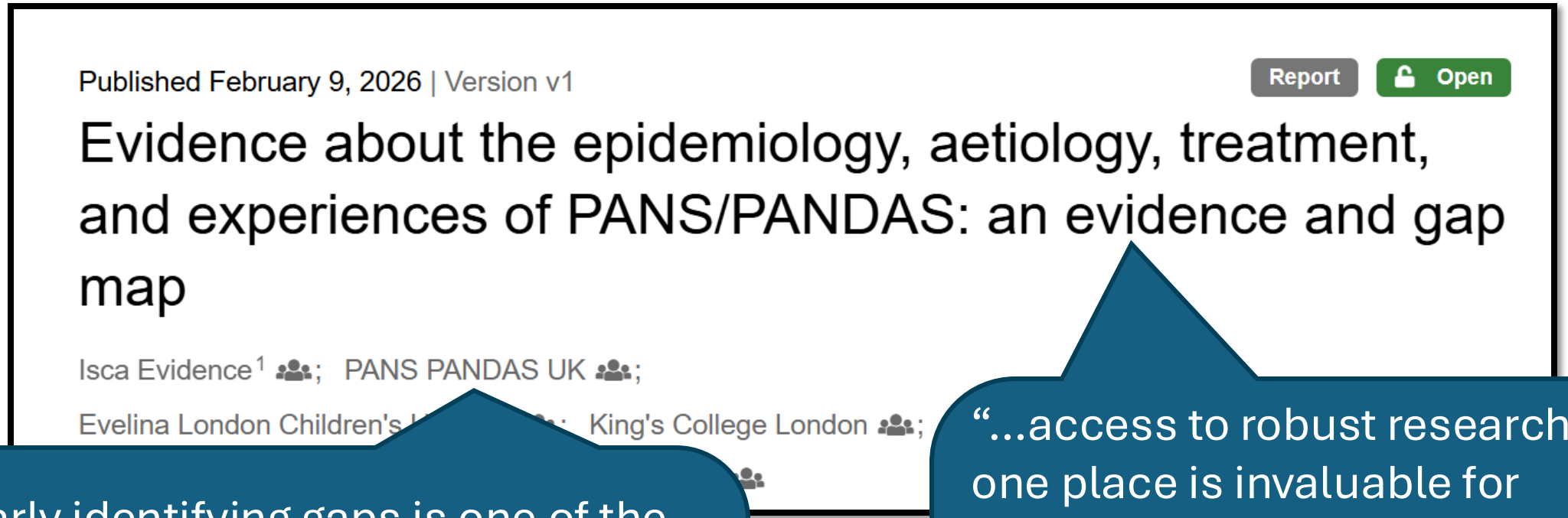








When patients, parents and communities become partners… **what happens *to the research?***



Published February 9, 2026 | Version v1

Report Open

Evidence about the epidemiology, aetiology, treatment, and experiences of PANS/PANDAS: an evidence and gap map

Isca Evidence[1]; PANS PANDAS UK;

Evelina London Children's ; King's College London;

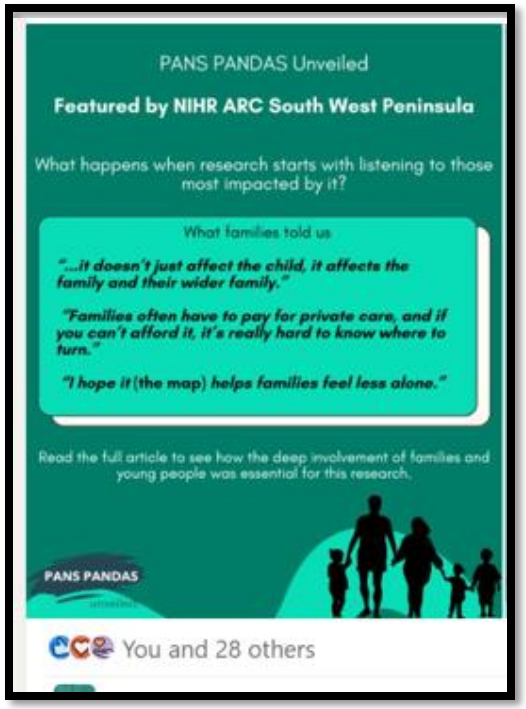
"Clearly identifying gaps is one of the most powerful ways to guide better-quality research, improve clinical understanding, and ultimately strengthen support for children and families."

"…access to robust research …in one place is invaluable for families. Many of us spend long nights searching for answers …Not everything we find is reliable, and as a community we can be particularly vulnerable to misinformation"

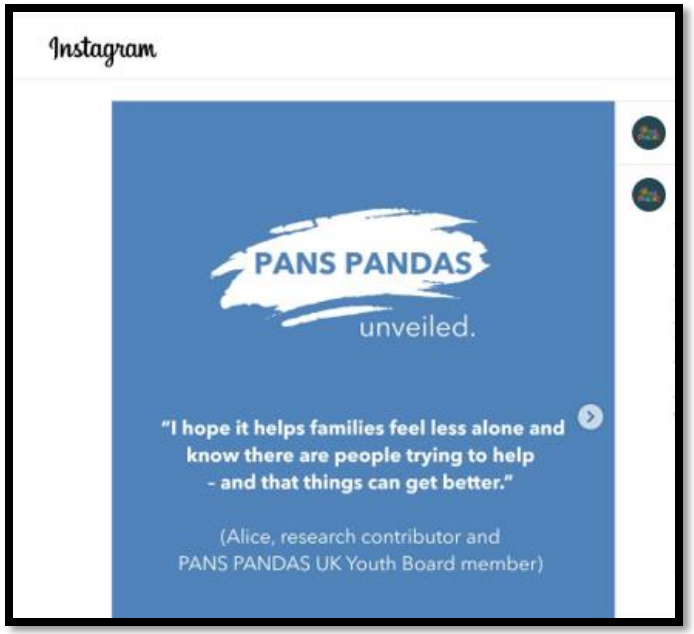
When patients, parents and communities become partners… **what happens *to the research?***

"Working together, it means the research can be presented in a way in which it lands well for each of the audiences, whether that's clinicians, young people or families in crisis." Lorna











When patients, parents and communities become partners… **what happens to the research?**

Protocol Development

Emerging Findings/Results

Interpretation

Writing & next steps

Review stages

What Matters?

- Experiences
- Treatments
- Outcomes

Sense-checking findings

- What's important
- What's missing
- What stands out

Does this resonate?

- Shaped themes
- Language changes







When patients, parents and communities become partners… **what happens to the research?**

"No two patients or families have the same experience, response to treatments, ages, course of the illness. So it's powerful to have those different perspectives represented." Parent



You're able to connect and understand the people that can hopefully benefit from it; but it provides a level of expertise that you could never get through research alone.
Researcher, ISCA Evidence



- It's the only way to understand what it's like
- Helps children who are poorly and ill to be heard

Tilda (8 years old)



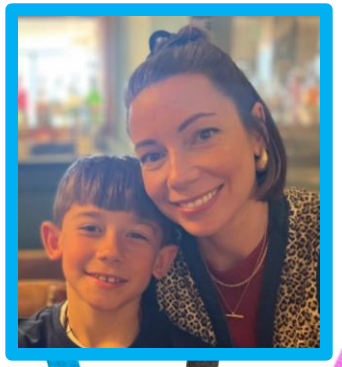


- New ideas and insights
- Point out what *doesn't* represent experiences

Ellen, young adult



When patients, parents and communities become partners… **what happens to the people**?



"They said we were their experts." Lorna

"They are your experts."

Researcher, ISCA Evidence



When patients, parents and communities become partners… **what happens to the people**?

"Those of us who have contributed feel heard, validated and important." Parent

"When you are in crisis with your child the world is a lonely place."
Carrie



"It helps children who are poorly and ill to be heard."
Tilda (8 years old)



When patients, parents and communities become partners… **what happens to the people**?

"Before my involvement, I was always **cautious**, about **who I spoke** to about PANS PANDAS, through **fear**, of people's **disbelief**, lack of understanding, people's **judgement**, not just of me as a parent, but also my children. I am now **confident** and able to **share our experience, without fear**…" Amanda



"That human side to what we're working on is important to have in mind."
Researcher, ISCA Evidence



When patients, parents and communities become partners… **what happens to the people**?

"People were willing to share those experiences because they wanted to ….ultimately improve things for other families." Parent



"That trust has also brought a strong sense of **responsibility**…"
Researcher, ISCA Evidence



When patients, parents and communities become partners… **what supports that to happen?**

"It's not just the coming together, but the way in which it has been done…"
Lorna









Online meetings with young people



Phase 1: 2 meetings
Phase 2: 6 meetings
10 young people. Ages 8–22



Youth worker
intermediary &
co-facilitator



WhatsApp &
Discord groups

Online meetings with parents

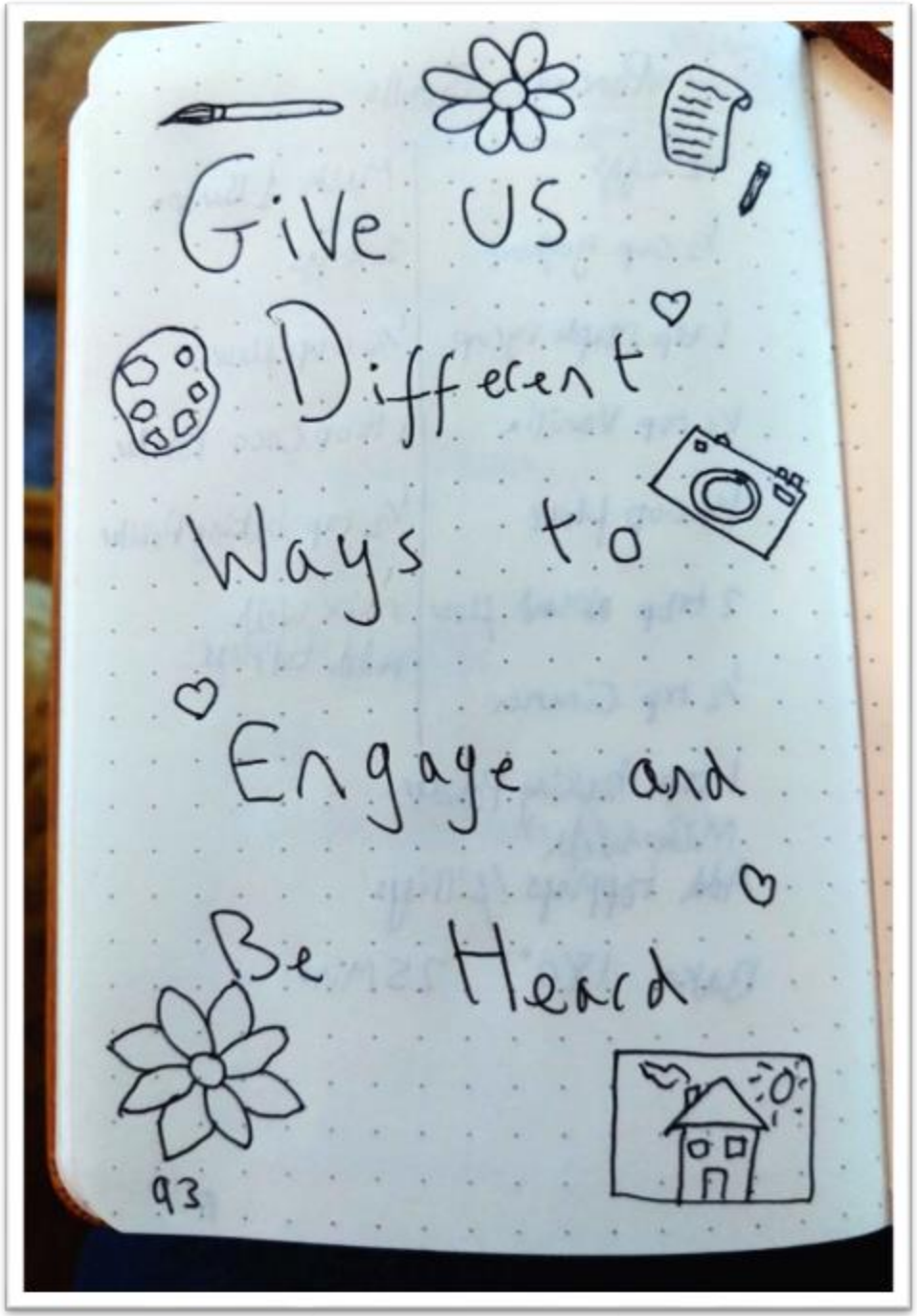


Phase 1: 4 meetings
Phase 2: 8 meetings
11 parents

Email &
one-to-one contributions

If you want young people involved in research, remember …





When patients, parents and communities become partners… **what supports that to happen?**

UK Standards *for* Public Involvement

NIHR | National Institute for Health and Care Research

Learning for Involvement

Resource

NIHR involving children and young people as advisors in research

NIHR | National Institute for Health and Care Research

Payment guidance for researchers and professionals involving people in research

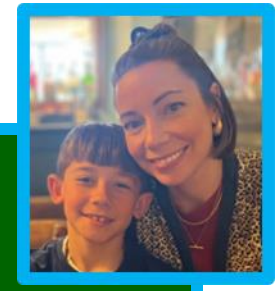




Trauma Informed Plymouth Network

HOSTED BY IMPROVING LIVES PLYMOUTH

When patients, parents and communities become partners… **what supports that to happen?**



"The forum that had been created felt like a safe space."
Lorna

Trauma Informed Plymouth Network

HOSTED BY IMPROVING LIVES PLYMOUTH

When patients, parents and communities become partners… **what supports that to happen?**

"Honestly… I thought **'uh oh'**…"
Parent reflecting on first meeting

Time



"I came away from each meeting feeling **understood**."
Amanda, reflecting on involvement now

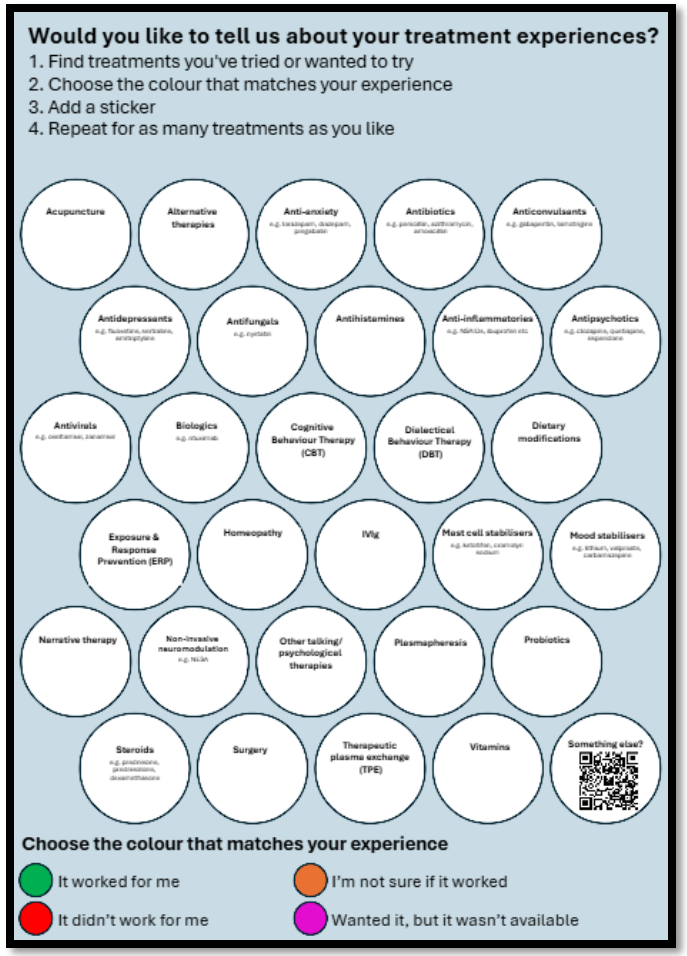
What's next?

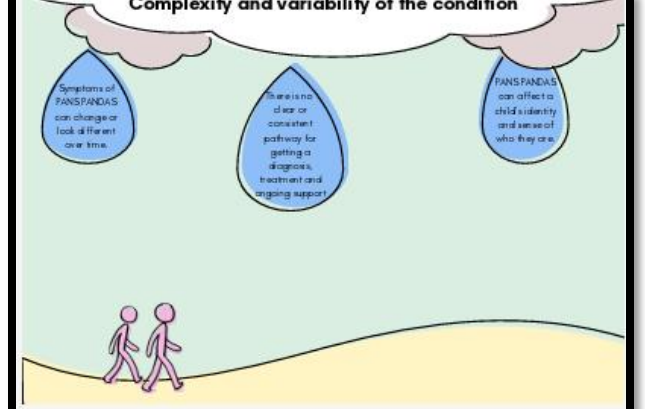
Phase 2: Continued involvement in the reviews

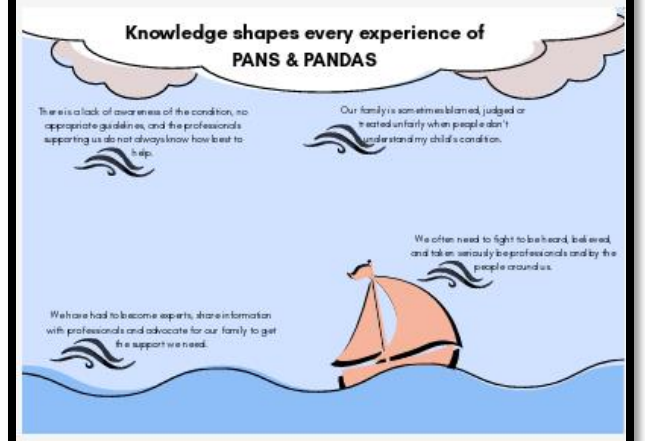
Community Day: Engaging with around 100 members of the PANS/PANDAS community

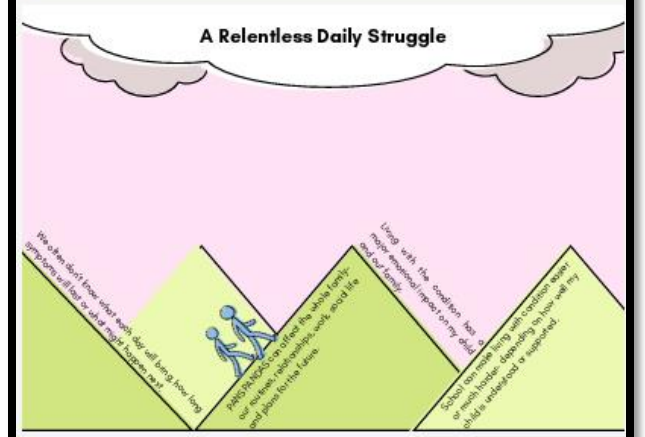














What happens when patients, parents and communities become partners in research?

The research can change

The people involved can change

The impact can extend beyond the research

