PANS PANDAS Unveiled: Mapping the research landscape

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King's College London

PANS PANDAS

NIHR | Applied Research Collaboration South West Peninsula

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Acknowledgements

- We represent a team
- Heavily informed by lived experience & clinical expertise

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The context

- Isca Evidence
  - Evidence synthesis
  - NIHR funded (UK)
  - Variety of topics
  - Methods expertise
- Initial brief
  - NHSE/PANS PANDAS UK (June 2025)
  - Effectiveness review, JLA priority



Image hand-drawn by A. Stitt using Sketchbook Pro

Methods

- PANS/PANDAS/CANS/PITANDS
- Collected empirical data
- Journal articles
- Conference abstracts
- Trial registrations
- Theses and dissertations
- Preprints
- No date or language restrictions

- 15 bibliographic databases (August 2025)
- Citation searching
  - Checking reference lists
  - Seeing who cited the studies we found
- Author searches
  - (Swedo, Frankovich, Murphy)
- Five websites
- Clinical trial registries
- Undermind AI

Methods

- Developing the map framework:
  - Clinical experts (Ashley Liew, Ming Lim)
  - Literature
  - PANS PANDAS UK (Katy Hindson)
  - Parents
  - Youth Board (via PANS PANDAS UK)

- Influenced:
  - Appearance
  - Research topics (access to services)
  - Population categories
  - Symptom list
  - Health professionals category
  - Setting category
  - Support category



Image hand-drawn by A. Stitt using Sketchbook Pro

What did we include?

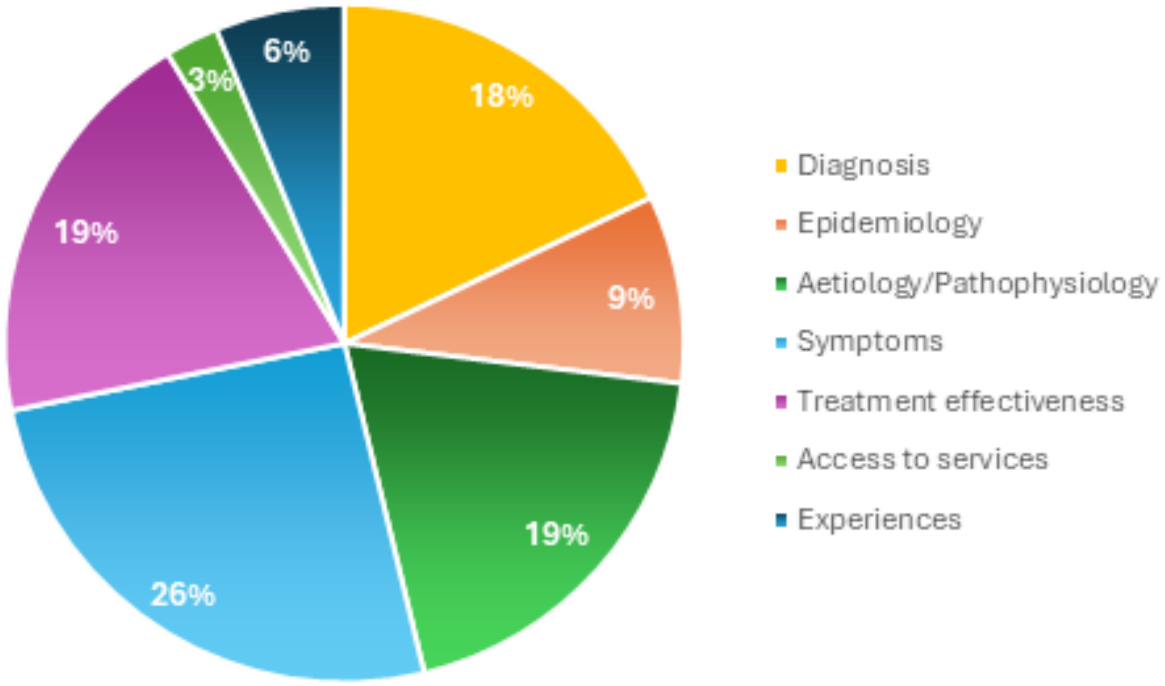
- Screened over 9000 studies
  - Nearly 2/3 from supplementary search methods
- Main reasons for exclusion at full text:
  - Not about PANS/PANDAS
  - Not empirical studies
- 445 includes
  - 34 from supplementary methods



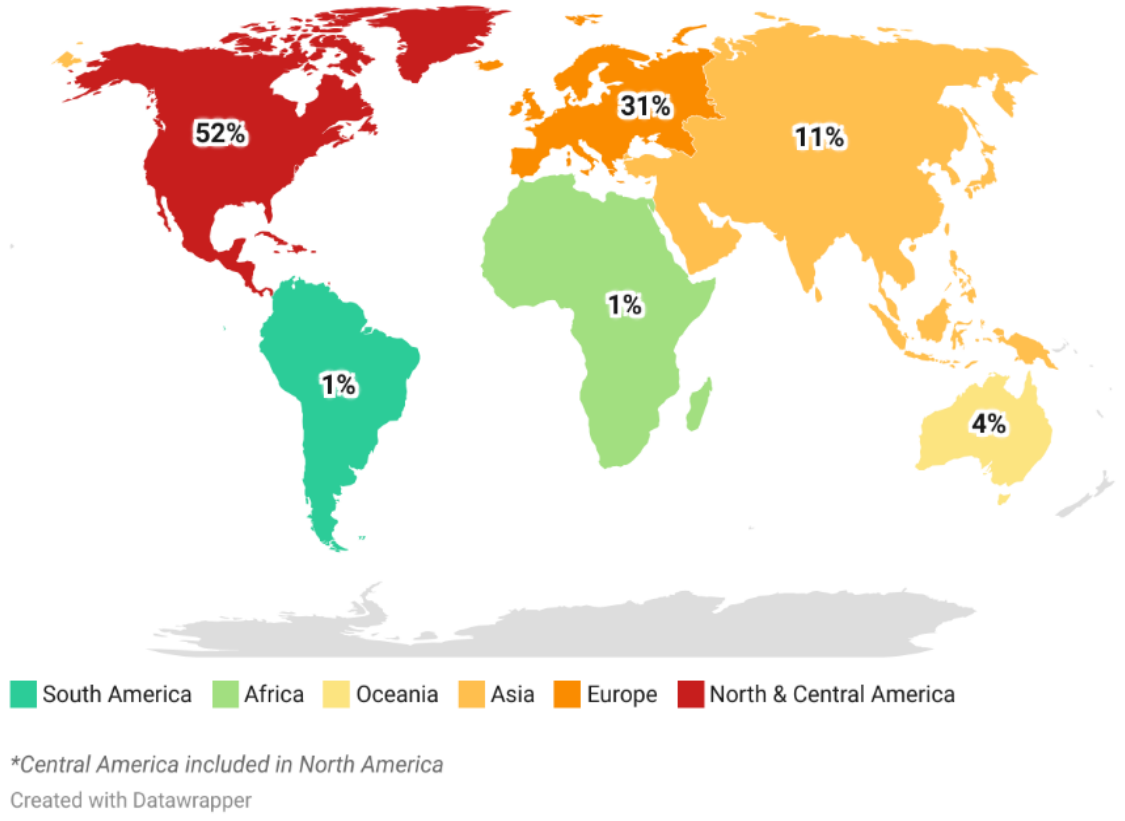
https://eppi.ioe.ac.uk/cms/Portals/35/Maps/PANS_PANDAS_EGM.html

Main observations

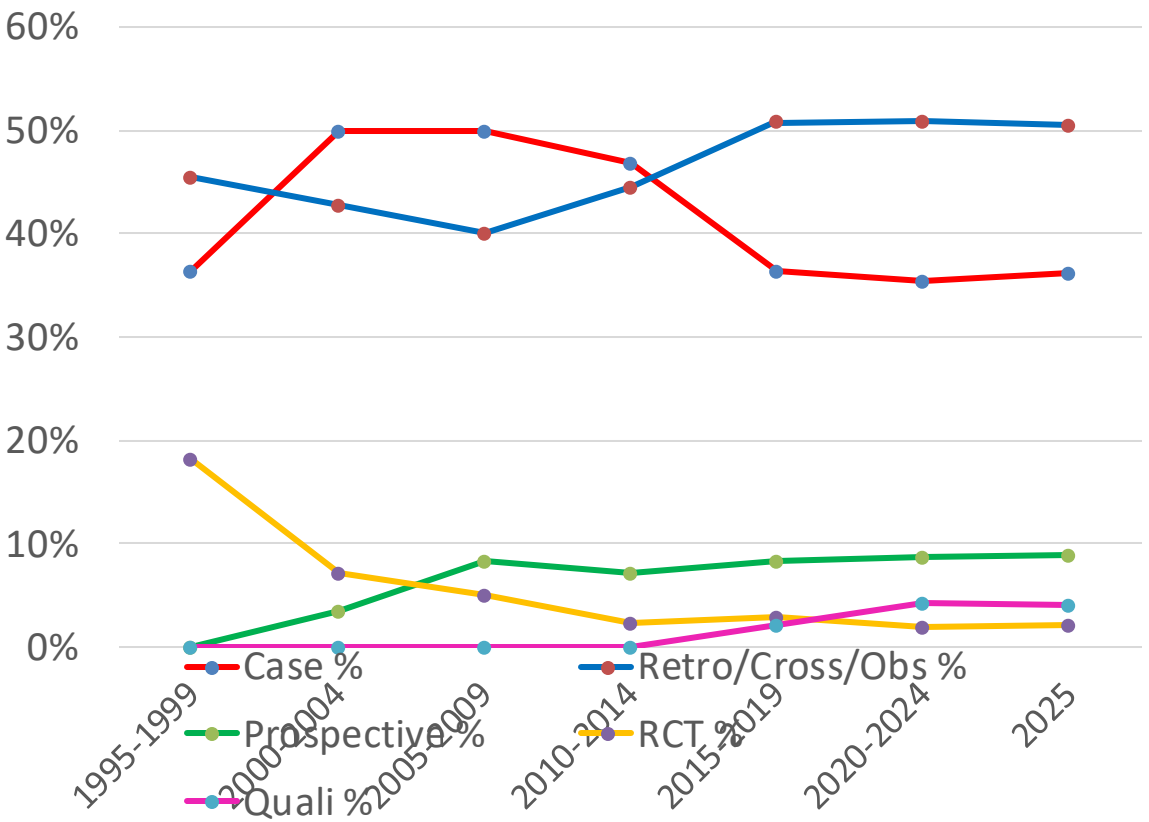
Distribution of evidence by research topic



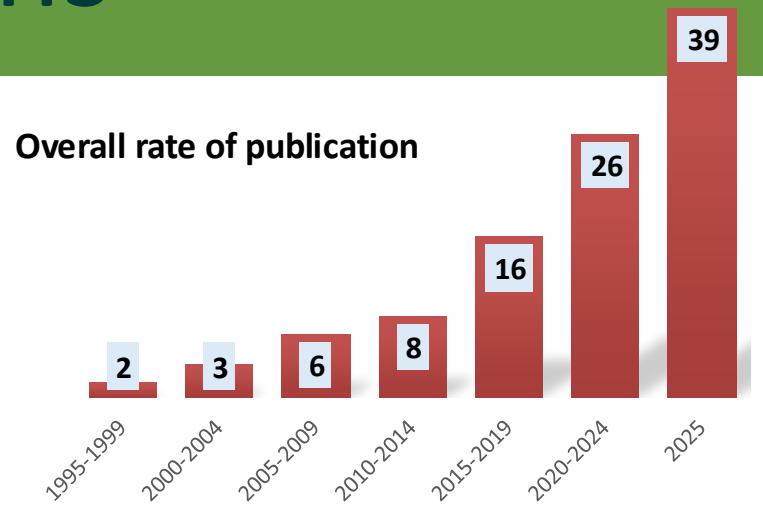
Distribution of coding across study regions

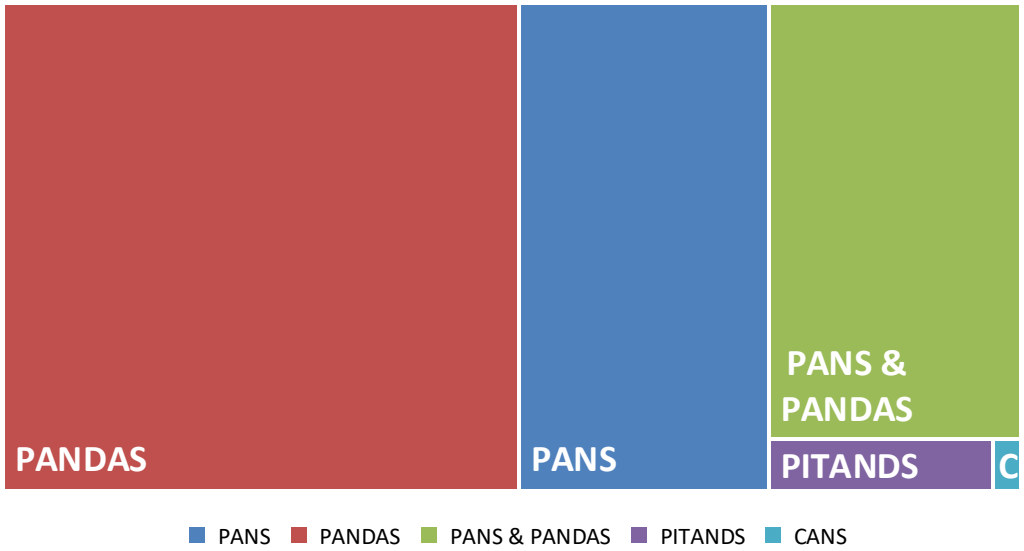


Main observations



Proportion of each study design over time





Diagnosis described in studies

Gaps

- Lots of opportunities for evidence synthesis
- A need for more (prospective) research on treatments
  - The issue with lag
  - The nature of treatment protocols
- Very little evidence about diagnosis as a process
- A lack of focus on access and equity issues
- Very little evidence in education settings



Illustration by Bruno Figueiredo on Unsplash

Opportunities

- Lots of opportunities for new work
- We can work out how to fill the gaps, collaboratively
- Additional drive to publish
- A valuable resource



Ongoing work

Qualitative review (2a)

- Experiences

Quantitative review (2b)

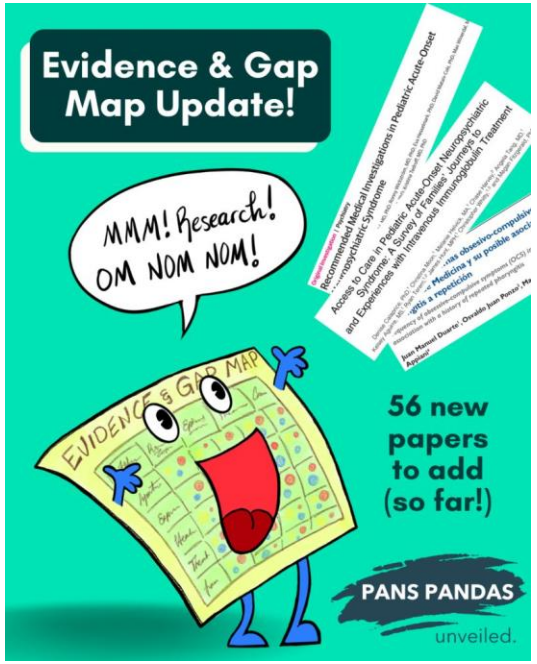
- Treatments

Completion of PANS PANDAS Unveiled

Updating the EGM

Update 1 – Autumn 2026

- Repeated searches, with some additional sources (LinkedIn, specific websites etc)
- Screened an additional 1115 at title/abstract, and 103 at full text, including 68 additional papers to the map
  - 46 journal articles/theses/reports (3 are full versions of prior records)
  - 20 conference abstracts
  - 2 abstracts
- **Summary of new studies and changes on Zenodo**



PEOPLE WITH PANS & PANDAS

SIBLINGS

PARENTS/ CARERS

HEALTHCARE PROFESSIONALS

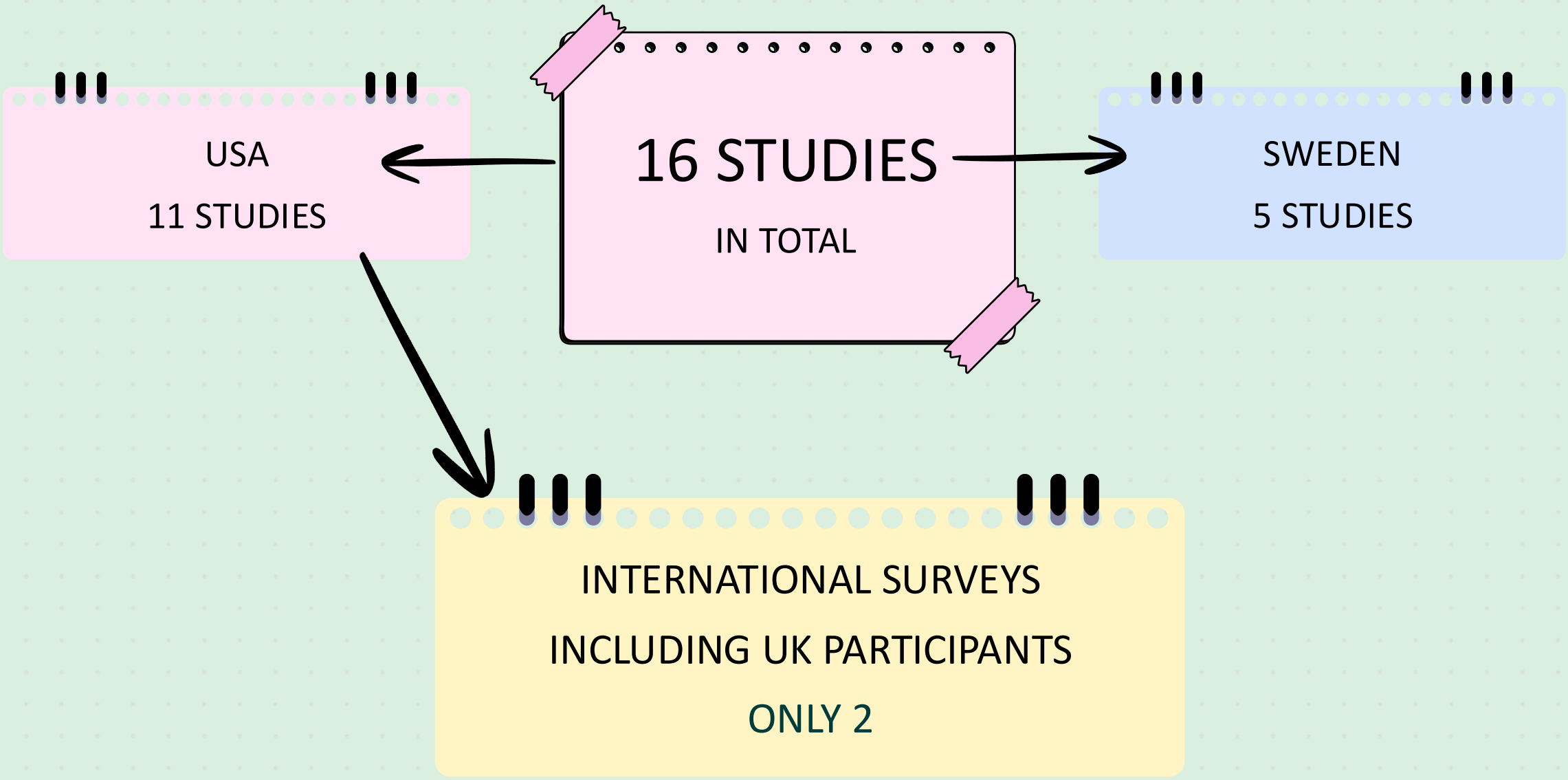
EDUCATION PROFESSIONALS

PANS PANDAS unveiled.

VIEWS & EXPERIENCES OF PANS & PANDAS

University of Exeter

FUNDED BY NIHR | National Institute for Health and Care Research


16 STUDIES
IN TOTAL
USA
11 STUDIES
SWEDEN
5 STUDIES
INTERNATIONAL SURVEYS
INCLUDING UK PARTICIPANTS
ONLY 2

PEOPLE WITH PANS & PANDAS

ONLY 5 STUDIES
2 INVOLVING ADULTS

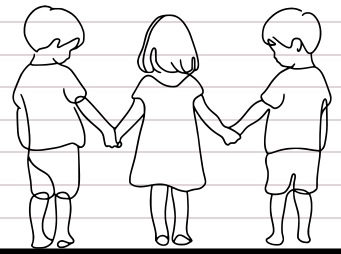
SIBLINGS

1 STUDY

PARENTS/ CARERS

13 STUDIES

ONLY 4 STUDIES INVOLVING CHILDREN AND YOUNG PEOPLE



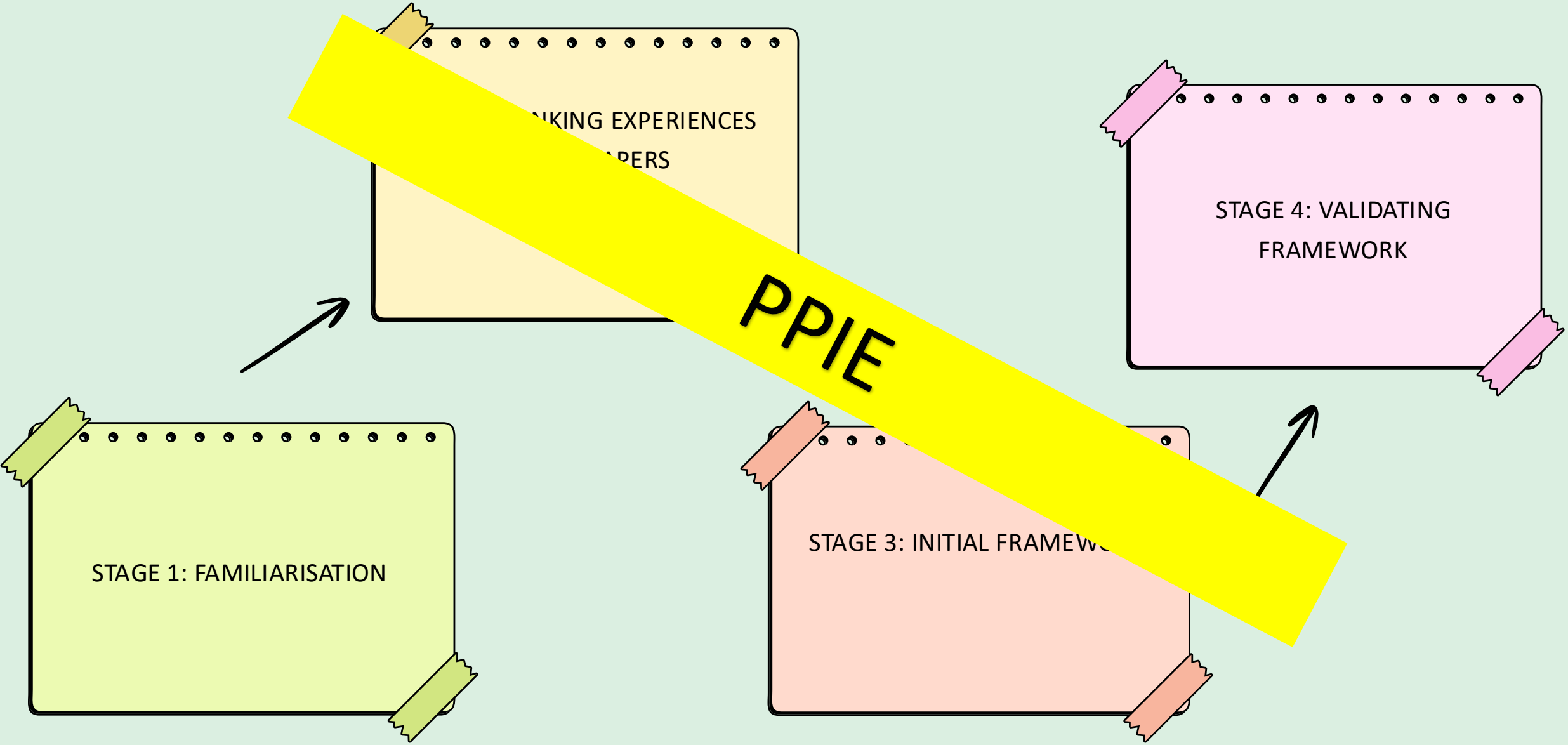
HEALTHCARE PROFESSIONALS

1 STUDY

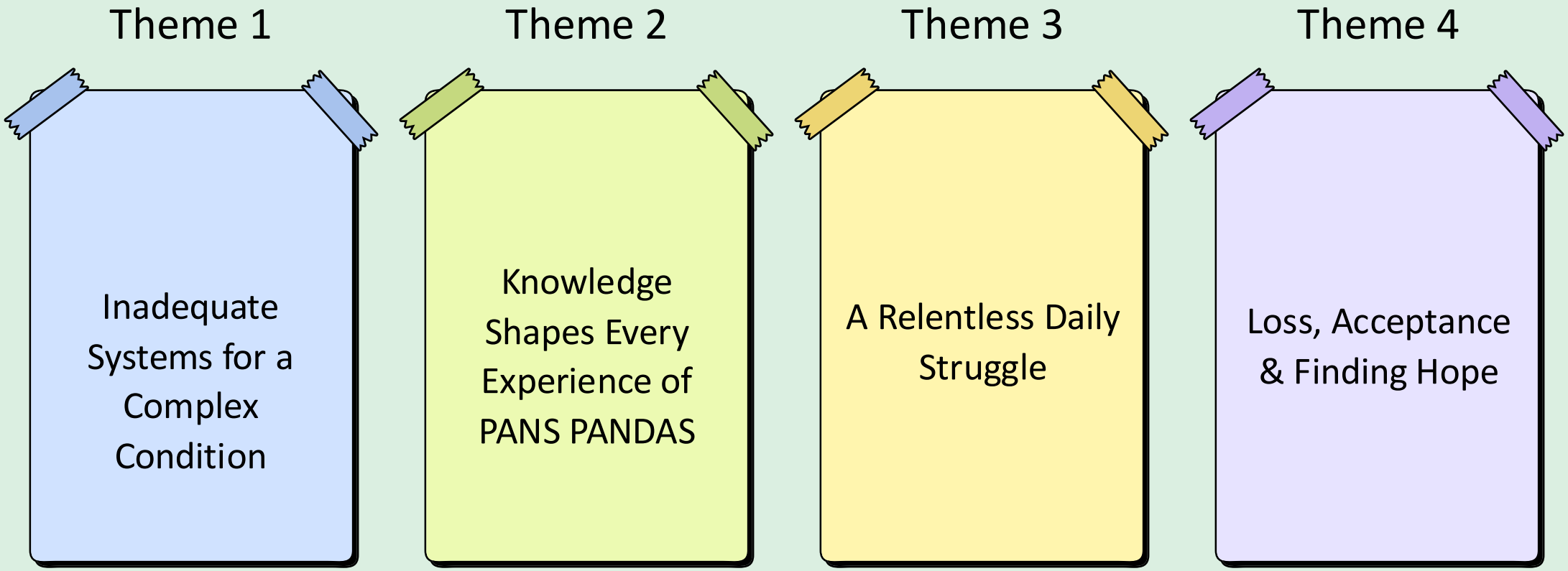
EDUCATION PROFESSIONALS

0 STUDIES

Development of themes



4 CONNECTED THEMES



Theme 3

A Relentless Daily Struggle

Patient embodied lived experience

Enduring unpredictability and uncertainty

Illness Takes Over Family Life

Educational environment shapes the illness experience

Emotional impact and impact on wellbeing

"There is not a moment it's not in my thoughts and there's not a way that our lives are not shaped by it and I think that on the good days and bad days."

"PANDAS for some reason...just drains a family emotionally, physically, financially, spiritually, socially."

Quantitative review – Effectiveness of treatments

- What were we interested in?
  - Immune treatments (e.g. IVIg, TPE)
  - Antibiotics
  - Behavioural/psychological therapies (e.g. CBT)
- Why these three?

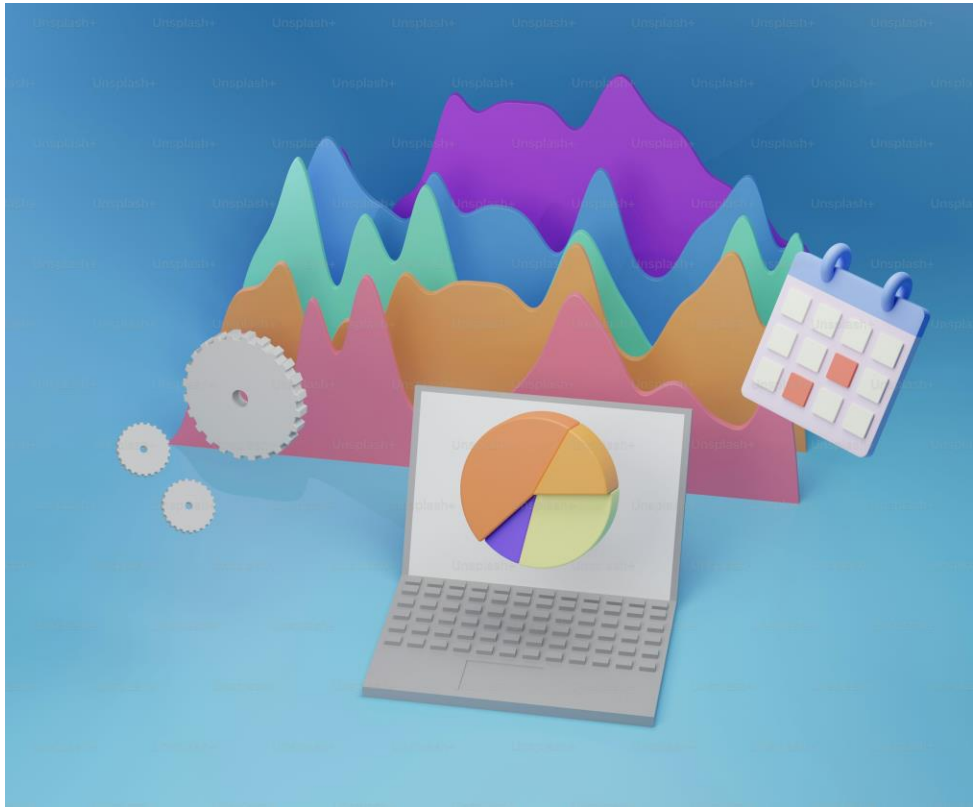


Illustration by Valeria Nikitina on Unsplash

Key methods points

- Included any longitudinal experimental or observational studies
  - Needed usable data
- Outcomes:
  - Responder analysis
  - Composite symptom score outcomes
- Open to meta-analysis…

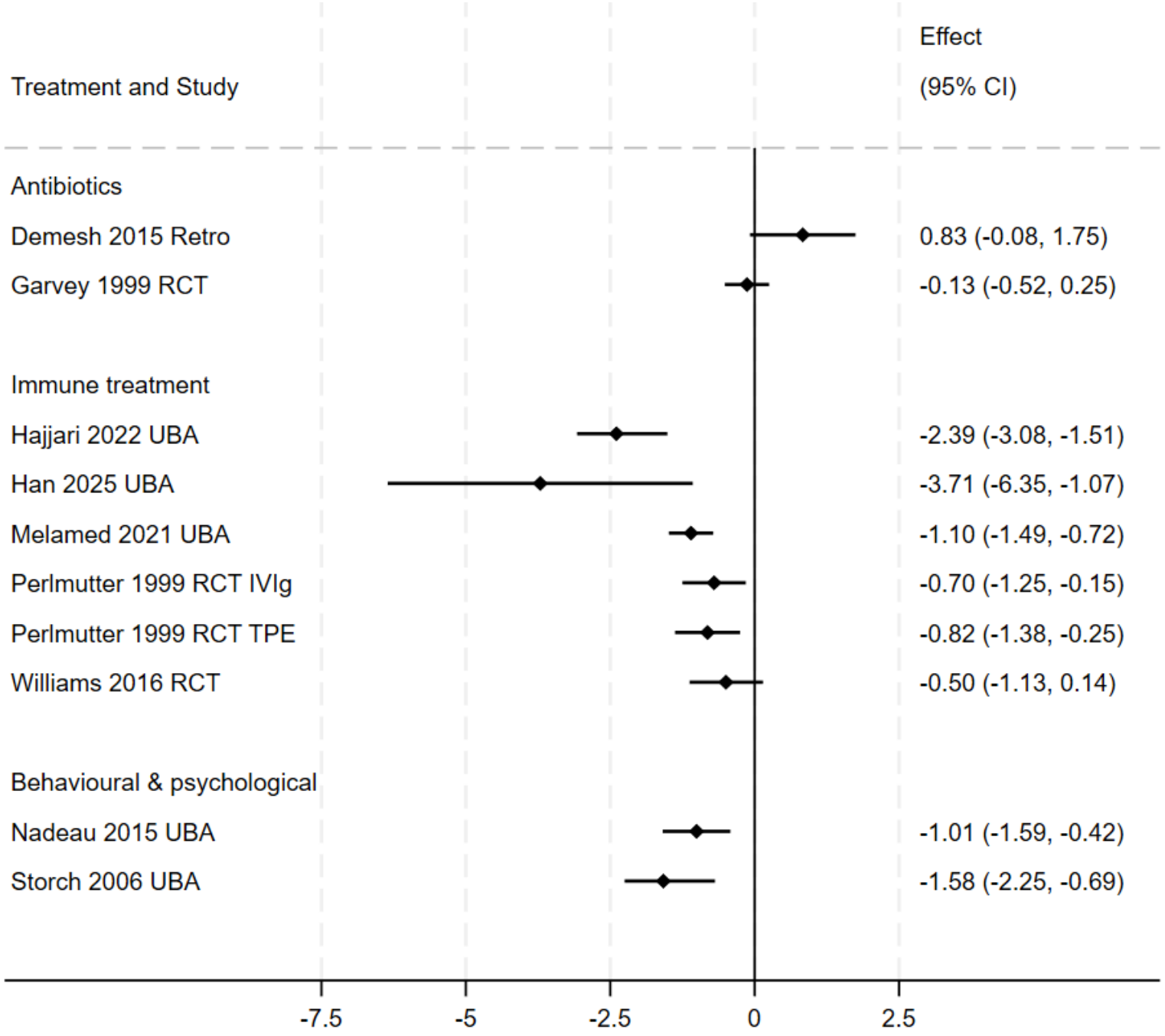


Illustration by Everyday basics on Unsplash

Results

- 14 studies included overall
  - 5 antibiotics (Snider 05, Demesh 15, Murphy 02, Murphy 17, Garvey 99)
  - 7 Immune treatments (Perlmutter 99, Williams 16, Melamed 21, Melamed 24, Hajjari 22, Han 25, Zheng 25)
  - 2 Behavioural/psychological (Nadeau 15, Storch 06)
- Meta-analysis was deemed inappropriate
- Numerous difficulties interpreting data or finding usable data

NOT a meta-analysis!



Study	Treatment	Definition of 'responder'	Findings
Williams 2016 RCT	Immune treatment (IVIg)	30% or better decrease on CY-BOCS, and 'Much' or 'Very much' improved on CGI-I (score 2 or 1)	**6 weeks** - 6/17 improved with IVIg vs 4/18 with placebo (OR, 1.91 [95% CI: 0.43 to 8.48])
Hajjari 2022 UBA	Immune treatment (IVIg)	Clinical response defined as > 30% reduction in symptoms and Impairment, or by a score of 1–2 on CGI-S and CGI-I.	**12 weeks** Symptom scores: 9/10 improved CGI-S: 4/10 CGI-I: 8/10
Murphy 2017 RCT	Antibiotics (Azithromycin)	Scored 1 or 2 on the CGI-I OCD or reduction of 30% on the CY-BOCS	**4 weeks** CGI-OCD: - 7/17 improved with azithromycin, vs 1/14 with placebo (OR, 9.10 [95% CI: 0.95 to 86.5]) CGI-Tics: - 7/17 improved with azithromycin, vs 6/14 with placebo (OR, 0.93 [95% CI: 0.22 to 9.91]) CGI-Neurocognition: - 3/17 improved vs 0/14 controls
Storch 2006 UBA	CBT	Score 1 or 2 on CGI-I	**7 weeks** - 6 of 7 improved

Interpretation

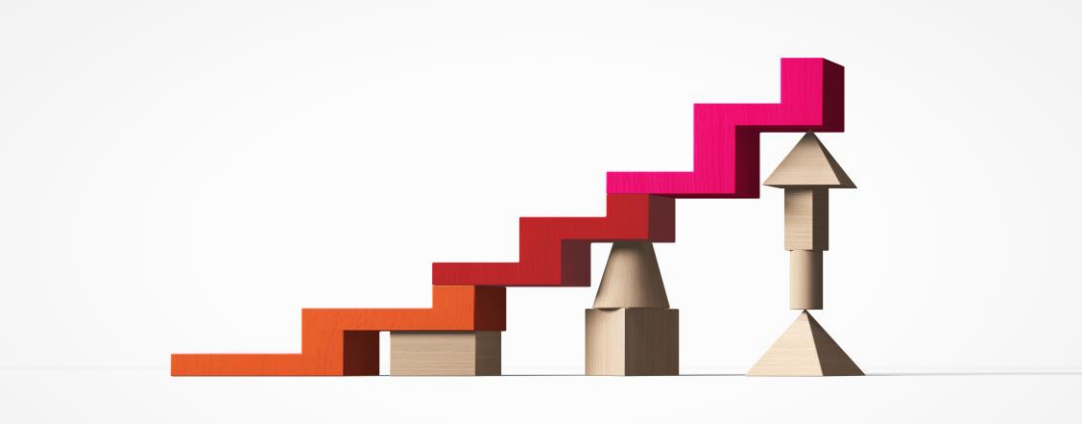
- Generally, values appear to show some benefit with all treatments, BUT
- Interpretation needs a lot of caution:
  - Mixed designs/varied time points/unclear definitions/variation in treatment strategy
  - Few controlled, prospective studies
  - Unclear reporting or complex patient flow
  - Small samples
  - Confounding treatments



Illustration by Markus Spiske on Unslpash

Next steps

- We want to say something useful, other than ‘we need more studies’
- Integration of qualitative evidence and PPIE
- Specifics of what research should happen next (evaluating protocols)



Thank you

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“I hope this report is used as a practical tool: to inform researchers and funders about priority questions, to help clinicians and services reflect on current practice, and to support families and schools seeking clearer, evidence-informed pathways.”

“Having access to robust international research brought together in one place is invaluable for families. Many of us spend long nights searching for answers, trying to make sense of complex and sometimes conflicting information. Not everything we find is reliable, and as a community we can be particularly vulnerable to misinformation”