UK Research Landscape

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Outline

1. James Lind Alliance and British Paediatric Neurology Association (BPNA) research priority setting partnership on Childhood Neurological Conditions

2. PANS Surveillance Study

3. PANS Delphi Study to develop national clinical guidelines

4. Future Research



James Lind Alliance
Priority Setting Partnerships

BPNA
British Paediatric Neurology Association

Childhood Neurological Conditions Priority Setting Partnership

To identify key areas where there is no clarity about the effectiveness of interventions, treatments, therapies or procedures aimed at improving the health and wellbeing of children and young adults with neurological conditions.

The survey aims to shape future research on childhood neurological conditions by bringing together patients, their parents and carers and health care professionals to identify and prioritise unanswered questions around treatments, therapies or procedures to present to researchers and funders

James Lind Alliance
Priority Setting Partnerships

BPNA
British Paediatric Neurology Association

Steering group and expert panel



STEERING GROUP

Suzannah Kinsella
Dr Ming Lim*
Professor Helen Cross
Philip Levine
Professor Manju Kurian
Dr Sam Amin*
Dr Richard Chin
Ben Green
Dr Andrew Mallick
Professor Jeremy Parr
Dr Jill Cadwgan*
Siobhan Hannan*
Dr Ava Easton
Barbara Babcock
Rhys Inward
Harriet Pollard
Molly Brick
Carol-Anne Partridge

EXPERT PANEL

Professor Robert McFarland
Dr Ruth Williams
Dr William Whitehouse
Dr Evangeline Wassmer
Dr Vijeya Ganesan
Dr Rachel Kneen
Dr Daniel E Lumsden*
Dr Anne-Marie Childs
Dr Anthony Hart
Jane Goodwin*

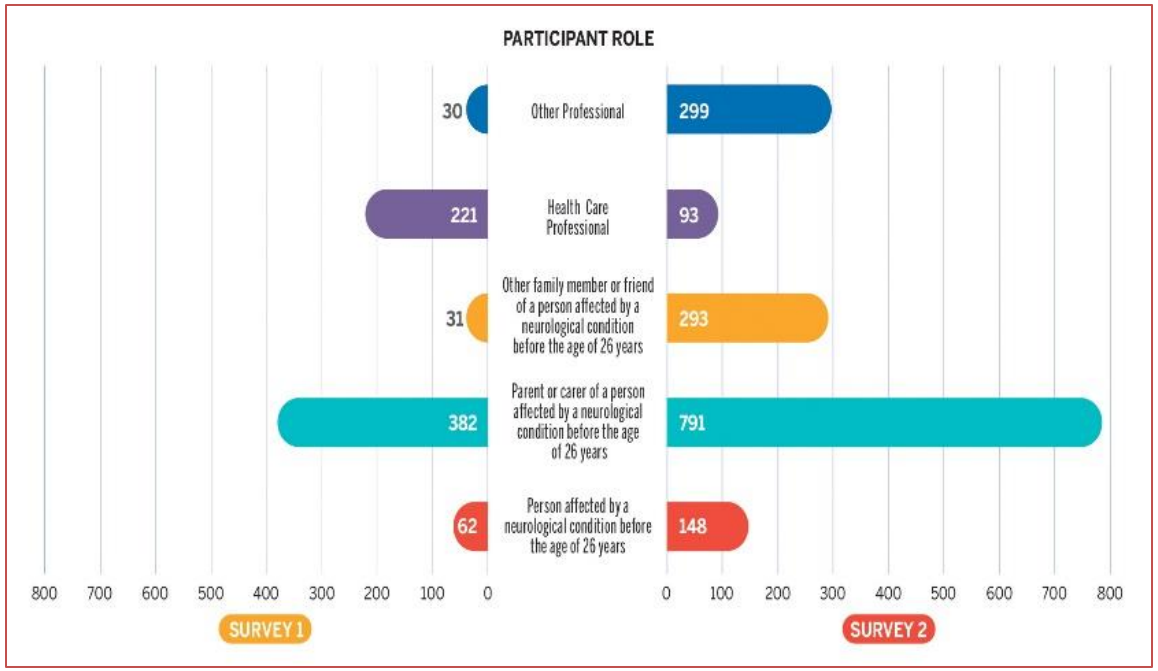


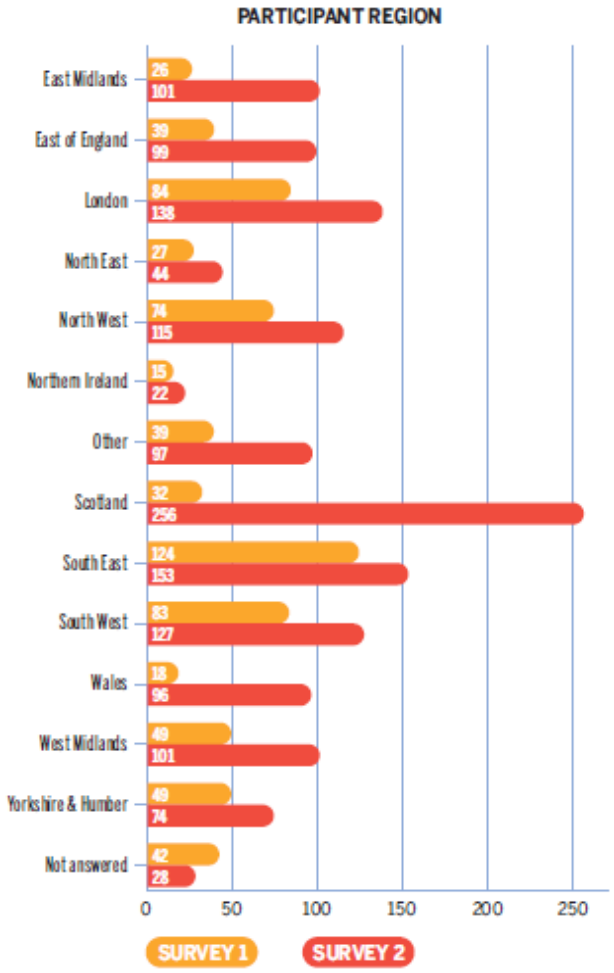
132 organizations: charities and professional organizations

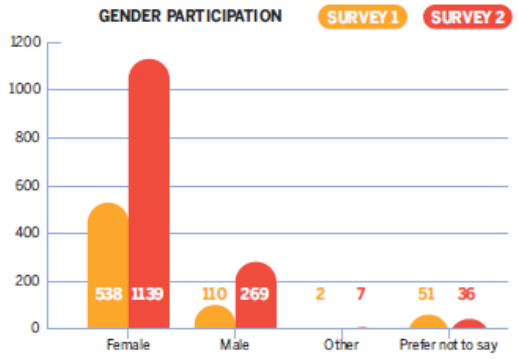
A large scope, over multiple stages taking 18 months

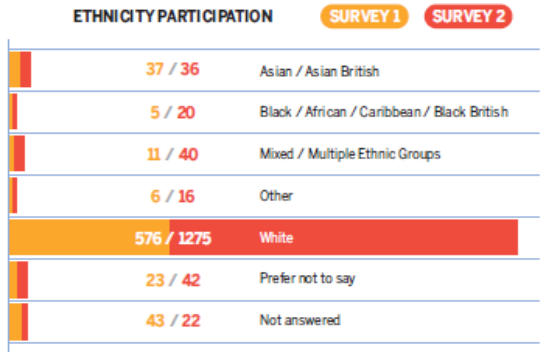
James Lind Alliance
Priority Setting Partnerships

BPNA
British Paediatric Neurology Association







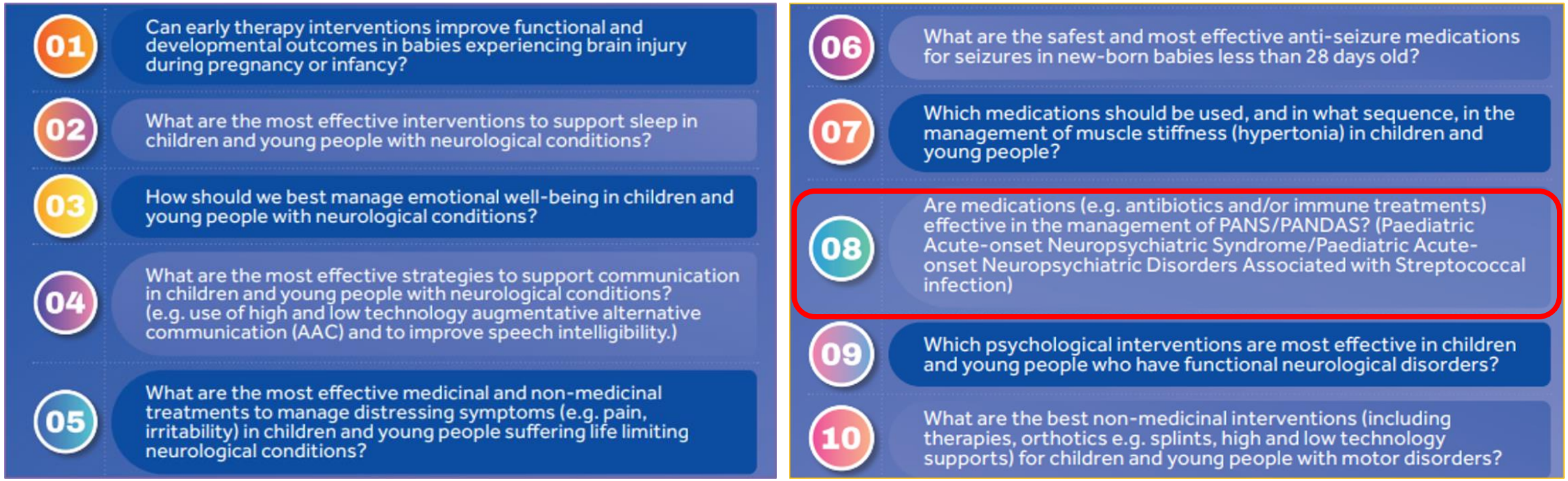


Represented geographically, across professions and inclusive

James Lind Alliance
Priority Setting Partnerships

BPNA
British Paediatric Neurology Association

Top 10 research priorities



Dev Med Child Neurol. 2024 Dec;66(12):1590-1599

Application for a UK & Ireland Surveillance Study of

Paediatric Acute-onset Neuropsychiatric Syndrome (PANS)

Surveillance of • BPSU • Rare Childhood Disease

British Paediatric Surveillance Unit

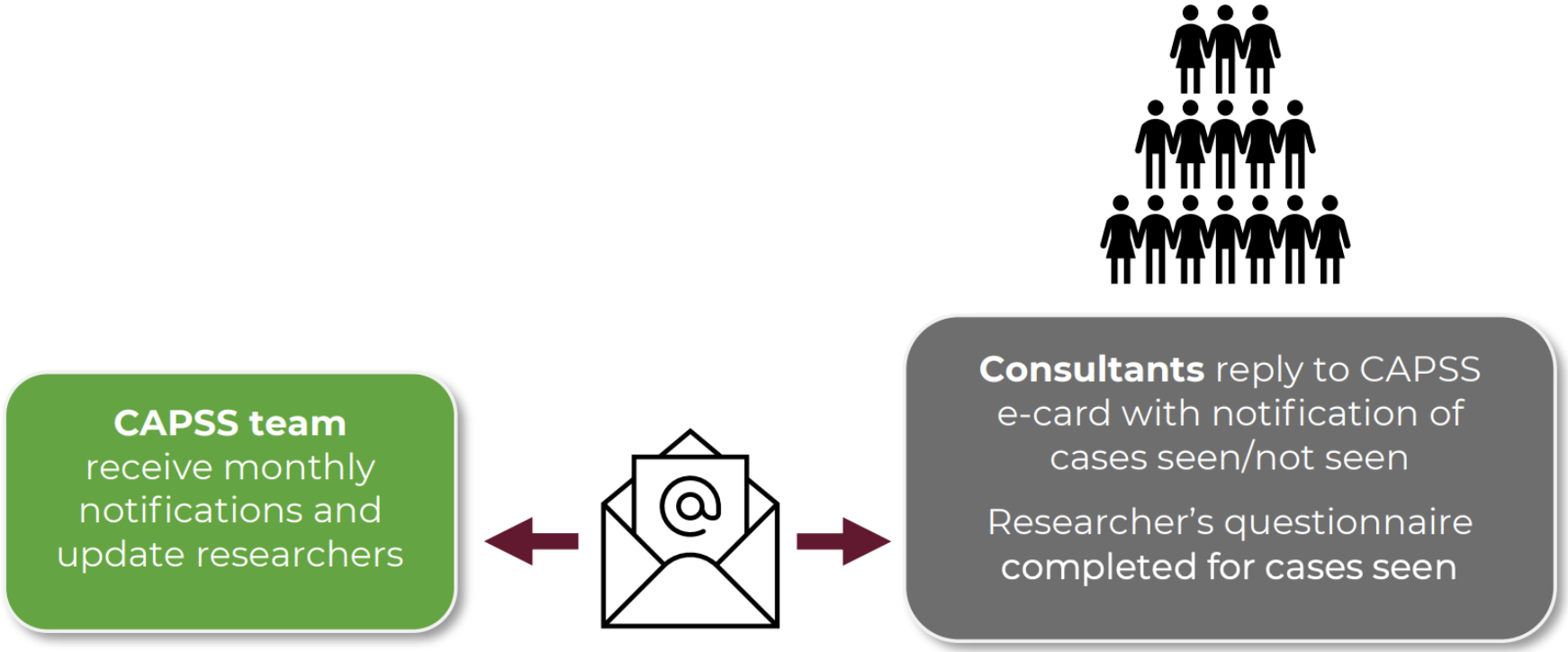
RC PSYCH ROYAL COLLEGE OF PSYCHIATRISTS

CAPSS
CHILD AND ADOLESCENT PSYCHIATRY SURVEILLANCE SYSTEM

BPNA
British Paediatric Neurology Association

British Paediatric Neurology Surveillance Unit (BPNSU)

Surveillance process



Previous Joint BPSU & CAPSS Surveillance Study

Sydenham's Chorea (SC)

A patient group led initiative to undertake surveillance with paediatricians via the BPSU and with child and adolescent psychiatrists through the CAPSS. The study aimed to examine the current pattern of SC, raise awareness of its course and complications and inform service planning.

Key Findings: Over 24 months there were 72 reports, all by paediatricians, 43 met the eligibility of suspected or confirmed SC. This translates to an estimated paediatric service-related incidence rate of new cases of 0.16 per 100 000 children aged 0–16 years old in the UK. Over 75% of cases presented with emotional and/or behavioural symptoms. Almost all cases were prescribed courses of antibiotics of varying duration, and around a quarter of cases (22%) received immunomodulatory treatment.

Study Outputs & Impacts: One paper has been published. It was felt that there is a further need for development of consensus around identification, diagnosis and management across child health settings.

Wooding, E. L., Morton, M. J. S., Lim, M., Mitrofan, O., Mushet, N., Sie, A., Knight, B., Ford, T., & Newlove-Delgado, T. (2023). Childhood/adolescent Sydenham's chorea in the UK and Ireland: a BPSU/CAPSS surveillance study. Archives of disease in childhood, 108(9), 736–741. https://doi.org/10.1136/archdischild-2023-325399

PANS Surveillance Study

Background

The Canadian Paediatric Surveillance Program published their 24-month national surveillance of children between the ages of 3 and 18 years who received a diagnostic label of PANS/PANDAS (Goren et al., 2025) and calculated a prevalence of 1 in 60,155 (0.0017%). Notably, they also reported that only 12% of their sample met core diagnostic criteria for PANS or PANDAS.

Study Questions

1. What is the incidence of PANS presentations to Paediatric services and CAMHS in the UK and Ireland?
2. What is the variability in presenting symptoms/features described within the case definition for PANS presentations?
3. What is the distribution of PANS presentations by age, sex and ethnic group?
4. What is the rate of a first degree relative with neurodevelopmental, neurological or psychiatric conditions in PANS?
5. What predisposing and precipitating factors are commonly associated with PANS presentations?
6. What are the current investigative approaches to PANS presentations?
7. What are the current management approaches to PANS presentations?
8. What proportion of children with PANS presentations have already been given a diagnosis of PANS or PANDAS, and how many received a new diagnosis of PANS or PANDAS?
9. What are the outcomes following PANS presentations after one year?

PANS Surveillance Study

Expected benefits

1. **Scientific knowledge & further research**
   - To help plan future high quality research studies of aetiology, clinical course, assessment measures, and both primary and secondary interventions for PANS presentations.

2. **Public health**
   - To raise awareness of acute presentations of neuropsychiatric presentations amongst Child & Adolescent Psychiatrists, Paediatricians and Paediatric Neurologists; and encourage earlier and more accurate identification.
   - To estimate the incidence of PANS to assist with planning of services at a local, regional and national level.

3. **Clinical practice & service development**
   - To improve understanding of treatment options accessed by children with PANS presentations in the UK & Ireland.
   - The multiagency nature of the surveillance study should encourage closer collaboration and aid the development of relevant care pathways and clinical services.

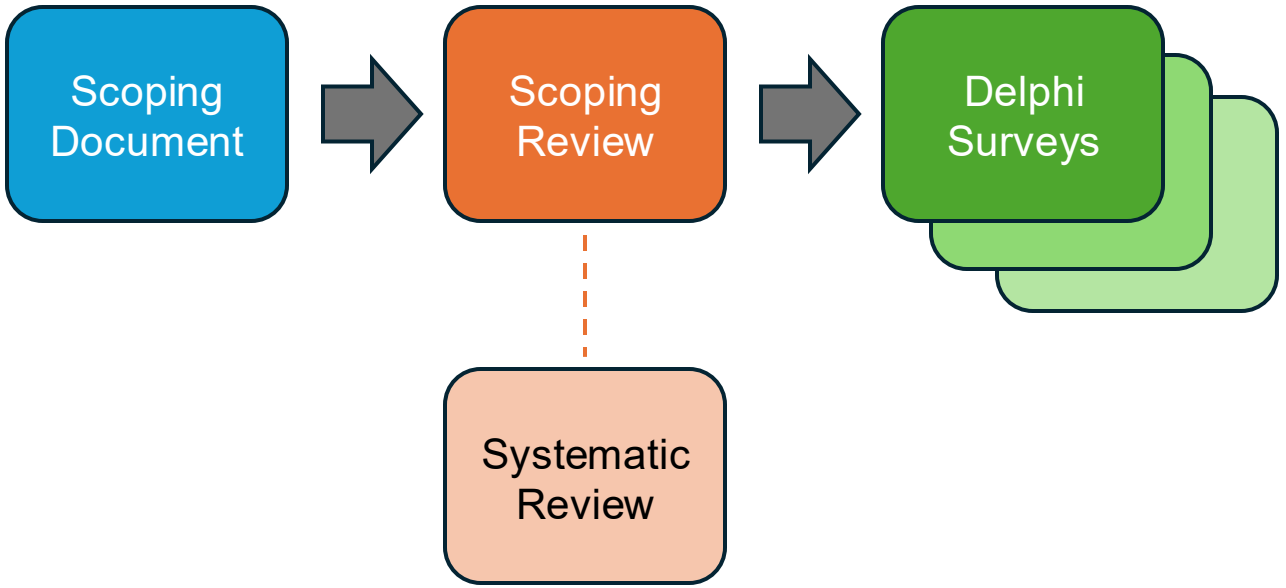
4. **Patients and families**
   - To understand further the feedback from young people and their parents which suggest wide variation of how CAMHS, community paediatric and acute paediatric services are managing children with PANS presentations.

PANS Surveillance Study

Progress

- Analytical case definition developed and refined in collaboration with BPSU and CAPSS committees
- Case definition and detailed data collection form piloted with 9 Paediatricians, 6 Child & Adolescent Psychiatrists, 8 parents/carers and 4 young people
- Part funding agreed in principle
- Awaiting full approval by BPSU and CAPSS Committees

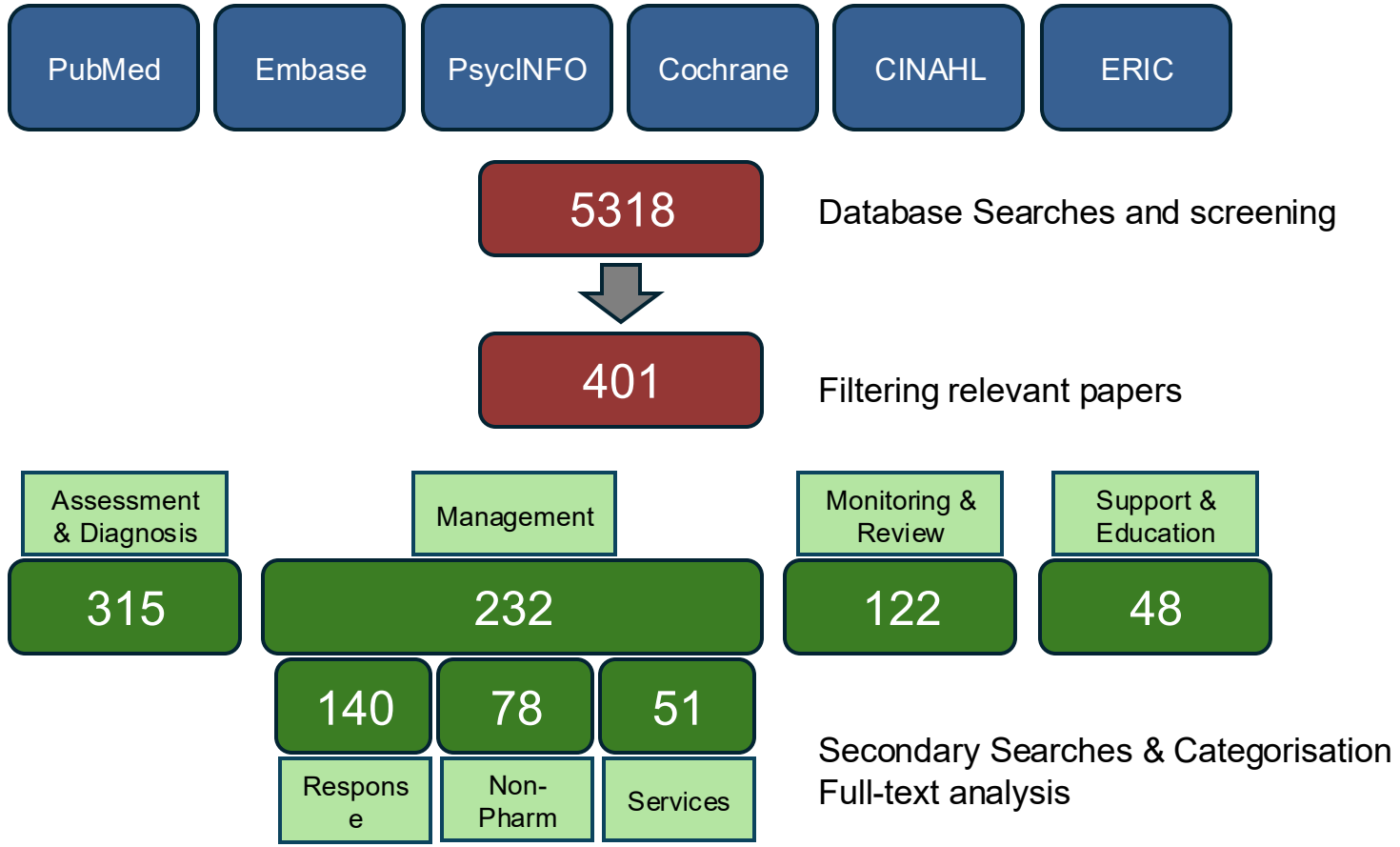
PANS Guideline – Delphi Survey



PANS Guideline – Delphi Survey

Scoping Document

Scoping Review



PANS Guideline – Delphi Survey

Scoping Document

Scoping Review



Consensus discussion
43 statements
Rated using GRADE criteria

GRADE (Grading of Recommendations, Assessment, Development, and Evaluation)

High certainty

There is high confidence that the true value of the estimate of interest is on one side of a threshold of interest or within a specific range.

Moderate certainty

There is moderately confidence that that the true value of the estimate of interest is on one side of a threshold of interest or within a certain range. The true value of the estimate may deviate slightly from the target of the certainty rating (i.e. may possibly fall in a different range).

Low certainty

There is low confidence that that the true value of the estimate of interest is on one side of a threshold of interest or within a certain range. The true value of the estimate may deviate from the target of the certainty rating (i.e. likely fall in a different range).

Very Low certainty

There is very low confidence that that the true value of the estimate of interest is on one side of a threshold of interest or within a certain range. The true value of the estimate may deviate significantly from target of the certainty rating (i.e. probably fall in a different range).

PANS Guideline – Delphi Survey

Scoping Document

Scoping Review

Delphi Surveys

Following ACCORD (ACcurate COnsensus Reporting Document) Guidelines [Gattrell WT et al, PLoS Med. 2024;21(1):e1004326]

Round 1 completed and due to commence Round 2

Future Research

1. Supporting the evidence synthesis by Isca Evidence commissioned by NIHR
    - Systematic reviews
    - Qualitative work

2. Multi-centre prospective studies, Eg.
    - Observational cohorts
    - Case Control studies

3. Build capacity for biological studies, Eg.
    - Biobank
    - Advanced imaging

4. Treatment trials including randomised controlled trials, Eg.
    - Antibiotics

PPSG

PANS PANDAS STEERING GROUP

Many thanks to the support of the PANS PANDAS Steering Group and National Institute for Health Research (NIHR)

Questions / Discussion