Perspectives on PANS

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Clinical Guideline Update

Speakers



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Why is a UK guideline important?

- PANS and PANDAS are relatively newly described conditions
- High-quality research is needed
- There is professional disagreement about how to manage them
- Children are receiving variable care due to lack of clear direction
- Where research evidence is poor, professional consensus is needed
- This must follow clear guidelines in order to be accepted by the relevant professional bodies such as RCPCH and RCPsych.



NICE guideline requirements

- **Evidence-based review**: Committees evaluate the best available scientific literature, real-world data, and economic evaluations to balance clinical effectiveness and cost-effectiveness.
- **Independent committees**: Guidelines are written by independent panels including healthcare professionals, researchers, social care practitioners, and lay members/service users.
- **Stakeholder consultation**: Draft scopes and recommendations undergo rigorous public and stakeholder consultation before final sign-off.
- **Prioritisation**: Topics are selected based on clear health and care needs, potential system impact, and ability to reduce health inequalities.

Why will our guideline not be a NICE guideline?

- Lack of evidence base
- However, the guidelines will be NICE curated.

Stakeholders

PANS Guideline Development Group

Independent chair
Experts by experience
Researchers
RCPCH guideline experts
Medical experts
PANS PANDAS UK representative



Included experts by experience:
parents and carers, young people over 14 and a detailed consultation held with an adult living with PANS.

Stakeholders



Stakeholders

Delphi panelists



Included experts by experience:
parents and carers, young people and siblings.

Included medical expert fields:
General Practice, Paediatrics
Neurology, Immunology
Infectious diseases
Psychiatry, Psychology and Nursing.

Patient and public involvement

Why it matters:

- Incorporates lived experience to ensure guideline reflects what matters most to patients and families
- Ensures parity across different perspectives
- Adds to knowledge from published research
- Evidences real-world impacts.

Patient and public involvement

Stronger together

PPI helps the guideline development group:

- identify gaps and assumptions
- take account of the realities of accessing and navigating care
- make the guideline clear and accessible.

Patient and public involvement

Critical for PANS and PANDAS

The value of lived experience is especially important in conditions where:

- patients encounter complex health journeys across services and disciplines
- there is variation in recognition, assessment and care
- there are gaps in the evidence base.

Patient and public involvement

Our aim

The PANS guideline group wanted patient and public involvement to help us produce recommendations that are:

- based on the best available evidence
- relevant and accessible to patients and families
- realistic to implement
- clinically credible.

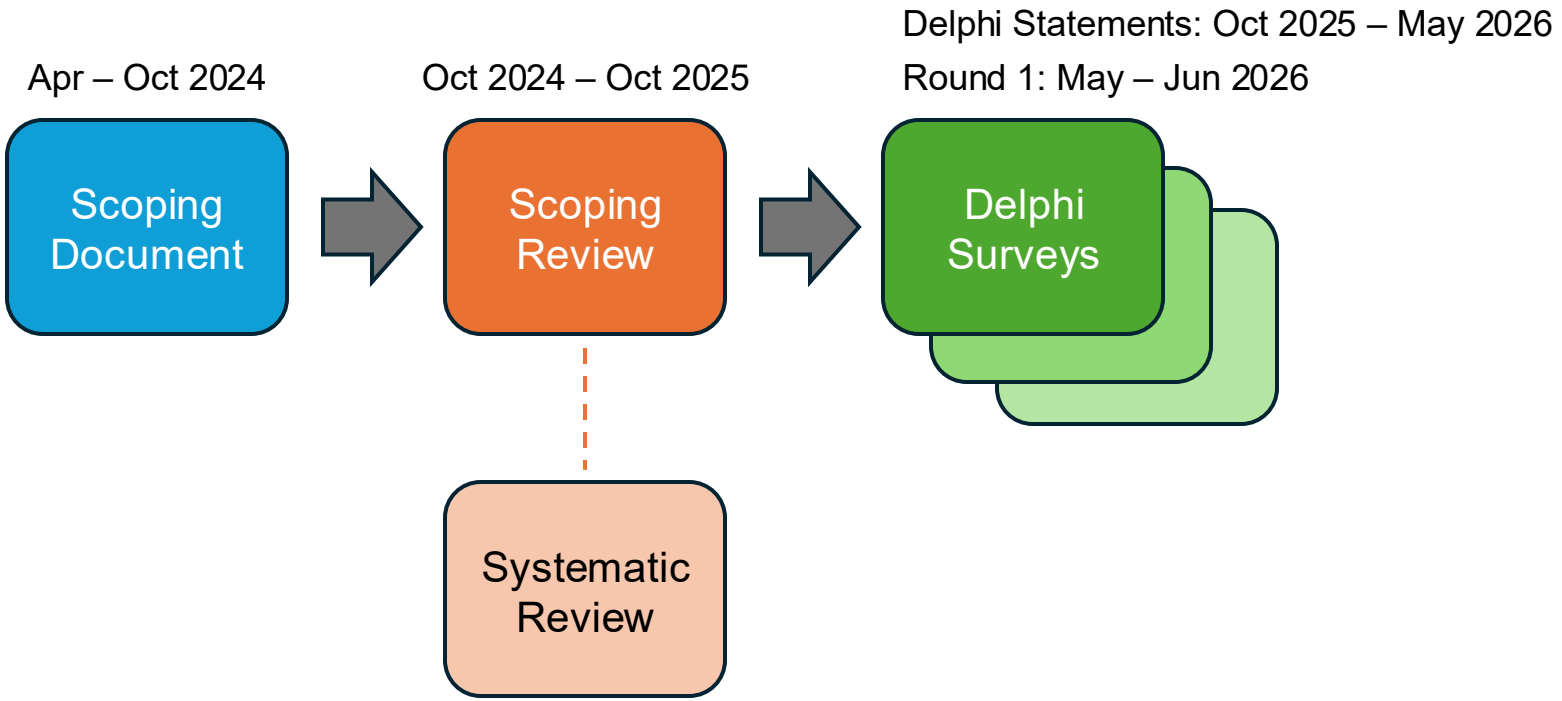
Patient and public involvement

What this looks like in practice:

- PANS PANDAS UK as a stakeholder
- early consultations with patients and families
- young people and caregivers on the guideline development group
- lived experience researchers supported the evidence review
- CYP, parents and sibling participants in Delphi process.



Guideline Development Process



Guideline Development Process

Scoping Document

1. Assessment

1.1 In CYP, what symptoms should prompt consideration of PANS?
1.2 In CYP with suspected PANS, what is the most clinically effective process of assessment?
1.3 In CYP with suspected PANS, can disability or assessment scales aid in identification of PANS?

2. Diagnosis of PANS

2.1 In CYP with suspected PANS, what are the criteria used to establish a diagnosis?
2.2 In CYP with PANS, what tests are effective in aiding diagnosis?

3. Management of PANS

In CYP with PANS:
3.1 what pharmacological interventions might be appropriate at initial presentation?
3.2 what is the clinical effectiveness of pharmacological interventions?
3.3 what is the clinical effectiveness of non-pharmacological interventions (such as psychological interventions)?
3.4 what is the clinical effectiveness of different models of multidisciplinary care, including team composition?
3.5 in what ways do treatment interventions differ depending on disease trajectory?
3.6 what constitutes a successful response to treatment and how can this best be assessed?
3.7 what should be the next steps for patients who do not respond to initial treatment?

Guideline Development Process

Scoping Document

4. Monitoring and review

4.1 In CYP with PANS, what is the most clinically effective method of monitoring people (given its relapsing-remitting nature) and who should take responsibility for this?

5. Information, education, and support

5.1 What information do CYP with PANS and their families and carers need?
5.2 What support do CYP with PANS and their families and carers need?
5.3 What educational planning and provision should be put in place for CYP with PANS?

Out of Scope:

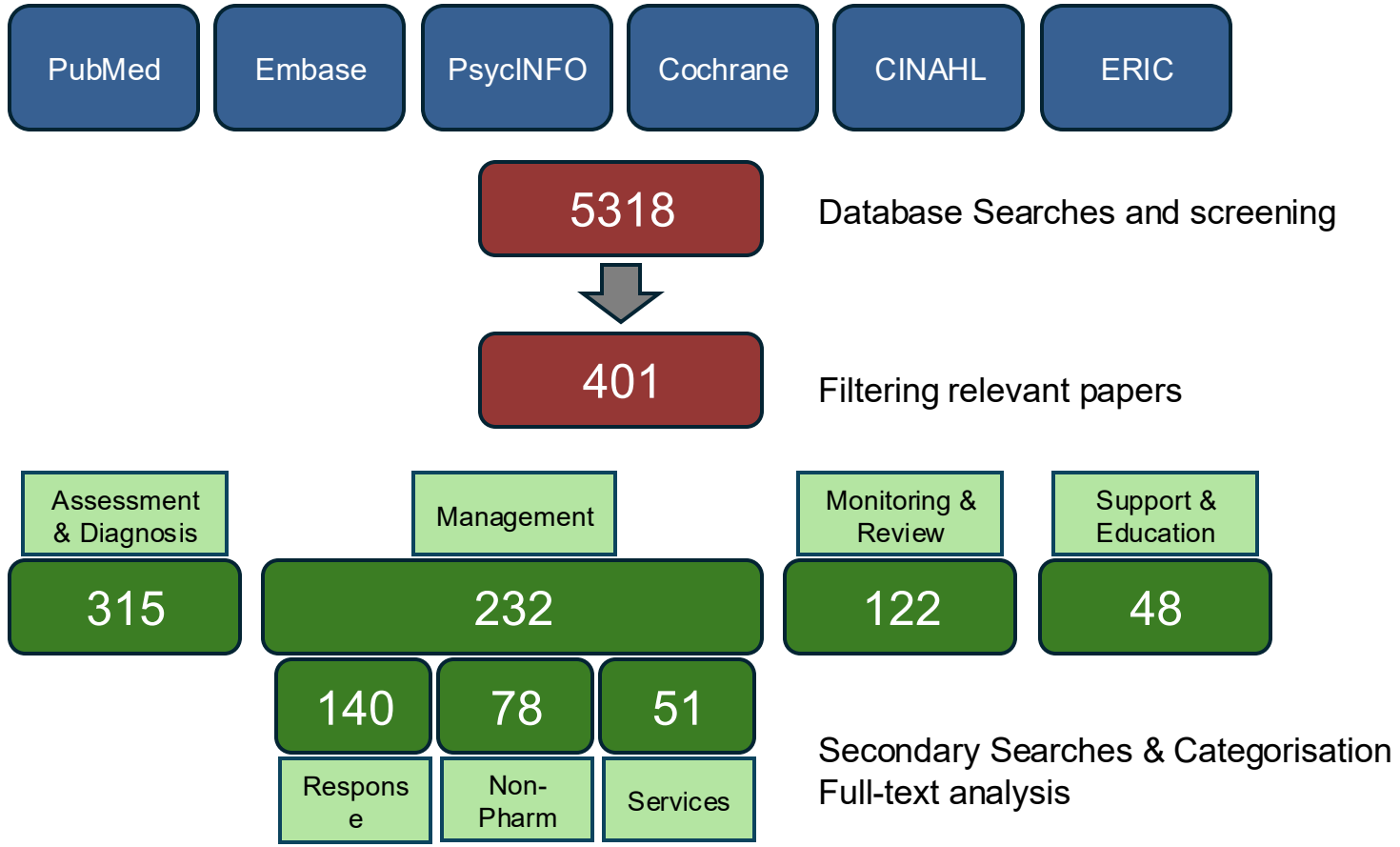
- Preclinical studies about eg. causes and mechanisms. We agreed focus on a clinical guideline.
- Non-health settings (whilst recognising the importance of education and social care)
- Adults (whilst recognising the literature and lived experience of adults with PANS)

Acknowledgements: Yasmine Nasser (postgraduate student), Dr Aysha Rasheed (resident doctor)

Guideline Development Process

Scoping Document

Scoping Review



Guideline Development Process

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Scoping Review



Each generated 64-112 statements



Consensus discussion
43 statements
Rated using GRADE criteria



Section	N of Statements
Assessment & Diagnosis	15
Management	17
Monitoring & Review	6
Information, Education & Support	5
Total	**43**

Guideline Development Process

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Scoping Review

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.	13
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).	18
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).	9
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).	3

Guideline Development Process

Scoping Document

Scoping Review

Delphi Surveys

Delphi Round One

- Included 30 statements (some statements also included multiple stems)
- Excellent response (84%) from Delphi Panelists
- One third of the statements met our consensus criteria

We agreed to progress Round Two of the Delphi

Thank you

PERSPECTIVES
ON PANS