

To: NHS Trust Chief Executives

PANS and PANDAS Update

May 2025

Dear colleagues,

We write to you as the PANS PANDAS Steering Group (PPSG), to share with you the latest information regarding work underway to address the variation in care available to children and young people presenting with acute-onset neuropsychiatric symptoms in the UK.

About the PANS PANDAS Steering Group

Formed in late 2022 with the support of NHS England, the PPSG has representation from the following organisations:

British Paediatric Neurology Association, PANS PANDAS UK, the Royal College of Psychiatrists, the Royal College of Paediatrics and Child Health, the Royal College of Nursing, the Royal College of Occupational Therapy, the British Paediatric Allergy, Infection and Immunology Group, the Royal College of General Practitioners and the British Association of Social Workers.

Our statements

We would like to draw your attention to the two statements issued by this steering group. Our first statement (February 2023), recognises that, following the release of the consensus statement by the British Paediatric Neurology Association (BPNA) in April 2021, there has been huge variety in how that statement has been interpreted and confusion as to how children with acute-onset neuropsychiatric symptoms should be managed. It acknowledges the huge challenges this situation poses, both to patients and to the professionals tasked with reviewing such cases.

This statement makes recommendations for all NHS Trusts to develop multidisciplinary team services to review and treat children with these presentations. It stresses that the absence of such a service should not lead to referrals of these patients being rejected, nor that clinicians should be prevented from exercising their own proficiency and judgement. It signposts clinicians to existing international peer-reviewed treatment guidelines and advises that regional and tertiary services may be contacted for discussion.

Our second statement reminds clinicians of the 2023 statement and draws attention to the establishment of the PANS Clinical Guideline Development Group.

Importantly, the Department of Health and Social Care officially recognises that our 2023 statement supersedes the 2021 BPNA Consensus Statement.

Key workstreams

We would also like to take this opportunity to give an update on the work currently taking place to develop standards of care for this group of patients.

Clinical guideline development

A clinical guideline development process, in accordance with the rigorous criteria set out by the Royal College for Paediatrics and Child Health, is underway led by independent co-chairs and a group of over 25 expert clinicians from relevant disciplines of medicine. Where a literature review finds evidence to be lacking, the guideline development group will employ a Delphi Process to reach expert consensus. Upon publication of the guideline, work will begin by a service specification taskforce who will look at creating practical pathways and services for PANS and PANDAS which will deliver the principles laid out in the guideline.

Surveillance studies

Applications have been submitted to both the British Paediatric Surveillance Unit and the Child and Adolescent Psychiatry Surveillance System to investigate how many children and young people are presenting with symptoms of PANS and PANDAS each year.

Education, Social Care and Health Group

Work is being undertaken by this multidisciplinary group to publish guidance for professionals and families which will improve support available across education, social care and health for those affected by the conditions. To support professionals and families in the interim period, the charity PANS PANDAS UK has recently disseminated information to all Local Authorities regarding the conditions.

At present, variation in care available across the country is causing families concern and distress. We emphasise the importance of ensuring that all relevant staff within your Trust are made aware of this latest information relating to PANS and PANDAS.

Two simple actions we urge you to take as a minimum at this juncture to improve awareness and patient care are:

- Distribution of information about PANS and PANDAS to all GP practices via your Primary Care Newsletter.
- Circulation of this information to all paediatric units within your Trust.

For ease, this update and accompanying information can be found at www.theppsg.org.uk.

Furthermore, we ask that you implement the principles set out in our statements whilst work to develop the guideline takes place.

Yours sincerely,



Vicky Burford

Chair of Trustees, PANS PANDAS UK on behalf of the PANS PANDAS Steering Group