

PANS PANDAS Working Group Statement

This statement is relevant to primary and secondary care physical and mental health NHS services that may come into contact with children and young people presenting with acute onset neuropsychiatric symptoms. It addresses the current variation across the UK in the management of patients presenting with Paediatric Acute-Onset Neuropsychiatric Syndrome (PANS) and Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS). It recommends the development of appropriate service models and pathways, and highlights that all children presenting with acute onset neuropsychiatric symptoms should receive a full medical evaluation. It signposts clinicians to existing international peer-reviewed treatment guidelines.

In November and December 2022, the initial meetings of the PANS PANDAS working group (PPWG) were held. Present were representatives from the 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, independent social workers and parents of PANS or PANDAS patients. This meeting was supported by NHS England, as will be all subsequent meetings of the PPWG and specific working groups.

The PPWG are embarking on collaborative work to develop standards of care and to define pathways and service models to assist all primary and secondary clinicians to manage patients with symptomatic presentations of both PANS or PANDAS in the UK.

The PPWG have become aware that, after April 2021 when the British Paediatric Neurological Association released a consensus statement on childhood neuropsychiatric presentations with a focus on PANS/PANDAS, there exists a UK-wide variation in how this consensus statement is interpreted and how children with acute onset neuropsychiatric symptoms are managed.

The PPWG recommend that all NHS Trusts develop comprehensive cross-specialty multidisciplinary team (MDT) provision to review and treat children with acute onset neuropsychiatric symptoms. Children should receive a full medical evaluation. Other known medical conditions, including other neuroinflammatory, autoimmune, and metabolic disorders, can also present with an acute onset neuropsychiatric presentation and should be considered as part of the differential diagnosis process.

The PPWG also recommends that referrals from primary care should not be rejected on the basis that a MDT service may not currently be in place, nor on the basis that there are, as yet, limited "gold standard" RCTs applicable to PANS or PANDAS. Any current local absence of a MDT should not prevent clinicians from exercising their proficiency and judgment, acquired through clinical experience and clinical practice, in treating children presenting with the PANS or PANDAS symptom complex.

Many children face difficulties in accessing local NHS care for PANS or PANDAS. In the current absence of PANS or PANDAS NICE treatment guidelines, the PPWG signposts clinicians/teams to existing international peer-reviewed and published treatment guidelines and advise that respective regional and tertiary services may be contacted for discussion.

Children with acute onset neuropsychiatric symptoms can have severely compromised access to education and a normal quality of life. They require access to care and educational supports as identified as appropriate to each individual child. We emphasize that the PANS and PANDAS conditions are ones where medical knowledge is still developing. We encourage all professionals involved with each patient to understand the difficulties that this presents to the patients, their families, educational settings, and clinicians.