Bath, North East Somerset, Swindon and Wiltshire (BSW) Integrated Care Board (ICB) Position Statement on PANDAS / PANS

May 2025

This position paper has been prepared by the BSW ICB Designated Medical Officer (DMO) and Designated Clinical Officers (DCOs) for Special Educational Needs and Disability (SEND) in response to an increase in requests for a diagnosis of Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections (PANDAS) to be included in the health sections of Education, Health and Care Plans (EHCPs).

Since being first defined in America in 1998, Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections (PANDAS) and its later, broader iteration, Paediatric Acute-onset Neuropsychiatric Syndrome (PANS), have gathered significant attention and controversy, mainly due to the lack of robust evidence around the autoimmune hypothesis.

Despite more than two decades of studying PANDAS / PANS it is still not possible to confirm its existence and determine whether it is a post streptococcal autoimmune disorder. Many controversies remain; the diagnostic criteria have not been validated, evidence of autoimmunity remains inconclusive, evidence of a genetic predisposition is weak, and streptococcal infections are common in childhood and could represent only a trigger of exacerbations of tics and obsessive-compulsive disorder. There is therefore not enough evidence to support PANDAS as a unique clinical entity.

This is likely to be why there is currently no national UK guidance about PANS or PANDAS written or endorsed by bodies such as the National Institute for Health and Care Excellence (NICE), NHS England, the Royal College of Paediatric and Child Health (RCPCH), the Royal College of Psychiatrists or the British Paediatric Neurology Association (BPNA).

Within the current International Classification of Diseases (ICD-11), although PANDAS is mentioned, no operational clinical diagnostic criteria for either PANDAS or PANS are defined. Nor are they classified or mentioned in DSM-5 (Diagnostic and Statistical Manual of Mental Disorders); the handbook used by health care professionals as the guide to the diagnosis of mental disorders.

The British Paediatric Neurology Association (BPNA) recognised this and chose to write a 'consensus statement' rather than a guidance document following a literature review which concluded there was a lack of robust clinical evidence (e.g. randomised controlled trials) available to provide a foundation for developing credible guidance, which would typically be used by professional bodies such as the UK National Institute for Health and Care Excellence (NICE).

The BPNA (2021) consensus statement (which is available via this link: 2021Consensusstatementonchildhoodneuropsychiatricpresentations_72d9cfce4e96a31e4f40cb3ba943cb43.pdf) suggests there's no evidence currently available to demonstrate these conditions are triggered by an immune system antibody response and recognise that studies showed a clinical overlap with OCD and tic disorders, which indicated over two thirds of children thought to have PANS / PANDAS achieved a reasonable response to conventional mental health interventions for these conditions. The BPNA (2021) statement also identifies that even when a child's clinical history suggests that mental health symptoms emerged following an infection, there is insufficient evidence to conclude that treatments targeting inflammation or immune-modulation are effective and suggest this may also risk diverting the focus away from delivering effective symptom-based treatment.

Treatment for children suspected of PANDAS / PANS is generally the same as the standard treatments for Tourette syndrome (TS) and OCD which include cognitive behavioural therapy (CBT) and medication to treat OCD such as selective serotonin reuptake inhibitors (SSRI's).

In conclusion the ICB do not endorse using the diagnosis of PANDAS or PANS on documents such as Education Health and Care Plans (EHCPs), preferring instead to describe a child or young person's presenting needs which may include repetitive type behaviours, vocal or motor tics.