Experiences of UK healthcare for patients with symptoms of PANS and PANDAS

As the strategic initiatives of the PANS PANDAS Steering Group (PPSG) gain momentum, with significant progress across all three working groups, it remains essential that current patient experience informs and guides all efforts.

Meaningful change is slow to implement, and this is reflected in anecdotal evidence from the patient community who report that the strategic work being undertaken has yet to make any practical difference to their experience of healthcare. Indeed, many feel that access to assessment, diagnosis and treatment for PANS and PANDAS has never been more challenging.

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Key themes

Awareness

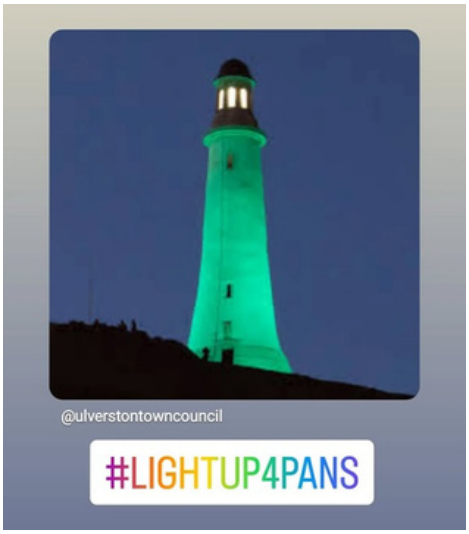
- **Limited awareness at primary care level** - Widespread lack of understanding among primary care providers regarding PANS and PANDAS ranges from reluctance to initiate diagnostic testing or therapeutic trials (e.g., antibiotics or NSAIDs), to the perception that these conditions are either extremely rare, not legitimate, or should be managed exclusively by CAMHS

- **Restricted clinical pathways and support** - GPs who are willing to support affected children often find themselves constrained by the absence of dedicated referral pathways. The lack of guidance and collaboration from secondary and tertiary care services undermines their confidence and capacity to manage these complex cases effectively

- **Disproportionate safeguarding concerns** - Families seeking help for children with suspected PANS or PANDAS encounter an unusually high number of safeguarding referrals, which may reflect systemic misunderstandings of the condition rather than genuine risk

- **Diagnostic overshadowing in neurodivergent children** - Children with pre-existing diagnoses such as Autism are particularly vulnerable to diagnostic overshadowing, where new or acute symptoms are misattributed to their existing condition, delaying appropriate investigation and treatment

- **Delayed professional awareness of latest guidance.** The 2021 BPNA Consensus Statement continues to be mistakenly perceived as the definitive UK guidance on PANS and PANDAS. This has led to its use as a rationale for declining to assess or treat patients presenting with symptoms consistent with these conditions, despite evolving international understanding and superseding statements issued by the PPSG.



> When it was PANS PANDAS Awareness Day the other day and I saw all the buildings lit up green (which was just amazing) it broke me completely. I was sat there, looking at these lit up buildings but just thinking about my poor daughter struggling alone with this horrific condition on a psych ward. I just keep thinking how can there be this much awareness of a condition the NHS is still not treating my child for??!
>
> - Parent of a child with PANS

Variation in care

> We're Manchester area and our GP wasn't very receptive. I was told down south they are more accepting which baffles me. Surely it should be the same regardless of where you live.
>
> - Parent of a child with PANS

A significant postcode lottery continues to affect families seeking diagnosis and treatment for PANS and PANDAS, with marked disparities in service provision across the UK:

- **Isolated examples of best practice** – In very rare instances, secondary and tertiary care settings demonstrate exemplary clinical practice, which then fosters increased awareness and coordinated support across local healthcare systems and educational settings

- **Systemic barriers in other regions** - Conversely, some hospitals are perceived as inaccessible or hostile environments for patients with suspected or confirmed PANS or PANDAS. Families report experiences of disbelief, dismissal, or ridicule—even when presenting with a formal diagnosis from another clinician.

Lack of NHS pathway

- **Lack of coordinated care** - Children with suspected or confirmed PANS or PANDAS are frequently passed between services without a designated lead clinician or central point of care. Multidisciplinary teams are rarely convened, resulting in fragmented and inconsistent management
- **No transition to adult services** - For the small number of children who do access NHS care, there is currently no established pathway for transitioning into adult services, leaving hundreds of young people not only without continuity of care, but wholly without care
- **Limited recognition of private diagnoses and treatment plans** - Many families feel compelled to seek private healthcare due to the lack of NHS provision. However, NHS clinicians often do not recognise private diagnoses or treatment recommendations, creating a cycle of financial burden and clinical uncertainty
- **Financial barriers and distress** - Families unable to afford private care frequently report feeling abandoned by the healthcare system.
- **Professional tensions between sectors** - Clinicians working in private practice who treat patients with PANS and PANDAS experience significant challenges when attempting to work collaboratively with NHS colleagues.

> It's like a merry go round getting passed from one doctor to another endlessly without getting anywhere and the fight wears you out as a parent.
>
> - Parent of a child with PANDAS

Poor experience and devastating outcomes

- **Significant burden on families** - Families affected by PANS and PANDAS face profound financial, social, emotional, and often physical challenges. The cumulative impact is frequently traumatic, with many reporting long-term consequences on family wellbeing

- **Children and young people endure not only the distressing severity of their symptoms but also the psychological harm caused by inadequate support**.- Inappropriate interventions (often based on the misperception that symptoms are purely behavioural) can exacerbate suffering and delay appropriate care

- **The lack of timely access to appropriate treatment is resulting in avoidable hospital admissions.** These include psychiatric inpatient care and admissions for nasogastric tube feeding. In psychiatric settings, it is particularly challenging to ensure that immune-mediated causes of symptoms are adequately considered

- **Self-harm and suicide among children and young people** with suspected or diagnosed PANS and PANDAS in the UK are a tragic but very real outcome of these conditions left unmanaged

The issues outlined in this report serve as a reminder of the critical importance of the collective efforts underway to improve healthcare for these patients. This document is intended not only to reaffirm the urgency of addressing the challenges faced by children, young people and adults with PANS and PANDAS, but also to prompt renewed discussion around further actionable steps that can accelerate improvements in care.

These patients and their families deserve better.