Improving Support for Children and Young People with Medical Conditions and Allergy.

(Department of Education: draft guidance).

PANS PANDAS UK's consultation response.

May 2026

Key themes raised by PANS PANDAS UK:

Needs-led support over diagnosis-led thresholds
Educational support should be based on a child's and young person's presentation and functional impact, not delayed while diagnosis is ongoing or uncertain.

Understanding sudden onset and fluctuating medical needs
Schools need guidance to respond flexibly to rapid changes in health, capacity and behaviour associated with acute medical conditions.

Avoiding misinterpretation of medical symptoms
Medically driven symptoms should not be mistaken for behavioural or disciplinary issues.

Flexible use of Individual Healthcare Plans (IHPs)
IHPs should be used early and adapt to relapse and recovery, rather than assuming stable or permanent need.

Attendance flexibility and appropriate recording of medical absence
Attendance expectations must reflect medical reality and support recovery, including use of remote or blended learning where appropriate.

Equity during diagnostic uncertainty
Support should not vary based on how, where or how quickly a clinical opinion is obtained. The guidance should also make it clear that schools and colleges recognise diagnoses and clinical assessments from appropriately qualified clinicians, regardless of whether these are obtained through NHS or independent pathways.

Alignment between education and access to healthcare
School policies should enable children and young people to access assessment and treatment in line with NHS care, not create additional barriers.

School environment, clean air and infection awareness
The school environment, including ventilation and infection management is an important consideration for pupils with infection-triggered conditions.

Consistency, accountability and informed decision-making
Clear leadership, oversight and guidance are needed to reduce variation between schools and improve confidence in supporting medical needs.

Full response overleaf

Q Do you agree with the principles we have identified for including children and young people with medical conditions as fully as possible in education?

A **We agree.** We welcome the principles set out in the guidance that education settings should actively remove barriers so that children and young people with medical conditions are safe, included and able to access education effectively. This is particularly important for children and young people with PANS and PANDAS, whose needs can arise suddenly and fluctuate significantly, often creating immediate barriers to learning, attendance and emotional wellbeing in the absence of timely, flexible support.

We welcome the guidance's recognition of a broad range of risks, including risks to learning and wellbeing, as children with PANS and PANDAS are frequently misunderstood, with medical symptoms misinterpreted as behavioural or attendance issues, leading to unnecessary exclusion from learning or inappropriate school responses. We also welcome references to policies and practices that reflect the impact of medical conditions on attendance, while noting that schools require appropriate systems to record medically related, relapse-based absence accurately so that children and young people are not penalised during periods of acute illness.

The term 'to attend as fully as possible' could reasonably be interpreted by schools in practice to mean full time in school attendance, exposure as an approach and to push through medical symptoms in order to attend school. We therefore suggest further clarification within the guidance- for example 'How the school, college or setting will ensure that children and young people with medical conditions (including allergy) are supported to access and participate meaningfully in education, to the fullest extent compatible with their health, wellbeing and safety, through flexible, individualised and timely adjustments.....' It is essential that schools avoid making assumptions about presentation or support needs and instead prioritise ongoing, collaborative communication with the child or young person, their parents and healthcare professionals.

Finally, we emphasise that it should be made explicit in the guidance that all children and young people have a right to timely and appropriate NHS care, in line with the NHS Constitution, and under Article 24 of the UN Convention on the Rights of the Child, and that education arrangements should actively support access to that care. This is particularly important for children and young people with PANS and PANDAS, for whom access to appropriate NHS assessment and treatment is often complex, delayed or fragmented, and whose presentation is frequently sudden and fluctuating. In this context, education responses can play a critical role either in facilitating access to care and recovery, or, if insufficiently informed, unintentionally creating additional barriers.

Q Do you agree with the proposals for promoting the wellbeing of children and young people with medical conditions (including allergy)?

A **We strongly agree.** We agree that medical conditions policies should clearly set out how the welfare of children and young people with medical conditions will be supported, including arrangements to promote mental health and wellbeing and to prevent and respond to bullying. We welcome the acknowledgement that children and young people with physical health conditions are at increased risk of poor mental wellbeing, and that emotional wellbeing should be considered as part of a holistic response to medical need.

This is particularly important for children and young people with PANS and PANDAS, where anxiety, distress, withdrawal or behavioural change are often symptoms of the underlying medical condition, rather than a separate or primary mental health condition. Failure to recognise this can lead to inappropriate responses that compound distress and delay recovery.

Alongside the primary symptoms of PANS and PANDAS, mental wellbeing can be significantly affected by sudden loss of functioning, social isolation, reduced participation in school life, and a lack of understanding from peers or staff. There is also a heightened risk of stigma or bullying where symptoms are misunderstood. Clear expectations within medical conditions policies around inclusion, anti-bullying practice and emotional wellbeing are therefore essential to prevent children and young people being excluded from learning or peer relationships and to ensure they are supported with compassion and understanding.

We also welcome the emphasis on involving children and young people and their parents in discussions about wellbeing and support. It is important that emotional wellbeing is explicitly addressed within Individual Healthcare Plans, recognising the close interaction between physical health, emotional wellbeing and educational access for children with medical conditions. The introduction of a statutory Individual Healthcare Plan template would support greater consistency and clarity across settings, particularly in the context of ongoing uncertainty about how mental health support arrangements proposed in the SEND and Alternative Provision White Paper will operate in practice. This should be underpinned by improved professional awareness of the overlap between physical health conditions and mental health or behavioural presentations.

Schools also require greater clarity on how wellbeing support arrangements such as access to quiet or safe spaces, flexible routines, phased engagement, and appropriate links to mental health support should be used in practice. While the proposals are helpful in recognising that wellbeing is not static, it is essential that this is consistently reflected in implementation. Wellbeing support must be flexible and responsive, rather than based on fixed expectations of emotional or functional capacity, particularly for children and young people with fluctuating or episodic conditions such as PANS and PANDAS.

Q Do you agree with the proposal that a named governor and named senior leader should be responsible for the medical conditions policy?

A **We strongly agree.** We agree with the proposal that a named governor and a named senior leader should be responsible for the medical conditions policy. Clear accountability at both governance and senior leadership levels is an important step in supporting consistent, effective implementation and providing clarity for families and staff.

This is particularly important for children and young people with PANS and PANDAS, whose needs are often sudden, severe and fluctuating, and whose symptoms are frequently misunderstood or misinterpreted as behavioural, attendance-related or emotional difficulties rather than medical need. Clear senior leadership responsibility can help ensure that decisions relating to attendance, behaviour, wellbeing and inclusion are appropriately informed by health needs and are applied consistently across the setting.

To be effective, it is important that these roles are not purely strategic or nominal. The named senior leader should have sufficient operational authority, knowledge and oversight to ensure the policy is actively applied in practice, including where medical needs cut across attendance, behaviour, safeguarding and SEND arrangements. This is particularly critical for fluctuating medical conditions, where timely, flexible responses are needed and inappropriate pressure or delay can worsen outcomes.

The role of the named governor is also important in providing oversight and constructive challenge, ensuring that statutory duties are met and that pupils with medical conditions are not subject to recurring barriers to access, inclusion or wellbeing.

With appropriate clarity around responsibility, authority and training, this proposal has the potential to improve coordination, reduce inconsistency and significantly strengthen support for children and young people with complex and fluctuating medical conditions, including PANS and PANDAS.

Medical conditions at school: statutory guidance
Review of medical conditions policy

Q Do you agree with the proposal that the medical conditions policy should be reviewed at least annually, and after any serious incident or near miss?

A **We strongly agree.** We agree that medical conditions policies should be reviewed at least annually and following any serious incident or near miss, as set out in the guidance. These minimum review points are important to ensure policies remain safe, relevant and effective.

For children and young people with PANS and PANDAS, whose needs can fluctuate rapidly and whose experiences in school may change significantly following illness episodes or incidents, it is important that policies remain responsive to emerging issues in practice. While annual review provides an important baseline, there is a risk that it could be interpreted as sufficient in itself, even where a policy no longer adequately reflects the needs of the school population or the realities of implementation.

We therefore consider it helpful for the guidance to emphasise that annual review represents a minimum expectation, and that schools should review and update their medical conditions policies more frequently where practice, risk, or the needs of pupils with fluctuating medical conditions indicate that this is necessary. Reviews should meaningfully involve children, young people and families, whose experiences can provide valuable insight into whether the policy is operating effectively in practice.

Medical conditions at school: statutory guidance
Scope of the medical conditions policy

Q Do you agree with the proposed scope of the medical conditions policy?

A **We strongly agree.** We agree with the proposed scope of the medical conditions policy. We consider it important that the guidance clearly reflects that duties apply equally to physical and mental health conditions, particularly where mental health impacts form part of a medical presentation. This is especially relevant for children and young people with PANS and PANDAS, where neuropsychiatric symptoms such as anxiety, distress or behavioural change arise from an underlying medical condition rather than constituting a separate or primary mental health need. Clear articulation of this within the scope of the policy is essential to avoid fragmented or inappropriate responses.

Q Do you agree with the medical conditions which we propose should be covered by the medical conditions policy?

A **We strongly agree.** We agree with the medical conditions proposed to be covered by the medical conditions policy. We welcome the clarity in the guidance that schools, colleges and early years settings should not wait for a formal diagnosis before putting support in place, and that decisions should be based on a child or young person's reported needs, available evidence and the potential risk of harm if support is not provided.

This approach is particularly important for children and young people with PANS and PANDAS, where diagnosis is often complex or evolving, clinical awareness remains limited, and presentation can overlap with conditions such as anxiety, obsessive–compulsive disorder or neurodivergence. In these circumstances, a needs-led approach is essential to ensure that children and young people are supported appropriately and are not excluded from education while diagnostic pathways continue.

In this context, it would be helpful for the guidance to set clearer expectations about when and why schools may seek further clarification about diagnosis or clinical opinion, including who such clarification should be sought from. Any requests for additional information should be proportionate, transparent and made with the involvement of families, and should ensure that advice is sought from appropriately informed professionals with relevant knowledge of the condition in question, rather than defaulting to delay, reassessment or challenge based on unfamiliarity.

For this cohort, it is also essential that schools do not make assumptions about needs or participation on the basis of diagnosis uncertainty or disagreement between professionals. Where conditions are less common or not widely understood, and where clinical views may differ, the guidance should make clear that children and their parents must be treated as key partners in decision-making, rather than solely as informants, and that support should not be withheld while disagreements are resolved. We also consider it crucial that the guidance is explicit that diagnoses and clinical opinions carry equal weight regardless of whether they are provided within the NHS or the independent sector, and that schools should not disregard or seek to override medical evidence solely on the basis of where an assessment was carried out.

Finally, while the guidance appropriately recognises that some medical conditions may have no impact on participation, it is important that its scope does not inadvertently allow informal thresholds or gatekeeping to develop for less common or emerging conditions. Flexibility is needed to ensure that conditions such as PANS and PANDAS can be appropriately recognised and evidenced, even where they are not widely understood within education or health systems, so that children and young people are not denied support despite clear and significant medical need.

Q Do you agree that our proposals set reasonable expectations for staff training on medical conditions?

A **We agree.** We agree that the proposals set reasonable expectations for staff training on medical conditions, including the expectation that governing bodies ensure all staff are aware of the medical conditions policy and understand their role in implementing it. A shared baseline of awareness across the workforce is essential to ensure safe, consistent and inclusive support for children and young people with medical conditions, including during before- and after-school provision and activities delivered by third-party providers.

Greater clarity is needed about what constitutes sufficient and appropriate training, and how this aligns with forthcoming guidance such as the Delegation of Healthcare Activities guidance and the proposed Experts at Hand service. Clear minimum expectations would help avoid fragmented training, inconsistent practice and uncertainty about responsibilities across settings.

This is particularly important for children and young people with PANS and PANDAS, where awareness remains limited and presentation is often misunderstood. For this cohort, anxiety, distress, withdrawal, aggression or behavioural change may be medically driven symptoms rather than indicators of behavioural or safeguarding concerns. Training should therefore support staff to recognise when difficulties may have a medical basis and to respond in a proportionate, health-informed way, rather than defaulting to inappropriate escalation.

We consider it reasonable and necessary that all staff have a baseline level of awareness, including an understanding of how medical needs may present, the risks of misinterpretation, and clear knowledge of who to seek advice from when concerns arise. More detailed or task-specific training should remain role-appropriate, focused on those staff whose responsibilities include providing direct or ongoing support to a child or young person with specific medical needs.

Training expectations should extend consistently to staff and volunteers involved in extended-day provision and third-party services operating on or around the school site, as inconsistent awareness across staff groups increases the risk of fragmented responses and distress for children with fluctuating medical needs.

Clear, proportionate guidance on staff training and access to informed advice would help ensure that a lack of familiarity does not become a barrier to support, and would strengthen safe, needs-led implementation of the medical conditions policy for all children and young people, including those with PANS and PANDAS.

Q Do you agree with the proposal for which children and young people will need an Individual Healthcare Plan?

A **We agree.** We agree that decisions about whether a child or young person requires an Individual Healthcare Plan (IHP) should be based on need rather than diagnosis, and that settings should not wait for formal diagnostic certainty before putting support in place. This approach is particularly important for children and young people with PANS and PANDAS, where diagnosis is often complex or evolving, clinical awareness remains limited, and medical symptoms can overlap with behavioural or mental health presentations.

In practice, however, these factors mean that medically driven needs are at risk of not being recognised as medical, increasing the likelihood that an IHP is not considered despite clear impact on attendance, learning or wellbeing. This is a concern frequently raised by families of children and young people with PANS and PANDAS.

It is therefore important that settings do not make assumptions about a child or young person's needs based on diagnosis, familiarity or periods of relative stability. Meaningful communication with children, young people and their parents should be central to decisions about whether an IHP is required, recognising that children with the same, or similar, diagnoses may present very differently and require different levels or types of support. For conditions such as PANS and PANDAS, fluctuation and variability are a key feature and should not be used as a reason to delay or rule out individualised planning.

To mitigate the risk of inconsistency, the guidance should place strong emphasis on impact- and risk-based decision-making, encourage professional curiosity where presentation is unfamiliar, and support the use of time-limited, interim or review-based IHP arrangements where needs are evolving. This can provide clarity and continuity across staff while understanding develops, and reduce the need for needs to be repeatedly reassessed following periods of relapse or improvement.

In the context of wider SEND reform, including proposals for Individual Support Plans, further clarity would be helpful to ensure that health-related support is not absorbed into education-led plans without clear responsibility for health oversight. Without this clarity, there is a risk that medical needs are reframed rather than addressed, particularly for children and young people with neuropsychiatric presentations arising from an underlying medical condition.

Finally, to support consistent and equitable practice, the guidance could usefully include a short set of prompts or questions to support professional judgement when considering whether an IHP is required. This would be particularly valuable for children and young people with complex, fluctuating or less well-understood medical conditions, and would help ensure that decisions are transparent, proportionate and centred on the child or young person's lived experience.

Q Do you agree with the proposal for which children and young people will need an Individual Healthcare Plan?

A **We agree.** We agree with the proposed scope of Individual Healthcare Plans (IHPs) and welcome the guidance's emphasis on IHPs as school-owned documents developed collaboratively with children and young people, their families and relevant professionals.

For children and young people with PANS and PANDAS, however, there are specific implementation risks that would benefit from greater clarity within the guidance. Awareness of these conditions remains limited, access to specialist clinical input can be complex or delayed, and symptoms may fluctuate or overlap with mental health or behavioural presentations. In practice, this can result in IHPs that are overly narrow, lack sufficient medical context, or focus only on isolated aspects of presentation, with families left to bridge gaps between education and health systems.

Clearer expectations around accessing proportionate and informed health input would help ensure that IHPs are timely, responsive and effective. This includes clarity about the role of school nursing services and other appropriately informed professionals in advising on the medical aspects of an IHP, particularly where conditions are less common or not well understood. Without this, there is a risk that plans are shaped primarily by educational interpretation rather than a balanced understanding of medical impact and risk.

Given the fluctuating and episodic nature of PANS and PANDAS, it is also important that the scope of IHPs supports a dynamic and review-based approach, ensuring plans can adapt as a child or young person's needs change. Sections relating to impact on wellbeing, participation in trips and activities, and arrangements for maintaining educational progress during absence are particularly important for this cohort, and require sufficient flexibility to reflect periods of relapse and recovery.

Finally, further clarification would be helpful on how IHPs should operate alongside other plans, including Education, Health and Care Plans and the proposed Individual Support Plans set out in the SEND reforms. Without this clarity, there is a risk that health-related needs are absorbed into education-led plans without clear responsibility for health oversight, leading to fragmented support. Clear articulation of how these plans interact would support coherence and ensure that medical needs remain visible and appropriately addressed.

Q Do you agree with the proposed approach for recording, reporting and learning lessons from serious incidents and "near misses"?

A **We strongly agree.** We agree in principle with the proposed approach to recording, reporting and learning lessons from serious incidents and near misses relating to medical conditions and allergy. The emphasis on early recording, shared learning and governance oversight is appropriate and particularly important for children and young people with complex and fluctuating medical conditions.

For children and young people with PANS and PANDAS, however, it is essential that this framework is interpreted and applied in a way that recognises that serious risk may also arise during acute medical flares through neuropsychiatric and behavioural manifestations, rather than through more traditionally recognised medical emergencies alone. In severe flares, children and young people may experience intense emotional dysregulation, impulsivity or loss of behavioural control that places themselves or others at immediate and significant risk of harm as a direct consequence of their medical condition. Where such risk is present, incidents and near misses should be clearly recognised as medical-related, even where the presentation is behavioural in nature or where the underlying medical condition was not fully recognised at the time. Without this clarity, there is a risk that serious events and near misses involving children or young people with PANS and PANDAS are recorded and reviewed solely through behaviour, attendance or safeguarding processes, resulting in missed opportunities for medical learning and prevention.

The guidance's emphasis on learning from near misses is particularly important for this cohort. Near misses can provide critical insight into early warning signs of deterioration, gaps in staff awareness, insufficient anticipatory planning, or weaknesses in Individual Healthcare Plans. Reviews should therefore consider whether earlier recognition of medical need, clearer health-informed planning, improved de-escalation approaches, or more timely access to appropriate health advice could reasonably have reduced risk and prevented escalation.

Where incidents or near misses involve healthcare activity, including medication, urgent clinical intervention or emergency response during a severe PANS and PANDAS flare, it is important that learning is informed by appropriate clinical oversight, alongside school governance and safeguarding review. Greater clarity on responsibility for investigation and learning in such cases would help ensure that medical factors are properly understood and addressed, rather than repeated through lack of knowledge or confidence.

Applied in this way, the proposed approach to incident recording, reporting and review has the potential to support earlier identification of risk, strengthen preventative planning, and reduce the likelihood of escalation to serious harm or exclusion for children and young people with PANS and PANDAS. Clear recognition of medically driven risk within this framework is essential if its preventative intent is to be realised for this group.

Do you agree that the inclusion of the specific considerations sections in this guidance is helpful?

We strongly agree. We welcome the inclusion of the specific considerations sections, including those relating to attendance, remote education, clean air, infection management, and home-to-school transport. These sections are important in recognising the broader context in which children and young people with medical conditions access education.

With PANS and PANDAS, attendance is often directly affected by relapse-based illness, infection exposure and access to medical care. Episodes of acute illness may arise suddenly and may require appointments, investigations or treatment that cannot reasonably be scheduled outside the school day, whether within NHS or private services. In such circumstances, expectations that appointments should normally take place outside school hours can place additional pressure on families and may not be realistic. It is important that the guidance is explicit that medically related absence should not result in pupils being penalised, disadvantaged or excluded from rewards, and that attendance expectations are applied flexibly and proportionately for children with fluctuating medical conditions. While the overall approach to attendance is welcome, greater clarity is needed to ensure consistency with wider DfE attendance guidance and to prevent medical absence being interpreted as poor attendance or lack of engagement.

For children and young people with PANS and PANDAS, the use of high-quality remote or hybrid education can be a vital reasonable adjustment during periods of acute illness or recovery. However, families frequently report reluctance by some schools to use existing coding and guidance designed to support this approach. Greater alignment between this guidance and the DfE guidance on providing remote education would help ensure that reasonable adjustments are applied confidently and consistently, rather than attendance expectations and medical support operating in tension.

We also welcome the inclusion of sections on clean air and managing infectious diseases, which are particularly relevant for children and young people with PANS and PANDAS, given the role infections can play in triggering or exacerbating relapse. Clear expectations around ventilation, infection control and timely communication with families about circulating infections can play an important preventative role for this group. Explicit recognition of the heightened risk infection exposure may pose for some medical conditions would further strengthen these sections.

Finally, we note positively that several sections of the guidance, including those on home-to-school transport, recognise the importance of clarity around when and how healthcare services are involved, so that responsibility for clinical decision-making and support is not assumed by education staff in the absence of appropriate healthcare input. This clarity is especially important for children with PANS and PANDAS, where needs may change rapidly and where close coordination between education and health is essential. Greater coherence across the guidance would help ensure that attendance flexibility, reasonable adjustments, infection management, and access to healthcare operate together, rather than in isolation, for children and young people with complex and fluctuating medical needs such as PANS and PANDAS.

Q Do you agree that post-16 institutions should be subject to a statutory duty to make arrangements for supporting learners in statutory education with medical conditions?

A **We strongly agree.** We agree that FE colleges and post-16 institutions should be subject to a statutory duty to make arrangements for supporting learners with medical conditions and allergy. This is particularly important for young people with PANS and PANDAS, whose needs may persist into adolescence and early adulthood.

For this group, transitions into post-16 education frequently coincide with reduced pastoral oversight, changing health provision and increased expectations of independence, while symptoms remain fluctuating and relapse-based. Without a clear statutory duty, there is a risk that medically driven difficulties are misinterpreted as mental health, behavioural or engagement issues, leading to inconsistent support and barriers to educational progression.

Extending statutory duties to FE and post-16 settings would support continuity, equity and safety, particularly for learners with an EHC Plan, and help ensure that medical needs continue to be recognised and appropriately supported at a critical stage of education.

Q Do you agree that non-maintained special schools should be subject to a statutory duty to make arrangements for supporting pupils with medical conditions and allergy?

A **We strongly agree.**

Q Do you agree that independent schools should be subject to a statutory duty to make arrangements for supporting pupils with medical conditions and allergy?

A **We strongly agree.**

Q Do you agree with the proposal that all schools should stock "spare" adrenaline devices for emergency use?

A **We strongly agree.**

" This consultation offers an important opportunity to help the Department of Education understand the medical needs of children with PANS and PANDAS. Families know better than anyone how these conditions affect daily life, learning, and school participation.

By sharing our knowledge, and learnings from our community, PANS PANDAS UK hope these responses will help shape guidance that reflects the realities that children and young people face; ensuring they receive the understanding and support they need in school. "

– Tina Coope, Education Lead, PANS PANDAS UK

PANS PANDAS UK