

The effectiveness of immune treatments, antibiotics and psychological therapies for PANS/PANDAS: a systematic review protocol

Plain Language Summary of the protocol

Why are we doing this study?

Paediatric Acute-onset Neuropsychiatric Syndrome (PANS) and Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections (PANDAS) are two related conditions that are characterised by the sudden onset of severe and distressing behavioural symptoms like obsessive-compulsive behaviours, tics, and restricted eating. The onset of PANDAS is specifically associated with a streptococcal infection, whilst PANS is a broader term in that it covers other types of infection or trigger.

Symptoms of PANS and PANDAS usually begin abruptly and may flare up and down in phases over the course of several years. These conditions primarily affect children and young people, but they have also been observed in adults. PANS and PANDAS are poorly understood and not widely recognised, which makes diagnosing and treating them very difficult, leading to long periods without a diagnosis or frequent misdiagnoses.

Patients with PANS or PANDAS and their families have limited access to knowledge about these conditions, and because of a lack of clarity across research into PANS and PANDAS, clinicians lack the evidence to support treatment decisions.

We will conduct a systematic review to improve understanding of how well treatments for PANS and PANDAS work. This review is part of a larger programme of work - more details are available on our website ([link](#)).

What do we want to know?

We want to know how well different treatments manage the symptoms of PANS and PANDAS. Our review will focus on the following treatments:

- Antibiotics: medicines that fight infection and can also be used to prevent an infection.
- Immune Treatments - treatments that target the immune system, such as: Intravenous immunoglobulin (IVIg) - a pooled antibody administered into the vein that can help manage autoimmune and infectious conditions and stabilise a compromised immune system; and therapeutic plasma exchange (TPE), also called plasmapheresis. TPE is a way of filtering the blood to remove any potentially harmful substances and reinfuses the blood with fresh blood cells.
- Psychological and behavioural therapies - including both talking therapy and behaviour modification therapies like cognitive behavioural therapy (CBT). These treatments aim to help patients identify the causes and triggers of disruptive and upsetting behavioural symptoms and learn strategies to manage them.

We are interested in all outcomes related to treatment effectiveness for PANS and PANDAS. This includes 1) how psychological and/or physical symptoms are improved, 2) the number/severity of infections, and 3) the number and severity of flares (periodic symptom exacerbations) experienced. We are interested in other ways that studies may report treatment effectiveness beyond those listed here.

What do we plan to do?

We will identify all the research studies that look at how well the treatments work in managing symptoms in people with PANS and PANDAS. We will extract all the relevant information from the studies and rate the quality of each study. We will then bring together and make sense of the findings of the individual studies.

Who has helped to create this protocol?

We have worked closely with:

- Clinicians
- A senior representative of the charity PANS PANDAS UK
- Young people with PANS or PANDAS
- The parents of young people with PANS or PANDAS

What will we do with this review?

We will write up the findings of this review in a several formats:

- A report documenting our methods and findings,
- An academic article, which we will publish in a journal,
- A briefing paper, which is a summary document for people (e.g. clinicians) who can use the findings in their decision making, and
- A plain language summary to convey our findings to wider audiences

We will work with PANS PANDAS UK, clinicians, children and young people and their families to develop other formats as necessary and to share the information with people who can use it to make a difference.