What are the views, experiences and perceptions of patients, families, and clinicians of PANS/PANDAS? Protocol for a qualitative evidence synthesis.

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 related conditions that affect the brain. Typically, it affects young people and occurs where a recent infection or illness leads to a sudden dramatic change in behaviour, with several physical and psychiatric symptoms like tics, aggression, anxiety and obsessive-compulsive behaviours being displayed.

PANS/PANDAS may persist for years, usually getting much worse at certain points during the year. The symptoms of PANS/PANDAS can be extremely severe and have a huge impact on families. There is no single test to diagnose the conditions, so a medical diagnosis, like many other neuropsychiatric disorders, is made based heavily on the basis of symptoms. There are other conditions that have similar symptoms which makes the diagnosis process difficult. People may be given an incorrect diagnosis, or no diagnosis at all. It may take a long time for a diagnosis to be made and for treatment to be started.

PANS/PANDAS are complex conditions and there are gaps in the knowledge about how and why the conditions start and how best to manage them. To explore current evidence on these conditions and highlight areas for further research we have designed the PANS PANDAS Unveiled project. During stage 1, we created an interactive tool, known as an Evidence and Gap Map (EGM), where we collected and organised the current evidence published on PANS/PANDAS. In the EGM, evidence can be organised by study design. One of the study designs was “qualitative”, which are studies about the experiences of PANS and PANDAS. In other words, they seek to find out what it is like for people who have the conditions, or treat them, or care for people with them. The findings of the EGM showed there are now several studies about the experiences of PANS/PANDAS, but that there are currently no systematic reviews that bring this evidence together.

What do we want to know?

For stage 2a of PANS PANDAS Unveiled, we will conduct a systematic review of qualitative evidence. Systematic reviews are a type of evidence synthesis that involves the use rigorous and reproducible methods to identify, collect and synthesise the available data on certain topic; with the use of strict criteria and procedures to reduce bias. We are interested in reviewing the current qualitative evidence

which looks at the experiences of PANS/PANDAS patients, their family members and the professionals who work with them. We will bring together these findings to explore how PANS/PANDAS shapes the lives of patients and their families, understand the perspectives of the clinicians who treat PANS/PANDAS, and identify where more research is needed.

What do we plan to do?

We plan to bring together all current published qualitative evidence on PANS/PANDAS into a systematic review. We will combine the findings within these studies to gain a deeper understanding of what they say, allowing us to answer the following questions:

1. How do children and young people with PANS/PANDAS, and the people who support them, experience the condition and what is its impact on daily life?
2. How do patients and their families experience the diagnostic process, treatment pathways, and access to services?
3. How do clinicians perceive the processes of diagnosing and managing PANS/PANDAS?
4. What barriers, unmet needs, and sources of distress are reported by patients, their families, and/or clinicians?
5. What gaps, limitations, or under-researched areas are evident within the existing qualitative evidence base on PANS/PANDAS?
6. What implications do these findings have for service delivery, clinical practice, and future research?

How will we do this?

To create the EGM, we gathered and categorised all current evidence published on PANS/PANDAS. For this review we will use the qualitative evidence identified in the map. We will analyse the quality of the data to understand the strength of the evidence base. We will look closely at all the evidence and identify any common themes, which reflect common perspectives and experiences with PANS/PANDAS.

Who has helped create this protocol?

To develop this protocol, we have worked closely with clinicians, a senior representative of the PANS PANDAS UK charity, young people, and parents of young people with the conditions. This input has provided knowledge and expertise which has informed our research questions and important topics surrounding experiences of PANS/PANDAS. We will continue to work with these groups throughout the whole project.

What will we do with this review?

A written report of the findings of this systematic review will be created. We will also write an academic paper of the findings for submission in a peer reviewed journal. Additionally, we will make a plain language version of the paper to help share the findings with a non-academic audience. Through our Patient and Public Involvement and Engagement, we will work closely with parents, young people, clinicians and PANS PANDAS UK to identify ways to share the findings and create suitable outputs which may include plain language summaries, blogs, podcasts, videos etc.