Report on the prevalence of PANS in Sweden

Sane

The Association for Autoimmune Encephalitis with Psychiatric Presentation in collaboration with the Immunopsychiatric Clinic in Östergötland

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Prevalence of PANS in Sweden – an investigation into the occurrence of Pediatric Acute-onset Neuropsychiatric Syndrome

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Introduction

Introduction

Pediatric Acute-onset Neuropsychiatric Syndrome (PANS) is a clinical syndrome, described since 2012, in which children suddenly develop obsessive-compulsive disorder and/or severe restrictive eating, often accompanied by separation anxiety, tics, sleep disturbance, bedwetting and mood swings. In more severe cases, hallucinations and suicidal behavior occur. When the onset of symptoms is temporally linked to streptococcal infection, the condition is called Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections (PANDAS), described as early as 1998.

Despite growing knowledge about disease mechanisms and international guidelines for diagnosis and treatment, registry-based data on prevalence are lacking, partly due to variation in diagnosis coding.

The purpose and development of the project

This report has several purposes: to shed light on the prevalence of PANS/PANDAS in the Swedish child population with a particular focus on Östergötland and to test the validity of the ICD-10 codes that are primarily used in practice in Sweden (F068 and F079) so that future registry analyses can rest on a more secure basis. Within the framework of an initiative by the Sane association, the purpose of this report is ultimately to contribute to increased mental health in children and to increased opportunities for suicide prevention efforts in a severely affected group of children in Sweden. The project is funded with support from the Swedish Public Health Agency.

The prevalence report has grown out of two central experiences. The patient and relatives association Sane – the association for autoimmune encephalitis with psychiatric presentation meets recurring families whose children are suspected of having PANS but who have difficulty accessing healthcare and therefore do not receive a diagnosis or treatment. At the same time, Maria Hellman, a specialist in child and adolescent psychiatry and senior physician in a multidisciplinary team, met recurring children with acute onset of compulsions, tics or restrictive eating, where connections with previous infections and treatment response spoke in favor of an immune-mediated mechanism, but where the path to diagnosis and treatment attempts has often been long and burdened with severe suffering.

The team's clinical experience shows that children who receive early treatment for PANS together with other relevant interventions from BUP and social services often quickly return to symptom-free status, while children who remain undiagnosed risk long-term disabilities and mental health problems.

This motivated both Sane – the Association for Autoimmune Encephalitis with Psychiatric Presentation and the immunopsychiatric team in Östergötland to want to disseminate information about the condition and the current state of knowledge to the team's potential referrers. Especially since this knowledge is not yet naturally integrated into basic training for healthcare professionals. At the same time, a joint educational initiative from healthcare providers and patient and relatives' associations would create the conditions for using Östergötland as a model region for calculating prevalence.

Several factors suggested that the immunopsychiatric team in Östergötland County could reduce underdiagnosis and subsequently describe the occurrence of PANS with a high degree of validity:

- access to secure data regarding county population from Statistics Sweden
- reasonable number of potentially referring care units and student health teams to be able to inventory and visit all of them over a period of one year
- limited geographical size with travel time of approximately one hour maximum from the city of residence Linkoping
- habit and acceptance after the pandemic around digital lectures
- currently high level of knowledge about the condition after educational efforts
- existing multidisciplinary team that could offer the opportunity for telephone consultation before referral if necessary
- immunopsychiatric clinic operating within public healthcare
- lack of private pediatric medical care, which does not report to the National Board of Health and Welfare's patient data register

Project leaders Catarina Löfgren & Katrin Pettersson
Sane – association of autoimmune encephalitis with psychiatric presentation

Background

Pediatric Acute-onset Neuropsychiatric Syndrome is a collective term for conditions in which children suddenly develop severe mental symptoms (Swedo et al., 2012). To meet the diagnostic criteria for PANS, the child needs to suffer from acute onset of obsessions, compulsions and/or refusal to eat. Separation anxiety, tics, sleep problems and mood swings often occur simultaneously and suddenly. Micturition disorders, new motor problems, impaired writing and drawing skills as well as new difficulties in completing schoolwork as before are also typical symptoms. In severe cases, children can suffer from depression, psychotic symptoms and even suicide attempts (Gagliano et al., 2023; Hesselmark & Bejerot, 2019; Pavone et al., 2020). A previous report from Sane – the Swedish Association for Autoimmune Encephalitis with Psychiatric Presentation has

demonstrated that 14% of families (n217) reported suicide attempts in children with a PANS diagnosis. Suicide attempts also occurred in this group in children younger than 11 years of age (Gerland, 2021).

Figure 1. Summary of diagnostic criteria (Swedo et al., 2012)

Diagnostic criteria PANS	**Description**
Acute onset OCD / Restrictive eating	Sudden onset (often within 24–48 hours of obsessive-compulsive disorder (OCD or severe restrictive eating disorder. Maximum seven days from onset to peak (Masterson et al., 2025
Simultaneous acute onset symptoms	In addition to the core symptoms, at least two of the following symptom areas must occur simultaneously: - Anxiety (especially separation anxiety) - Emotional lability or depression (incl. self-structiveness) Irritability, aggressiveness, or difficulty regulating emotions - Regressive behavior (the child "goes back" in development, e.g. baby talk, needing help with the toilet, starting to eat with his fingers) - Impaired school performance (attention, memory, executive functions, decline in mathematical ability) - Motor and sensory symptoms (tics, hyperactivity, impaired fine motor skills e.g. writing style, hypersensitivity to sound/light/touch) - Somatic symptoms such as sleep problems, frequent urination, bedwetting.
Exclusion	The symptom picture cannot be better explained by other known neurological or psychiatric conditions.

Infections and immunological reactions appear to be able to trigger the acute symptom picture. (Falcini et al., 2014; Gromark et al., 2019; Johnson et al., 2019). If symptoms occur after a streptococcal infection, the condition is called Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) (Swedo et al., 1998).
The course of the disease often progresses in relapses, that is, in periods of deterioration (Masterson et al., 2025; Vreeland et al., 2023).

Studies suggest that PANS and PANDAS may be due to inflammation in the basal ganglia of the brain (Giedd et al., 2000) and that children with PANS often also later develop or have other autoimmune or psychiatric diseases (Frankovich et al., 2015; Gromark et al., 2019; Ma et al., 2024; Tang et al., 2025). Registry studies have previously shown an association between autoimmunity and tics (Dalsgaard et al., 2015) and obsessive-compulsive disorder (Mataix-Cols et al., 2018). Epidemiological studies have also shown an association between having tested positive for streptococcal infection and the occurrence of tics and OCD (Orlovska et al., 2017). Recently published research results show that children with a PANS diagnosis report more infections and a higher rate of regression in early childhood than controls. In addition, epigenetic abnormalities and immune dysregulation are demonstrated in the PANS group compared to controls, which may be central to the pathophysiology of the disease. The described immunological and epigenetic abnormalities appear to be affected by immunological treatment with intravenous immunoglobulin (Han et al., 2025).

Treatment usually includes three parts: 1) treatment of any infection, 2) anti-inflammatory drugs, and 3) psychiatric interventions (Cooperstock et al., 2017; Frankovich et al., 2017; Pfeiffer et al., 2021). However, the American Academy of Pediatrics (AAP) in its first clinical report on PANS recommends only parts 1 and 3 (Board of Directors, 2025), which has been criticized by researchers (Bernstein et al., 2025; Madan et al., 2025).

How is the care for children with suspected PANS organized in Sweden today

In Sweden, three of the country's 21 regions have special immunopsychiatric teams aimed at children and adolescents; in Stockholm, Västra Götaland and Östergötland. These teams investigate children with suspected PANS or PANDAS and treat children whose symptoms and clinical presentation correspond to the diagnostic criteria for PANS or PANDAS. This is carried out in close collaboration between expertise from pediatrics and child and adolescent psychiatry, in so-called multidisciplinary teams. The Swedish immunopsychiatric teams have contributed to research in the field (Gromark, 2019; Gromark, 2022; Hajjari, 2022; Isung, 2020; Johnson, 2019; Johnson 2021; Mataix-Cols 2018; Pérez-Vigil, 2016) and to ongoing research (Gillberg Neuropsychiatry Centre, 2020; Octapharma, 2024).

What do we know today about the incidence and prevalence of PANS?

Knowledge of how widespread the diagnosis of PANS is is limited. The variation described among different diagnostic groups is large. In a study with 136 children affected by OCD, 5% criteria for PANS (Jaspers-Fayer et al., 2017) while Professor Swedo, who first identified the condition PANDAS and later PANS as separate entities, in interviews has

estimated the prevalence of PANDAS in children with OCD or tics to be 25% (Westly, 2010). 11% of children with tics experienced worsening of symptoms after streptococcal infection in one study (Singer et al., 2000). A study of 100 consecutive patients at an eating disorder clinic reported that as many as 52% of the patients had a symptom picture similar to that described in PANS including acute onset of OCD and/or restrictive eating (Aman et al., 2022). The result was based on a short form for parental screening of PANS symptoms and the patients were never assessed for the PANS diagnosis through a doctor's visit, or by a multidisciplinary team. The authors discussed that symptoms accompanying severe eating disorders often resemble the symptoms included in the diagnostic criteria for PANS, making it the incidence was most likely overestimated.

In an American retrospective study from 2023, the incidence of PANS was estimated to be approximately 1 cases/11,765 children aged 3-12 years in the years 2017-2019. The total population amounted to approximately 51,000/year. A continued potential underdiagnosis was emphasized in the discussion (Wald et al., 2023). This incidence level corresponds to approximately 4.6 new cases/year in an area with the Östergötland population for the age group of 3-12 years. A Canadian survey study aimed at pediatricians estimates the prevalence of PANS in the entire population of children aged 3-17 years in their surrounding areas to be 0.0017%. This would correspond to 1.4 children in the Östergötland County population between 3-17 years. (Goren et al., 2024).

The few studies conducted to date have thus reported varying percentages, which is partly due to possible underdiagnosis, differences in methodology, whether strict fulfillment of diagnostic criteria has been applied, the structure of healthcare systems and access to reliable registers, and lack of uniform use of diagnostic codes for PANS and PANDAS.

In Sweden, the state of knowledge regarding prevalence is even more limited. No epidemiological survey regarding prevalence has previously been carried out. This makes it important to analyze data from national registers, such as the Swedish Patient Register and statistics from Statistics Sweden on population size to approach more reliable estimates of prevalence.

What do we know today about age and gender distribution at PANS?

Data from previous Swedish cohort studies (Gromark, 2019; Johnson et al., 2019) and international studies on PANS (Calaprice et al., 2017; Falcini et al., 2014; Gagliano et al., 2023; Ma et al., 2024; Masterson et al., 2025; Wald et al., 2023), with the exception of a new Asian study (Zheng et al., 2025), show clear similarities in gender distribution with a small but consistent preponderance of boys. A comparable age of onset was reported in all cohorts (7.5–9.5 years). Thus, the condition PANS at the first relapse seems to affect children of primarily preschool and primary school age and more often boys. The hypothesis is that our statistics should also show overweight for boys in the material. We will not, through our

The survey will be able to report age of onset but, on the other hand, age at first diagnosis code corresponding to PANS in the register if this is registered from 2020. Thus, we can describe age at diagnosis of PANS but not age at onset based on register data.

What do we know today about comorbidity in PANS?

Previous studies suggest an increased risk of co-occurrence of autoimmune diseases and neuropsychiatric conditions (Frankovich et al., 2015; Gromark et al., 2019; Johnson et al. 2019; Masterson & Gavin, 2024). For example, it is reported from Australia that the previous PANS debut had 38% autism diagnosis and 28% ADHD diagnosis (Han et al., 2025). The risk of patients with PANS developing autoimmune diagnoses after the illness is increased (Ma et al., 2024). Interest is growing in the connection between autoimmune processes and the development of neuropsychiatric disorders (Cox et al., 2015; Endres et al., 2022; Murphy et al., 2010; Vreeland et al., 2023; Xiu et al., 2024).
Registry studies have shown associations between tics, OCD and autoimmune conditions, as well as with streptococcal infections (Dalsgaard et al., 2015; Köhler-Forsberg et al., 2019; Mataix-Cols et al., 2018; Orlovska et al., 2017; Wang et al., 2016).

What do we know today about ICD-10 codes for PANS and PANDAS?

The three Swedish pediatric immunopsychiatric teams use ICD-10 (International Classification of Diseases, 10th Revision) codes F068 (“Other specified mental disorders due to known physiological factor”) or F079 (“Unspecified personality and behavioral disorder due to known physiological factor”) for PANS.
F068 is used by the teams in Stockholm and Östergötland. In Västra Götaland, F079 is registered instead for the diagnosis of PANS.

Outside of these regional specialized teams, alternative diagnosis codes are sometimes used in Sweden, such as F428 (“Other obsessive-compulsive disorder”), D899 (“Disease involving the immune system, unspecified”) and G099 (disease of the autonomic nervous system).

PANDAS is listed in the US-modified alphabetical index of ICD-10, but not in the original WHO version. PANDAS is mentioned in the US version under diagnosis code D89.89 “Other specified disorders involving the immune mechanism, not elsewhere classified” and code B94.8 “Sequelae of other specified infectious and parasitic diseases” (American Academy of Pediatrics, 2025).

There is no specific ICD-10 code for PANS, and the syndrome is not included in the alphabetical register (WHO, 2015). In terms of American recommendations, however, the American Academy of Pediatrics in 2025 supplemented its clinical report on PANS (Board of Directors, 2025) with a guide aimed at American clinicians on diagnostic coding of the condition (American Academy of Pediatrics, 2025). In a PANS diagnosis, US healthcare providers are asked to report all codes for the documented manifestations of the syndrome, e.g. OCD, tics, eating disorders, as well as any manifestations that are not an integral part of the syndrome criteria, e.g. psychosis, see summary of their guidance below.

For PANDAS specifically, the American Academy of Pediatrics recommends that diagnosis be registered with ICD-10 code D89.89, where in Sweden we have closest access to D89.8 "Other specified diseases involving the immune system, not elsewhere classified" and B94.8 "Late effects of other and unspecified infectious and parasitic diseases" as well as codes for the manifestations.

ICD-10 coding for PANDAS according to the American Academy of Pediatrics (AAP), 2025

D89.89 "Other specified disorders involving the immune mechanism, not elsewhere classified" and B94.8 "Sequelae of other specified infectious and parasitic diseases" and manifestation codes, see examples below in Figure 2.

Figure 2. ICD-10 coding for PANS according to AAP, 2025

Main criteria	**Further manifestations**
Obsessive-compulsive disorder, unspecified (F42.9) or compulsive behavior (R46.81). In Sweden, the closest is other symptoms and signs of illness regarding appearance and behavior (R46.8).	• Anxiety (e.g. F41.9, anxiety disorder, unspecified) • Emotional instability (R45.86) and/or depression (e.g. F32.89, other specified depressive episodes. In Swedish, other symptoms and signs of illness relating to the emotional state R45.8, other specified depressive episodes F32.8.
Severely restricted food intake, suggested F50.82 avoidant/restrictive eating disorder (F50.82). In Sweden, closest to other specified eating disorders (F50.8)	• Irritability (R45.4), aggressiveness (e.g. R45.5, hostility) and/or severe defiance syndromes (e.g. F91.3, defiance syndrome) • Regression of development (e.g. F84.9, pervasive developmental disorder, unspecified) • Impaired school performance (e.g. Z55.3, underachievement in school) • Sensory or motor abnormalities, including increased sensitivity to sensory stimuli (e.g. R20.3, hyperaesthesia), hallucinations (category R44 codes), dysgraphia (R27.8, other coordination disorder), and complex motor and/or vocal tics (category F95-codes) • Somatic signs and symptoms, including sleep disturbances (e.g. F51.5, nightmares), enuresis (N39.44, nocturnal bedwetting). In Sweden, closest to other specified urinary incontinence (N39.4) or increased micturition frequency (R35.0, frequent micturition) In Sweden, closest to other micturition difficulties (R39.1), not better explained by known neurological or somatic disease

What do we know about the upcoming coding of PANS and PANDAS in ICD-11?

In the upcoming diagnostic coding system ICD-11 (International Classification of Diseases, 11th Revision), the category 6E64 “secondary obsessive-compulsive disorder or related syndrome” has been introduced, which can be used for autoimmune or post-infectious OCD such as PANDAS (Endres et al., 2022; World Health Organization, 2025). PANDAS is also listed as one of several examples of diagnoses under the code 8E4A.0 (“Paraneoplastic or autoimmune diseases of the central nervous system, brain or spinal cord / Autoimmune movement disorder”)(World Health Organization, 2025). ICD-11 is not yet used clinically in Sweden. When ICD-11 is introduced, there will thus be two different diagnostic codes proposed by WHO for the streptococcal-associated condition PANDAS, but no clear guidance on how the more general condition PANS should be recorded and coded.

Why might epidemiological knowledge about PANS/PANDAS be important?

Knowing the incidence and spread of PANS and PANDAS is of central importance from several perspectives. Reliable prevalence figures facilitate the allocation of healthcare resources for investigation, treatment and follow-up. Do more teams need to be created to assess and treat these children? Data can also demonstrate regional differences in diagnostics and access to specialized care. It is important to clarify any regional differences in prevalence and estimation of possible hidden numbers in Sweden. This is crucial to ensure that children throughout the country receive equal opportunities for diagnosis and treatment. PANS/PANDAS can have serious consequences for both the child and the family, including severe disability and in some cases suicide risk.

If our data in terms of gender, age and comorbidity are consistent with other studied groups of patients, so-called cohorts with PANS, it can provide guidance on whether the condition can be a valid diagnosis or not. If the cohorts of different research groups are homogeneous, for example in terms of phenotype - observable characteristics; gender, age and comorbidity, it suggests that there are special characteristics in the patient groups that are shared across national and cultural borders. If the cohorts are very different from each other in characteristics, it instead suggests that the patients have different conditions and that the diagnostic criteria, in this case for PANS and PANDAS, fail to narrow down a specific disease state.

Why is it important to examine the validity of the diagnostic codes used in Sweden for PANS?

Validity refers to the degree to which a measurement, diagnostic code or variable truly reflects the phenomenon it is intended to represent. A high degree of validity for a diagnostic code for a medical condition means in practice that the code in the medical record or registry data truly corresponds to the clinical condition it is intended to represent.
In this report, we focus on whether F068 has high validity for the condition PANS in the Östergötland Region and whether F079 has high validity or not for the condition PANS in the Västra Götaland Region.

Studies validating or investigating the predictive value of different diagnostic codes for PANS have, to our knowledge, never been conducted. We therefore do not know whether the current ICD-10 diagnostic codes used in Sweden or internationally correspond to a large extent to specific PANS and/or PANDAS or not. These codes could be used by other clinics and specialties for completely different conditions, which still fit into the diagnostic code headings “Other specified mental disorders caused by known physiological factor” (F068) or “Unspecified personality and behavioral disorder caused by known physiological factor” (F079).

By conducting a validation study prior to the registry study, we hoped to gain an understanding of whether the diagnostic codes F068 and F079 are used specifically for PANS or rather for other conditions.

There is a compiled overview of 132 scientific articles regarding the usefulness of the national patient data register (NPR), managed by the National Board of Health and Welfare, in research. The NPR was considered a valuable resource for large-scale register-based research. Available data indicate that the positive predictive value (PPV) for diagnoses in the register is generally around 85–95% (Ludvigsson et al., 2011). The part that was explored was inpatient visits. According to a later compilation of 89 studies, the completeness of the patient data register for outpatient visits is generally good, although some underreporting occurs, especially from private healthcare providers. The PPV was on average 84% for examined diagnoses in the outpatient part of the patient data register (Everhov et al., 2025).

Positive predictive value (PPV) is a way of describing validity numerically as a percentage. PPV corresponds to the proportion of patients who have the diagnosis code and who, upon manual medical record review or structured clinical assessment, actually have the diagnosis.

If a diagnosis code has high validity, registry data can be used more reliably in epidemiological studies, since misclassification is low. With high validity, data from the condition that is actually intended to be analyzed is analyzed to a large extent. If, on the contrary, the diagnosis code has low validity, there is a high risk that data that is mixed with other disease states is analyzed.

Specificity is another way of describing validity. If a diagnostic code has high specificity it is not widely used for other conditions that are similar to the diagnosis, for example.

If a diagnosis code for a medical condition or suspected entity has low validity, it may be because doctors use different codes for the same condition, or that the coding is mixed up with related diagnoses. In this case with PANS where F068 stands for “Other specified mental disorders caused by known physiological factor” and F079 stands for “Unspecified personality and behavioral disorder caused by known physiological factor”
For example, one could imagine confusion with mental symptoms caused by brain tumors or brain damage. One could also imagine residual conditions with altered behavior after, for example, brain inflammation (encephalitis). Such confusion with other medical conditions, if it occurs, can distort research results and significantly complicate the interpretation of registry extracts.

Epidemiological studies (e.g. on incidence, prevalence, risk factors) are often based directly on registry data. Lack of validity means that conclusions about, for example, disease burden and resource needs can be misleading.

Regarding PANS, it is central to examine the validity of the diagnosis codes in the Swedish patient data register, partly because this has never been carried out before and the validity has so far been unknown, partly because the degree of validity determines whether register-based analyses are useful. In the case of a low degree of validity, a method other than register analysis is required for studies of prevalence, incidence, gender and age distribution, etc. as a supplementary medical record review with collection of clinical data. As reported previously, there is no national or international consensus on diagnostic coding, which is why it is not obvious which diagnostic code clinicians should use in practice when suspecting or diagnosing PANS. An investigation of the validity of the diagnostic codes currently used in Sweden for the condition can provide guidance on whether these diagnostic codes can be useful or not in future research.

Surveys included in the current project on the prevalence

-Inventory of the number of patients in the Östergötland Region

- Inventory of the number of patients in Västra Götaland
- Analysis of the referral flow to the immunopsychiatry team in Linköping in 2023 and 2024
- Validation of diagnosis code F068 for PANS in Region Östergötland
- Validation of diagnosis code F079 for PANS in Västra Götaland
- A registry study regarding, among other things, prevalence, gender and age distribution, and comorbidity based on extracts from the National Board of Health and Welfare's Patient Data Register (NPR) –still ongoing

Method

Method inventory of the number of patients in Region Östergötland

The multidisciplinary team at Her Royal Highness (HRH) Crown Princess Victoria's Children's Hospital in Linköping's pediatric neurology clinic in Linköping investigates and assesses children with suspected PANS or PANDAS in the Östergötland Region has taken stock patients linked to the clinic based on close and current knowledge of the patient group. The inventory included children and adolescents under 18 years of age, residing in Östergötland County, with diagnosis code F068 corresponding to PANS or PANDAS. In Östergötland, ICD code F068 is only used when strict diagnostic criteria for PANDAS (SE Swedo et al., 1998) and or PANS (Swedo et al., 2012) are met, including the definition of acute onset (Masterson et al., 2025) with an interval from onset to peak within 7 days.

Method inventory of the number of patients in the Västra Götaland region

The corresponding inventory was carried out at Gillbergcentrum, Gothenburg.
University/Children's Neuropsychiatry Clinic (BNK), Sahlgrenska, where a multidisciplinary team investigates and assesses children with suspected PANS or PANDAS in Västra Götaland Region. The inventory included children and adolescents with diagnosis code F079, who were assessed to meet the diagnostic criteria for PANS or PANDAS. During the first year after diagnosis, diagnosis code F079 is often used with the additional text “Suspected PANS” while waiting for the course and treatment response to clearly confirm the diagnosis. These patients were also included. The team also identified the number of newly diagnosed patients during the year 2024.

Method analysis of referral flow

The number of incoming referrals to the immunopsychiatric multidisciplinary team, via the pediatric neurology clinic, at HKH has been monitored for the years 2023 and 2024, as well as the percentage outcome in PANS
diagnosis of incoming referrals. Referrers have been classified according to BUP (outpatient and inpatient care), Pediatrics (clinic, emergency department and inpatient care), Health Center, Student Health, Self-referrals. We have also monitored the number of out-of-county referrals. In connection with the clinical assessments, time to onset has been obtained as part of the medical history. Time from onset to treatment has been noted as part of the clinic's follow-up work and for this report.

Method validation of diagnosis code F068 for PANS in Region Östergötland

In Östergötland County, the hypothesis was that the ICD-10 code F068 was exclusively used for PANS and PANDAS. We investigated whether the occurrence of the diagnostic code F068 accurately and specifically reflected the occurrence of the conditions PANS or PANDAS among children and adolescents aged 0–17 years in Östergötland County by matching all individuals in the NPR's inpatient and outpatient section with ICD-10 diagnostic code F068, registered as residents of the Östergötland County NPR, with patients who were clinically diagnosed according to strict criteria for PANS or PANDAS at the Linköping multidisciplinary immunopsychiatric team. This matching required ethical review and approval from the Swedish Ethics Review Authority, which has been obtained (Ethics Review Authority, 2024).
The National Board of Health and Welfare had views based on a stricter confidentiality assessment, which is why the number of individuals eligible for medical record review was adjusted to a minimum through the procedure below.

The patients in the reception were inventoried as above and the personal identification numbers without other linked data were transmitted to the National Board of Health and Welfare in a password-protected compressed file in a special computer system, in accordance with the authority's security procedures. NPR administrators then identified any additional pediatric patient cases, written in Östergötland County, with diagnosis code F068 indicated at any care visit in outpatient or inpatient care during the calendar year 2024. These personal identification numbers were transmitted back in a special postal dispatch of a USB with a password-protected file. These returned personal identification numbers were then subject to medical record review. The reviewers used a standardized template to ensure consistency in the assessments. Each case identified by the Patient Data Register, but not by the region's immunopsychiatric team, was classified in connection with medical record review as either confirmed PANS, confirmed PANDAS, possible PANS (e.g. due to insufficient information) or non-PANS. This was based on diagnostic criteria described by Swedo's research group (Swedo et al., 1998; Swedo et al., 2012). We used the definitions of hyperacute and acute onset proposed by Masterson et al. (2025) in the medical record review. Non-PANS cases were subclassified

based on a system used in previous reviews of the validity of diagnoses in Swedish registries (Ludvigsson et al., 2011; Nilsson et al., 1994):

(i) **Diagnostic error:** The patient was incorrectly diagnosed with PANS/PANDAS and received an ICD diagnosis of PANS/PANDAS without meeting the criteria.

(ii) **Translation error:** A correct non-PANS diagnosis and corresponding ICD code in the medical record incorrectly matches another ICD code in the Patient Register (NPR), leading to the patient being misregistered as PANS.

(iii) **Coding error:** A correct non-PANS diagnosis was made, but an incorrect ICD code was recorded in the medical record and transferred to the Patient Data Registry as possible PANS.

For further specification, additional subcategories were added under (i) **Diagnostic error:** :

(ia) **Atypical PANS without treatment response:** The diagnostic code refers to a probable immunopsychiatric condition that does not fully meet the criteria and has not responded to typical PANS treatment.

(ib) **Atypical PANS with treatment response:** The diagnostic code refers to a probable immunopsychiatric condition that does not fully meet the criteria but has responded to typical PANS treatment.

(ic) **Other psychiatric condition intended:** The diagnosis code refers to another organic psychiatric disorder consistent with the description of the ICD code.

Method validation of diagnostic code F079 for PANS in Västra Götaland

In Västra Götaland County, the hypothesis was that the ICD-10 code F079 was used exclusively for PANS or PANDAS. We investigated this in a similar way by matching all cases with diagnosis code F079 in Västra Götaland via registry data with the patient group diagnosed with PANS or PANDAS by the immunopsychiatric team at the Gillberg Center, University of Gothenburg and Child Neuropsychiatry (BNK), Sahlgrenska University Hospital. We reviewed, as described above, the medical records of the patients who were registered in the Patient Data Register with code F079 but who were not identified as PANS or PANDAS patients at the aforementioned clinic. The medical record review was carried out according to the same structure and with an identical assessment template as in Östergötland.

Method register study

In order to reduce the possible, but presumed, number of underdiagnosed children and to be able to more accurately describe the occurrence of PANS in a defined region (Östergötland), an educational initiative was carried out there in 2023. Information about PANS and knowledge about referral options and referral routes were offered in the form of lectures at units such as in healthcare

or school primarily comes into contact with children and young people with physical and mental symptoms.
Units reached by the offer were active within Region Östergötland's children's healthcare, Child and Adolescent Psychiatry (BUP) clinics, first-line psychiatry aimed at children and young people and the county's child health centres (BVC). The same information with adaptation for school staff was also communicated to the student health departments of all thirteen municipalities in Östergötland. All units were offered an alternative digital lecture for increased accessibility.
In addition to lectures for each unit, knowledge was also disseminated through invitations to joint open digital question and answer sessions that began with, for example, summaries of new research findings in the field. These “check-ins” were directed at all units.

In 2025, a register extract was requested from the Swedish National Board of Health and Welfare's patient data register (NPR). The patient data register collects information from outpatient and inpatient visits within Swedish public healthcare. The requested data concerned individuals with diagnosis codes hypothesized to correspond to PANS (F068 and or F079). De-identified data concerning identified individuals 2019–2023 were requested in order to calculate the prevalence, as well as the number of new individuals with the current diagnosis codes per year, in order to estimate the new disease (incidence) annually. We also wanted to describe epidemiological data regarding gender and age, see Table 1.

Table 1. Delimitation and requested data for PANS (Sweden, 0–17 years, 2019–2023)

Delimitation Age	**Requested data**
0–17 years	Number
Diagnostic code F068 and or F079	Gender (boys/girls)
Period 2019–2023	Age (at the end of the year)
	Serial number (de-identified data)
	County

In addition, additional data were obtained for the patient group that appeared in the patient data register sometime during the calendar year 2024 in order to be able to explore the existing comorbidity in
terms of psychiatric diagnoses (diagnosis chapters F00-F99), but also autoimmune conditions. A list of ICD-10 diagnosis codes was established in collaboration with other research groups regarding autoimmune diagnoses. In order to sort out irrelevant data and request a smaller amount of sensitive data, the extract was limited as below, see Table 2.

Table 2. Delimitation, requested and excluded data for PANS in 2024 (Sweden, 0–17 year)

Demarcation	**Requested data**	**Excluded data (diagnosis chapter)**
Children 0–17 years	Number	O00–O99 Pregnancy
Diagnostic codes corresponding to PANS	Sex	S00–T98 Injuries
Year 2024	Age	U00–U99 Special purpose
	Serial number (de-identified data)	V01–Y98 External causes
	County	Z00–Z99 Factors affecting health
	Diagnosis code	

In summary, the method for the register study aimed to partly follow the incidence and new cases in the counties of Sweden and to be able to report age, gender. For the population in 2024 with a diagnosis code corresponding to PANS, the method also aimed to be able to describe comorbidity with psychiatric and autoimmune diagnoses. The latter by requesting a limited number of diagnosis code chapters for analysis by matching against predefined autoimmune ICD-10 codes and the psychiatric diagnosis chapter. Following the prevalence in the coming years is not included in the scope of the project, but permission from the Swedish Ethics Review Authority is available for such a future study (Ethics Review Authority, 2024).

Results

Result: inventory of patient numbers

Table 3. Inventory of patients with PANS/PANDAS and estimated prevalence in 2024

Region	Number patients (2024)	Population 3–17 years (2024)	Prevalence (per 100,000)	Prevalence (‰
Östergötland	52	81593	64	0.6
Västra Götaland	40	306331	13	0.1

Inventory of the number of patients in the Östergötland Region

49 children under 18 years of age, registered in Östergötland County, were identified as patients with a PANS or PANDAS diagnosis at HRH Crown Princess Victoria's Children's Hospital pediatric neurology clinic in Linköping. An additional 3 children with F068 diagnosis were identified by the National Board of Health and Welfare and met diagnostic criteria for either PANS or PANDAS upon medical record review. The total patient group in Östergötland County with diagnosis code F068 amounted to 52 individuals. Calculated on this basis, without taking into account a number of factors such as recovery, the lifetime prevalence can be up to 17 years is estimated at 0.6 per thousand or 64 children per 100,000 inhabitants aged 3-17 in Östergötland.

Inventory of the number of patients in the Västra Götaland region

40 children under 18 years of age, registered in Västra Götaland County, were identified as patients with a PANS or PANDAS diagnosis at Gillberg Center, BNK, Sahlgrenska University Hospital in Gothenburg. One of these patients did not have the F079 code registered in his medical record, which could not be adjusted retroactively for technical reasons.

The National Board of Health and Welfare identified two additional patients with diagnosis code F079, but none of these patients met diagnostic criteria for PANS upon medical record review. The total patient group in Västra Götaland County with diagnosis code F079 ever consisted of approximately 40 individuals. Calculated on this basis, the lifetime prevalence can be up to 17 years is estimated at 0.1 per thousand or 13 children per 100,000 inhabitants aged 3-17 in Västra Götaland.

Estimated occurrence in the kingdom

If it is assumed that the prevalence in Östergötland based on recent knowledge dissemination and access to a multidisciplinary immunopsychiatric team is a reasonably accurate prevalence, with the assumption of some continued prevalence of underdiagnosis, the prevalence for Sweden can be calculated, as below, see Table 4.

Table 4. Estimated number of patients under 18 years of age with PANS/PANDAS in Sweden in 2024

	Calculated number patients based on prevalence in Östergötland County (2024)	Population 3–17 years (2024)	Prevalence (per 100,000)	Prevalence (‰)
Sweden	1183	1848794	64	0.6

Results: Referral flow and outcome 2023–2024

Referral inflow 2023

During the calendar year 2023, a total of 12 referrals were received regarding the same number of children with the question PANS/PANDAS (Table 5). One referral concerned a child registered outside Östergötland. All referrals resulted in new visits. Half, 50%, came from the county's Child and Adolescent Psychiatry (BUP) units. The Child and Adolescent Psychiatry (BUP) Psykiatripartners Linköping in the central county accounted for 50% of the referrals from Child and Adolescent Psychiatry (BUP). Child and Adolescent Psychiatry (BUP) US, including the inpatient ward, in the central county accounted for 33% and Child and Adolescent Psychiatry (BUP) Capio in the western county accounted for 16.7% of the number of referrals received from Child and Adolescent Psychiatry (BUP). No referrals were received from Child and Adolescent Psychiatry (BUP) ViN in the eastern county. In addition, two referrals from pediatrics (16.7% of the total number of referrals), two from health centers (16.7%) and one self-referral (8%). No referrals were received from student health.

Referral inflow 2024

In 2024, 20 referrals were received regarding 18 children, of which two referrals were self-referrals. Three referrals concerned children registered outside Östergötland County. A total of 18 new visits were carried out based on the referrals received in 2024, of which 15 children were registered in Östergötland County. Data regarding the patients who were updated for new visits and who were registered in Östergötland County is presented below (Table 5). Of the referrals received, eight came from Child and Adolescent Psychiatry (BUP) units in Region Östergötland, mainly from Child and Adolescent Psychiatry (BUP) Capio in the western part of the county (50% of the Child and Adolescent Psychiatry, BUP, referrals), followed by Child and Adolescent Psychiatry (BUP) US in the central part of the county (25%), Child and Adolescent Psychiatry (BUP) Psykiatripartners Linköping in the central part of the county (12.5%) and Child and Adolescent Psychiatry (BUP) ViN from the eastern part of the county (12.5%). One referral was received from pediatrics (5.9%), two from health centers (11.8%), one from youth health (5.9%) and one referral from school health care (5.9%).

Table 5. Referral flow 2023 – 2024 patients written in Östergötland

	2023	2024	Change (n and %)
Number received referrals	11	17	+6 (+55%)
Number of new visits	11	15	+4 (+36%)
Referrals from BUP in Östergötland	6	8	+2 (+33%)
Referrals from pediatrics	2	1	-1 (-50%)
Referrals from health centers	3	3	Unchanged
Referrals from student health care	0	1	+1
Self-referrals	1	2	+1 (+100%)

Change between the years 2023–2024

The referral flow increased by 55% between the years (from 11 to 17) concerning children residing in Östergötland. The number of new visits increased by 36% (from 11 to 15). The number of referrals from Child and Adolescent (BUP) units rose from 6 to 8 (+33%). The number of self-referrals increased from one to two, while the inflow from pediatric medicine decreased. Referrals from health centers were at an unchanged level.
New for 2024 were referrals from school health care and from youth health.

Outcome of assessments 2023 – children enrolled in Östergötland

Of the 11 new visits in 2023, five children (45%) were assessed as meeting the criteria for PANS or PANDAS, see Table 6. Two of these had a streptococcal-associated onset of symptoms and were diagnosed with PANDAS. Two children (18.2%) were followed up under the diagnosis of suspected or atypical PANS, while four cases (36.4%) were closed after assessment.
The average waiting time from symptom onset to diagnosis (doctors delay) was 16.7 months, the median waiting time was 1.5 months. The shortest time from onset to treatment was 0.5 months.
The longest time from onset to diagnosis was 6 years and 4 months. The gender distribution among children diagnosed with PANS or PANDAS was 20% girls and 80% boys.

Outcome of assessments 2024 - children enrolled in Östergötland

Of the 15 new visits in 2024, seven children (46.7%) were diagnosed with PANS (n = 5) or PANDAS (n = 2), see Table 6. These were offered continued care contact with the immunopsychiatry clinic. Three children (20%) were followed up under the diagnosis of suspected or atypical PANS, while five cases (33.3%) were closed from the immunopsychiatric team at the Children's Neurology Clinic after assessment. The average waiting time for children in Östergötland who were referred in 2024 and subsequently received a diagnosis was 6.9 months. The median waiting time was 2 months (range 1 day – 34 months). The gender distribution among diagnosed children was 28.6% girls and 71.4% boys.

Table 6. Assessment outcomes assessment with PANS questionnaire 2023–2024

	2023 (n and % of new visitor ratings)	2024 (n and % of new visitor ratings)	Change (n and %)
Result: PANS/PANDAS	5 (50%)	7 (46.7%)	+2 (+40%)
Result: Suspicious/Atypical PANS	3 (30%)	3 (20%)	Unchanged
Finished after assessment	2 (20%)	5 (33.3%)	+3 (+150%)
Average waiting time (months)	16.7	6.9	–9.8
Median waiting time (months)	1.5	2	+0.5

Change between years

The number of children diagnosed with PANS/PANDAS increased from five to seven (+40%).
The percentage of new visits that resulted in a PANS or PANDAS diagnosis was stable at around 50%.
When children with suspected or atypical PANS are also included, the group that was followed up further increased from eight children in 2023 to ten children in 2024.
The percentage of cases closed increased from 20% (n = 2) to 33.3% (n = 5), corresponding to an increase of 150%. The average waiting time was more than halved from 16.7 to 6.9 months, although the median waiting time increased slightly (from 1.5 to 2 months).

Validation of diagnostic codes for PANS - preliminary results

Validation of diagnosis code F068 for PANS in Region Östergötland and F079 in Västra Götaland

The results in this section are preliminary as we aim to publish the results of this investigation into the validity of the diagnostic codes. A detailed report would jeopardise the possibility of publishing the results at all, which would mean that the research results would never be of benefit to the research community, the healthcare system or ultimately the patients.

The validity was explored through journal review in accordance with the method description above. Based on our results, the validity, described by positive predictive value, is and specificity, for ICD-10 code F068 very high for PANS including the condition PANDAS in Östergötland County.

Register study based on the Patient Data Register - preliminary results

The results in this part are also given provisionally and without giving exact figures. We are awaiting supplementary data from the National Board of Health and Welfare's Patient Data Register in order to obtain more accurate figures because data from the register extract we received earlier this year revealed suspected shortcomings in the reporting from certain regions to the Patient Data Register for the year 2024. We are awaiting new data after updating after consultation with administrators from the National Board of Health and Welfare. At least one region has, after suspicions of incomplete data were raised, discovered shortcomings in its reporting and completed it. However, we can already draw certain conclusions. These are described below in general terms without figures or tables, as advised by the prospective editor at the scientific journal we have begun a dialogue with. A detailed report would jeopardize the possibility of later publishing the study at all.

The final results will be communicated to the Public Health Agency when they are available. published, which is the ambition. Scientifically published and reviewed data must be the basis for the dissemination of information that can subsequently take place.

The study is a register-based cohort study with national coverage for the years 2019–2024. All individuals aged 0–17 have been included, which corresponds to just over 2.3 million children annually.

The ICD-10 codes that in this study were considered to correspond to PANS (F068 and F079) have a very low incidence in large parts of the country, indicating that these diagnostic codes are not used for other possible medical conditions. Thus, it does not appear that, for example, pediatric brain injury teams or similar use these ICD codes in clinical practice, in at least not to any great extent. The same applies preliminarily in almost all counties for code F069, which in Östergötland is used for suspected or atypical PANS.

Preliminary data suggests a very large difference in prevalence across the country's healthcare regions. The prevalence of PANS is highest in Östergötland County in 2024.

The preliminary outcome suggests that several hundred children are undiagnosed nationwide.

The prevalence of PANS is compared in the study to the prevalence of OCD in different counties. This ratio also varies greatly across the country. The highest ratio is higher than that described in studies so far.

Discussion

Overall interpretation of main findings

Our preliminary results indicate that the incidence of PANS in Östergötland is estimated to be on par with previous studies on incidence and prevalence from North America.
According to preliminary unpublished results, the prevalence is significantly higher than in other Swedish counties. This can primarily be explained by the fact that the country's few immunopsychiatric clinics were established in Östergötland in 2018, increased awareness after targeted educational efforts, more consistent use of diagnosis codes and the lack of private pediatric medical care in the region, which means that a larger proportion of patient visits have been reported to the National Board of Health and Welfare. These underlying factors seem more likely than, for example, genetic variation between populations in different counties. Taken together, the results suggest substantial underdiagnosis, especially in most regions without structured expertise and clear referral pathways for immunopsychiatric conditions in children and adolescents. This means that many children risk unequal access to care with delayed or absent diagnosis and treatment, with negative consequences for functional level, schooling and family, as well as for the child's time in potentially treatable suffering.
Alternatively, there is overdiagnosis in Östergötland County regarding PANS and the use of diagnostic code F068. However, the patients who are connected to the multidisciplinary team in Östergötland have, according to the team's routines, received diagnostic code F068 only if strict criteria for PANS or PANDAS are met. The medical record review identified three additional children with criteria fulfillment, where the team had classified them as suspicious or atypical, which rather suggests a conservative interpretation of the criteria in Östergötland.

According to preliminary unpublished data, the ratio of cases of PANS vs. OCD in Östergötland that PANS criteria are met in a not insignificant proportion of children and adolescents with obsessive-compulsive disorder.

Validity in diagnosis coding (F068/F079)

Journal review indicates a high positive predictive value for F068 in Östergötland and an almost equally high value for F079 in Västra Götaland. At least in these two regions, these codes are well suited for register-based research. Our analyses did not show any

cases where F068 or F079 have been intentionally used for conditions other than PANS or suspected PANS, which further strengthens the usefulness of the codes.

A challenge for epidemiological registry research is that the Patient Data Registry does not capture edited diagnostic text, such as “Preliminary hypothesis PANS” or “Suspected PANS”. As clinicians, one is not always aware that edited diagnosis text does not accompany the data that is then available in the Patient Data Register. This means that uncertain cases cannot be distinguished from certain diagnoses in the register data. Here, a need for a special ICD code for unspecified or atypical immunopsychiatric conditions is identified in both current and future diagnostic coding systems. Such cases may, for example, be patients who are presented with the PANS question after unintentional improvement in OCD or tics due to, for example, prescribed antibiotic or NSAID treatment. This without having a symptom picture that, upon later team assessment, corresponds to full criteria fulfillment. Another example is patients who do not debut in their symptom picture as acutely as the criteria require, but where the symptom flora is typical including a sporadic course temporally linked to infections. It would be important for future studies that only symptom pictures that strictly meet the diagnostic criteria for PANS or PANDAS continue to receive diagnosis code F068 or F079.

Regional differences and access to care

When referral pathways and expertise are in place, identification will likely increase and waiting times will be shortened. A mandate to support new teams through a national consultation function could be considered with the aim of offering more equitable care. An alternative is to test a model for national highly specialized care, which would strengthen the ability to maintain expertise, develop care and gather patients for research.

Underdiagnosis and “doctor's delay”

The wide spread in waiting times and the occurrence of self-referrals suggest that some families experience obstacles in the chain from onset to diagnosis. As Wald et al (2023) discuss, there is still ignorance about the diagnosis within the healthcare system, which is why common symptoms that often signal the condition when they debut pre-acutely are not associated with – such as separation anxiety, restrictive eating, tics or OCD – with a possible triggering infection. In addition, there have been clinicians who consider the published scientific evidence for PANDAS/PANS to be insufficiently convincing and who therefore seek less supportive findings, such as cultures or serology, in children with acute onset of neuropsychiatric symptoms.

"Doctor's delay" appears to be reducible through targeted educational efforts. Our material shows that the number of referrals has clearly increased and that the average waiting time has been halved after educational efforts, which suggests that such measures can have an effect.

Relationship to previous literature

Gender and age patterns in our data are consistent with previous cohorts, with a clear male predominance and a prevalence primarily in younger school-aged children. This convergence may strengthen the assumption that PANS represents a distinct clinical phenotype.

Coding now and in the future (from ICD-10 to ICD-11)

High validity suggests that ICD-10 code F068 can be used as the primary identifier for PANS until the transition to ICD-11 in selected regions. This diagnostic code is well suited to be used for PANS in other counties as well, as the risk of confusion with other medical conditions diagnosed within, for example, oncology or neurology seems to be very small. Additional coding 8 is used for specified conditions, but which do not have their own more specific code, which is well suited for PANS.

It seems to continue to make sense to use diagnostic code F069 in suspected or atypical cases of PANS, even though this diagnostic code has not been validated in any county. According to preliminary results, F069 is used to a very low extent in almost the entire country, which reduces the risk of confusion with other conditions. Additional coding with 9 signals that the condition is unspecified.

In order to improve the quality of registry data, clinics should also consistently record manifestation codes for, for example, OCD, tics, eating disorders and micturition disorders. Regarding the manifestation codes, the guidelines from the AAP are of good support (American Academy of Pediatrics, 2025). In addition to coding for PANS, it would be valuable to use a diagnostic code to mark that the condition is specifically PANDAS in cases where the symptom manifestations are considered to be temporally related to a previous streptococcal infection. When the condition is considered to be PANDAS, the diagnostic code B94.8 “Late effects of other specified infectious and parasitic diseases” recommended by the AAP could be used to distinguish PANDAS in later registry studies. Coding PANDAS with an additional code in addition to the code for PANS, instead of with two additional codes as proposed by the AAP, seems more reasonable, among other things, based on administrative burden. B94.8 specifically highlights that the condition is a consequence of a specified type of infection (streptococcal), which is the main distinguishing feature of PANDAS compared to PANS. D89.8 “Other specified diseases involving the immune system, not elsewhere classified”, which is the other diagnostic code that the AAP recommends for PANDAS, does not distinguish PANDAS from PANS. There may be insurance reasons in the USA why the AAP recommends both B94.8 and D89.89 for PANDAS. In several US states, legislation has been introduced that requires health insurers to reimburse IVIG treatment for PANS/PANDAS.
Reimbursement policies for IVIG may include codes D89.89 and/or D89.9 (immune system disorder, unspecified) as part of the diagnostic codes required for

to grant reimbursement for the administration of immunoglobulin (American Academy of Pediatrics, 2025).

The lack of a separate ICD-11 entity for PANS is problematic. The WHO specifies code options for PANDAS, but these codes are shared with other, not entirely uncommon conditions such as NMDA-R encephalitis, which reduces specificity. A Swedish additional code for PANS and PANDAS would therefore be of great importance for research opportunities after the introduction of ICD-11. This is particularly important in the Nordic countries where we have well-established and reliable registers with unique opportunities for epidemiological research.

Distinguishing PANDAS from PANS in ICD-11 also through diagnostic coding seems meaningful as PANDAS may be a subgroup of PANS with its own possible phenotype, pathophysiology and epidemiological profile (Swedo et al., 2022).

A national and preferably Nordic coding guideline would be welcomed to ensure uniform use and comparability between regions and Nordic nations, as well as to facilitate future register-based research.

Data quality in the Patient Data Register

Our research process has been hampered by the lack of a sufficiently well-functioning feedback loop between the regions and the National Board of Health and Welfare to detect deficiencies in reporting. This makes national analyses more difficult. For register-based research to be reliable, continuous updating and quality assurance of reporting is required.

Conclusion

The studies within this project indicate that the condition PANS likely has a similar prevalence as North American studies have suggested, around 0.6‰.

If this is true, there is significant underdiagnosis in almost all Swedish regions. Hundreds children in Sweden are, based on the prevalence in Östergötland County, affected by PANS without having been identified. The results tentatively point to significant regional differences. This is probably due to differences in knowledge dissemination and differences in access to specialized care, rather than an actual regional variation in disease prevalence.

The reliability of the diagnostic code F068 is very high in the Östergötland region, making the code useful in register-based research.

For the future, it is important to:

- reduce underdiagnosis and "doctor's delay", for example through educational initiatives
- expand the number of specialized multidisciplinary teams
- alternatively try a model for national highly specialized care
- ensure uniform coding nationally and preferably in the Nordic countries
- maintain a high level of data quality in the Patient Data Register through consistent reporting from healthcare units
- pending ICD-11 in ICD-10 it is proposed to use F068 for PANS, additional code B94.8 in PANDAS and to additionally code for symptom manifestations
- prior to the introduction of ICD-11, discuss the possibility of a specific additional code for PANS in relevant specialty associations • in addition, for increased precision in research, the possibility of coding for PANDAS, as well as for suspected/unspecified immunopsychiatric manifestations

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