

Evaluating the Economic Impact of PANS/PANDAS in the UK

Archie Bhattacharyya, Magdalena Walbaum

Care Policy and Evaluation Center (CPEC), The London School of Economics and Political Science (LSE)

Summary

- There are significant costs to the health and social care sector of UK associated with the lack of diagnosis and treatment for PANS and PANDAS
- Families carried a substantial financial burden as most caregivers opted to go for private medical care, which was further compounded as caregivers were forced to reduce hours of work or leave employment altogether to care for the child.
- There is considerable disagreement among medical professionals about the appropriate forms of treatment, along with a lack of awareness, leading to delays in getting adequate medical and social support.

Introduction

- Pediatric acute-onset neuropsychiatric syndrome (PANS) and pediatric autoimmune neuropsychiatric disorder associated with streptococcal infections (PANDAS) are often mistaken as other psychiatric conditions, leading to delays in diagnosis and treatment (O’Dor et al., 2022).
- Lack of awareness about the conditions creates a persisting barrier to access care through the NHS, and caregivers often have to visit multiple professionals for a diagnosis. Diagnosis and treatment delays also push families to seek private care, and this leads to significant resource utilisation within the health and social care sector of the UK.

Objectives

- To understand the economic impact of PANS and PANDAS within the UK by exploring direct and indirect resource utilisation across the health and social care sector

Methods

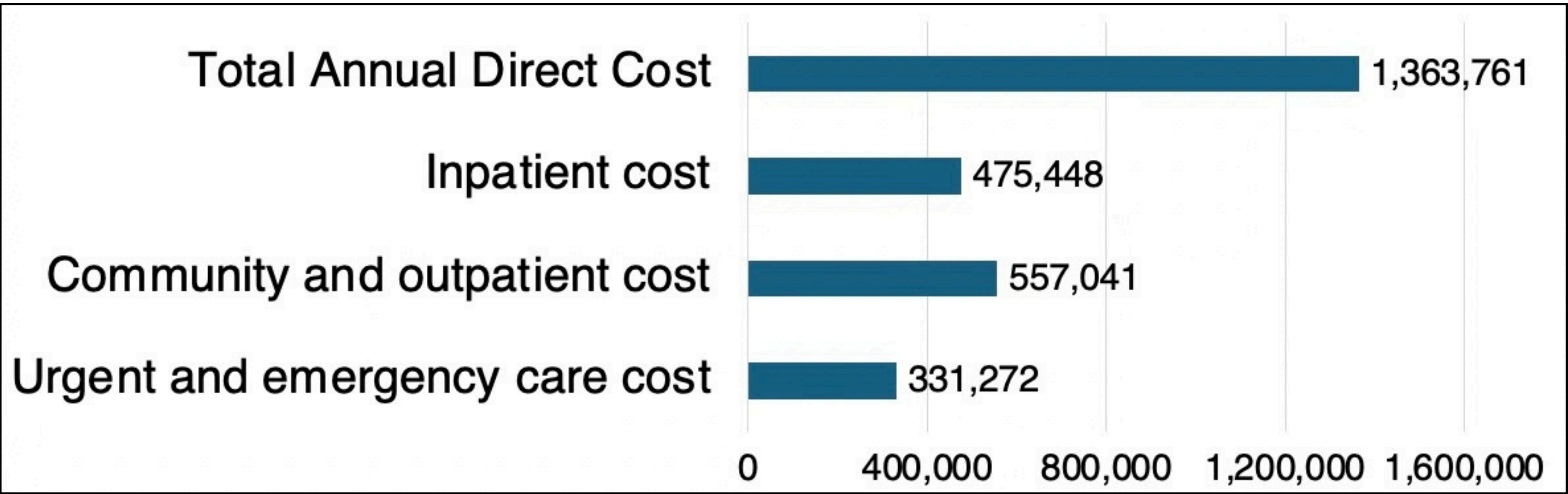
- Secondary survey data collected by PANS and PANDAS UK in collaboration with the University of Exeter was used for this study. Unit costs were estimated using the Health and Social Care 2025 manual (Jones, 2026). Descriptive analysis was conducted using Stata to summarise the distribution of resource usage, including urgent care costs, community care costs and symptom management. One outlier was identified, with a yearlong inpatient stay and sensitivity analyses was conducted by excluding this case, which reduced the direct care cost by 24.1%.

Bibliography

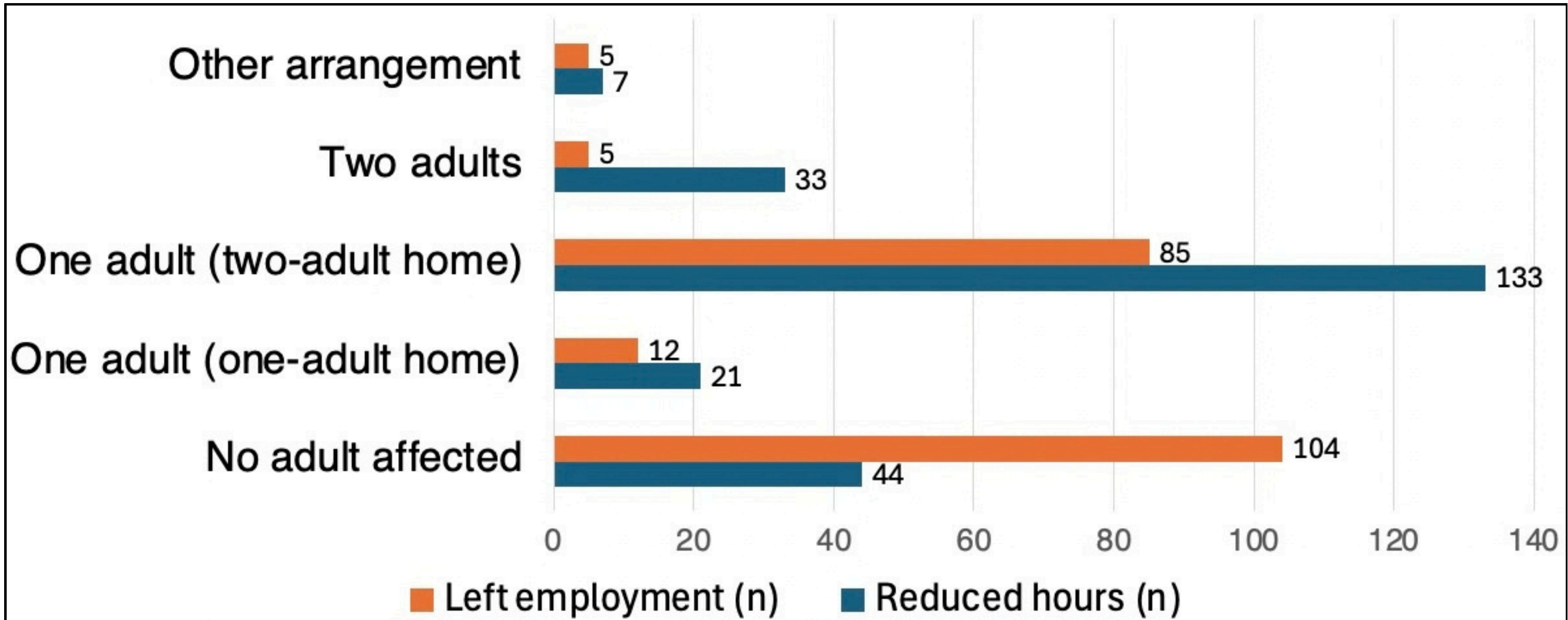
- Jones, Karen C. and Weatherly, Helen and Barker, Amy and Birch, Sarah and Castelli, Adriana and Dargan, Alan and Findlay, Douglas and Hinde, Seb and Markham, Sarah and Smith, Deborah and Teo, Hansel (2026) Unit Costs of Health and Social Care 2025 Manual. Technical report. Personal Social Services Research Unit (University of Kent) & Centre for Health Economics (University of York), Kent, UK [10.22024/UniKent/01.02.115569](https://doi.org/10.22024/UniKent/01.02.115569). (doi:10.22024/UniKent/01.02.115569)
- O’Dor, S. L., Homayoun, S., Downer, O. M., Hamel, M. A., Zagaroli, J. S., & Williams, K. A. (2022). A Survey of Demographics, Symptom Course, Family History, and Barriers to Treatment in Children with Pediatric Acute-Onset Neuropsychiatric Disorders and Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections. Journal of Child and Adolescent Psychopharmacology, 32(9), 476–487. <https://doi.org/10.1089/cap.2022.0063>

Results

- Data was analysed from 411 caregivers of children with suspected/diagnosed PANS and PANDAS. The median age of onset was 7 years (IQR 4-10). For 75.2% (n=309) of the children, symptoms were severe at their worst. Children were primarily diagnosed by private medical professionals (n = 194), with only 6 % receiving a diagnosis through the NHS (n = 25). 287 caregivers reported delays in treatment and 167 went without any treatment for more than a year.



Annual Direct Cost by Component



Impact on Employment

Outcome	Treated within 1 year	More than 1 year untreated	p
At least one adult reduced working hours	64/81 (79.0%)	92/113 (81.4%)	0.82
At least one adult left employment	32/71 (45.1%)	54/103 (52.4%)	0.42
Household financial loss ≥£20,000	44/94 (46.8%)	69/133 (51.9%)	0.54
Household financial loss >£100,000	11/94 (11.7%)	19/133 (14.3%)	0.71
Private medical spend ≥£10,000	29/86 (33.7%)	40/128 (31.2%)	0.82
Annual direct cost, median (IQR)	£1,008 (£0–£3,580)	£1,026 (£247–£2,919)	0.56

Comparison of Financial Impact

- Financial impact did not differ between families whose child began treatment within a year of symptom onset and those who waited longer (financial loss ≥£20,000: 51.9% vs 46.8%, p=0.54; median annual direct cost £1,026 vs £1,008, p=0.56).
- 66% of all annual direct costs were borne by 10% of the participants.

Limitations

- The evidence is based on a predominantly White, English population, which reduces the generalisability of the results.
- High direct costs are concentrated within 10% of the respondents, so estimations of per person resource usage are likely to be skewed.