PANS PANDAS UK

Steven Malcherczyk
Rising Researchers

PERSPECTIVES ON PANS

Jo Joyner and Gareth Costello



In memory of Steven Malcherczyk

This session is generously supported by

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Caregiver Burden in PANS/PANDAS: The Role of Family Accommodation, Symptom Severity and Flare Status

Riann Alexander & Sharon Morein

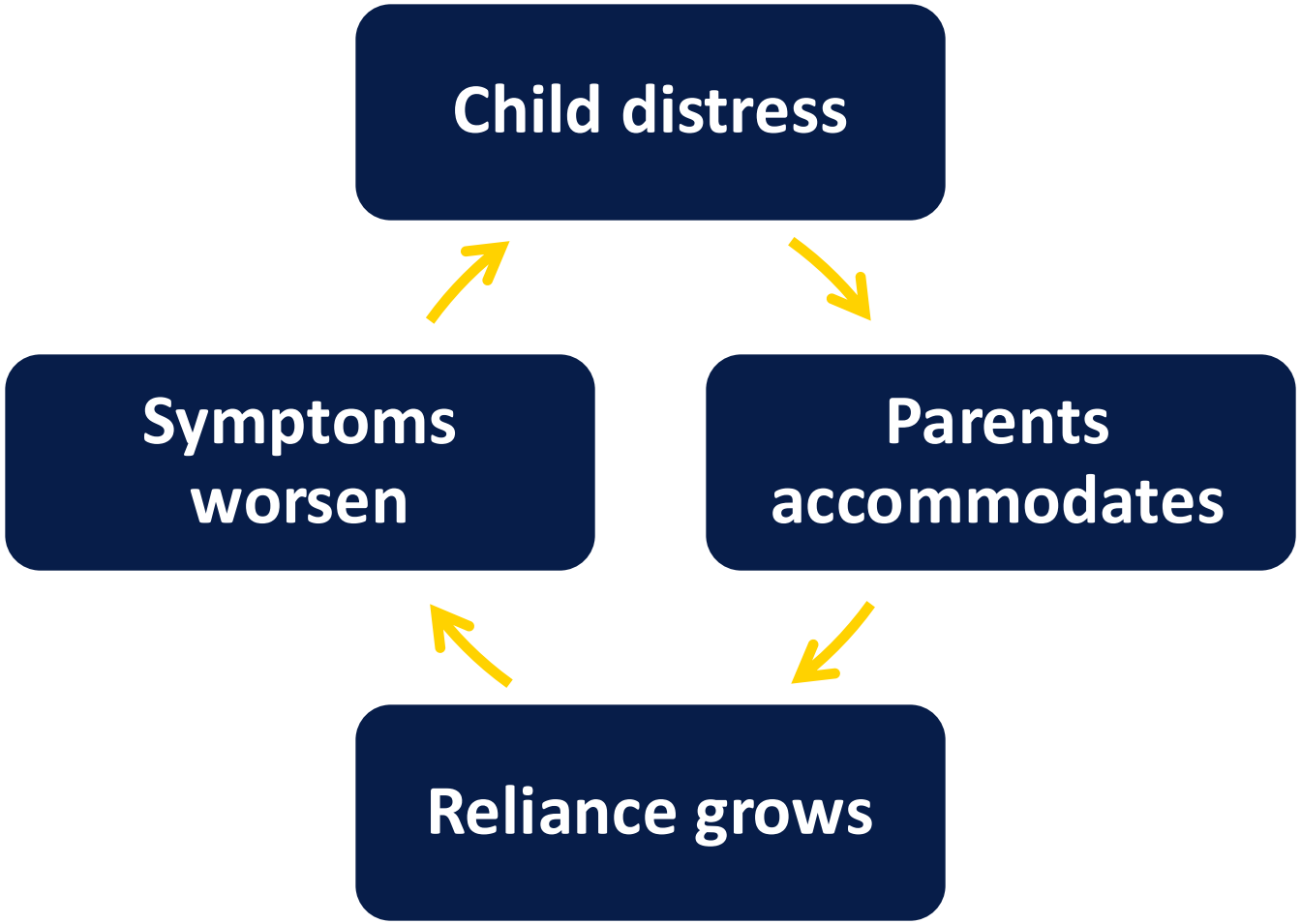
Anglia Ruskin University

“One day you will tell your story of how you overcame what you went through, and it will be someone else’s survival guide.”

Brené Brown

Family accommodation

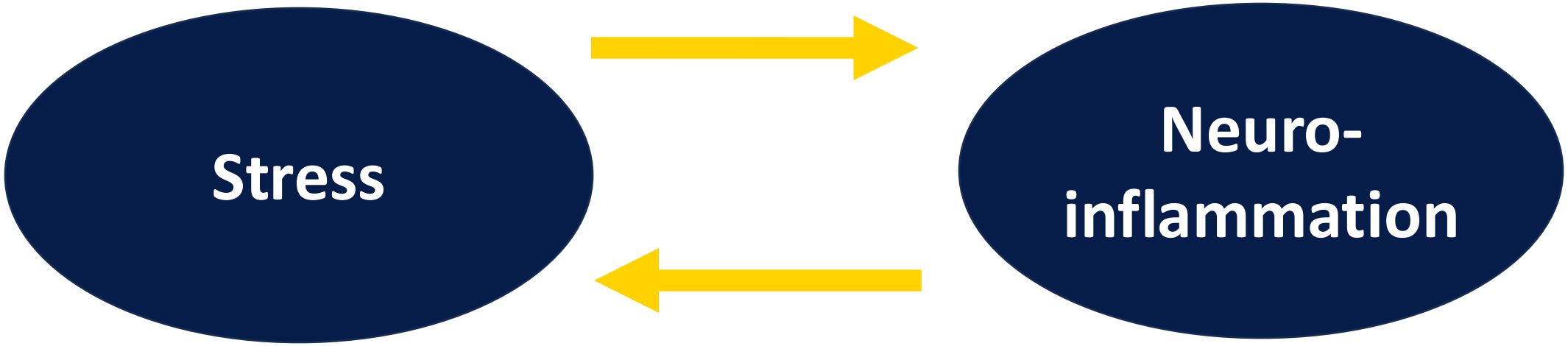
& the negative reinforcement cycle *(Lebowitz et al., 2012)*



↻ repeats and the child does not learn their own resilience.

What's different in PANS/PANDAS

Stress has been linked to worsening inflammation in the wider literature (Calcia et al., 2016)



PANS/PANDAS is understood to involve neuroinflammation. It is not just learnt behaviour.

The clinical landscape is complex and diagnosis can be controversial, adding an extra layer of burden for caregivers.

What we did

N = 120

parents/caregivers, UK online survey

recruited via PANS/PANDAS networks (e.g., PANS PANDAS UK FB support group)

Symptom Severity

measured by Symptom Rating Scale (PANS-31)

(Bernstein et al., 2024)

Family accommodation

measured by Family Accommodation Scale for Anxiety (FASA)

(Lebowitz et al., 2013)

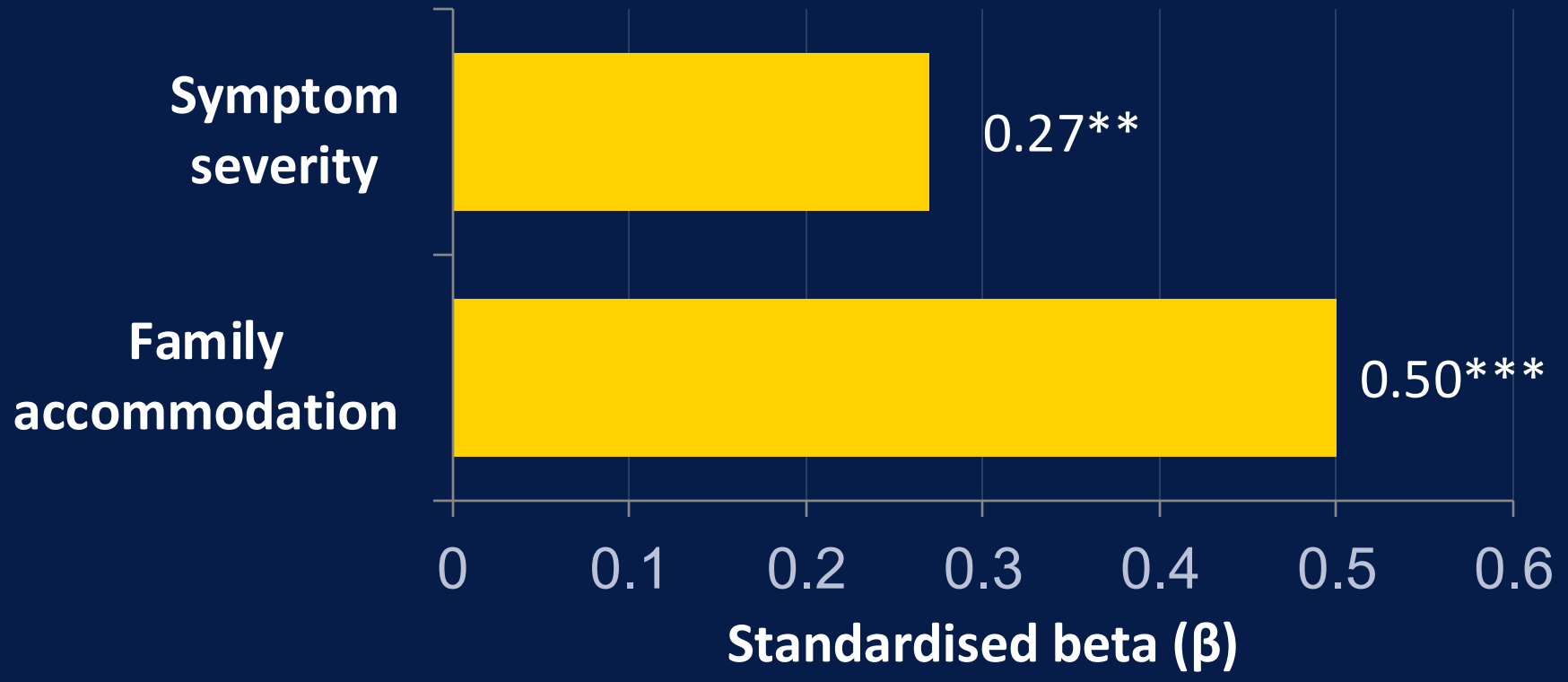
Caregiver burden

measured by Zarit Burden Interview (ZBI)

(Zarit et al., 1980)

What we found

Accommodation showed the strongest association

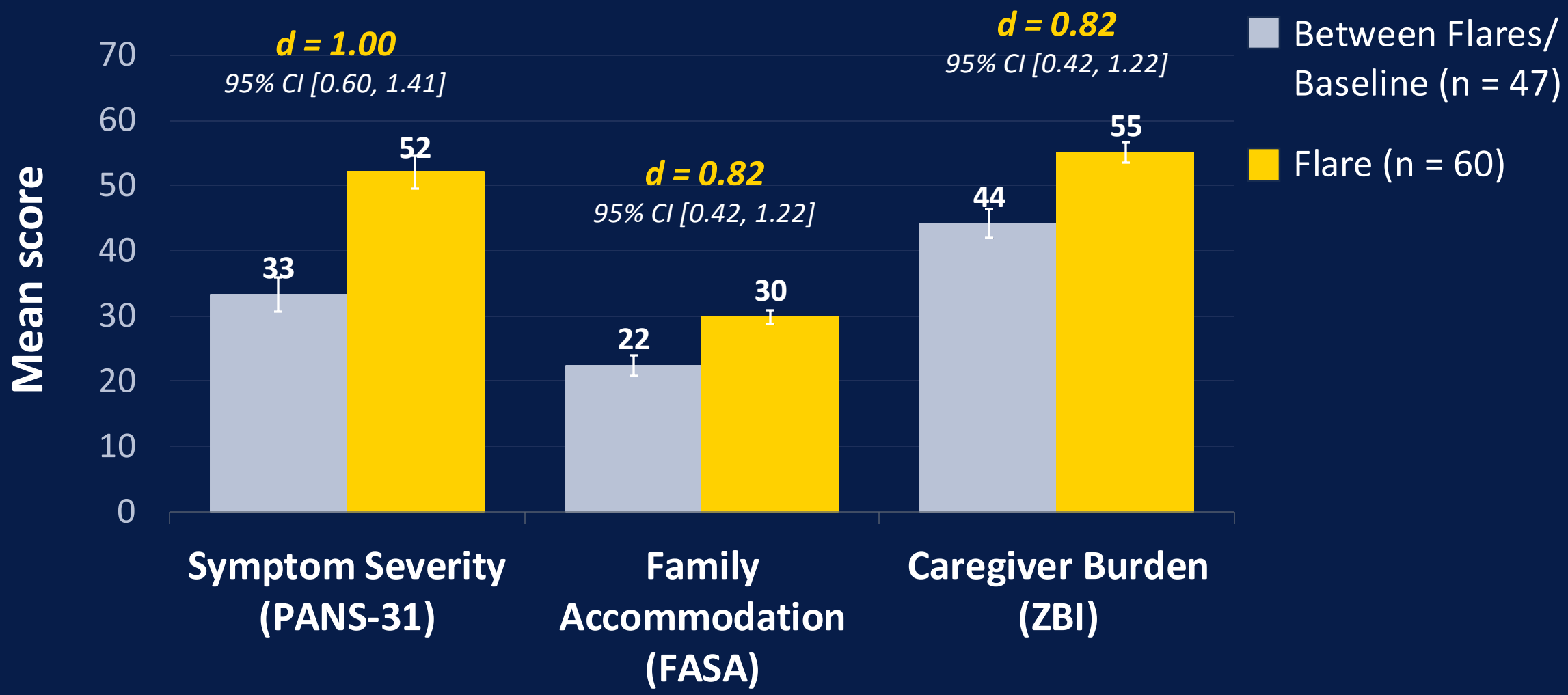


**p < .01, ***p < .001

$R = .68$, $R^2 = .46$, $F(2, 117) = 50.82$, $p < .001$

What changes in a flare

Flares mark a distinct period of heightened vulnerability



Why this matters

No clear guidance for families

Accommodation: a modifiable target

Timing must be built into support

I hope this research can help guide better support for families.

Thank you

Full findings in preparation for peer-reviewed publication • Contact: riann.alexander@aru.ac.uk

Economic Impact of PANS and PANDAS in the UK

Presented By: Archie Bhattacharyya

Introduction

- PANS and PANDAS are often mistaken for other psychiatric conditions and a lack of awareness creates persistent barriers to accessing care through the NHS for affected children.
- Due to significant delays in diagnosis and treatment, families are often forced to go for private medical care and visit multiple healthcare professionals, leading to high economic costs for the health and social care sector in the UK.

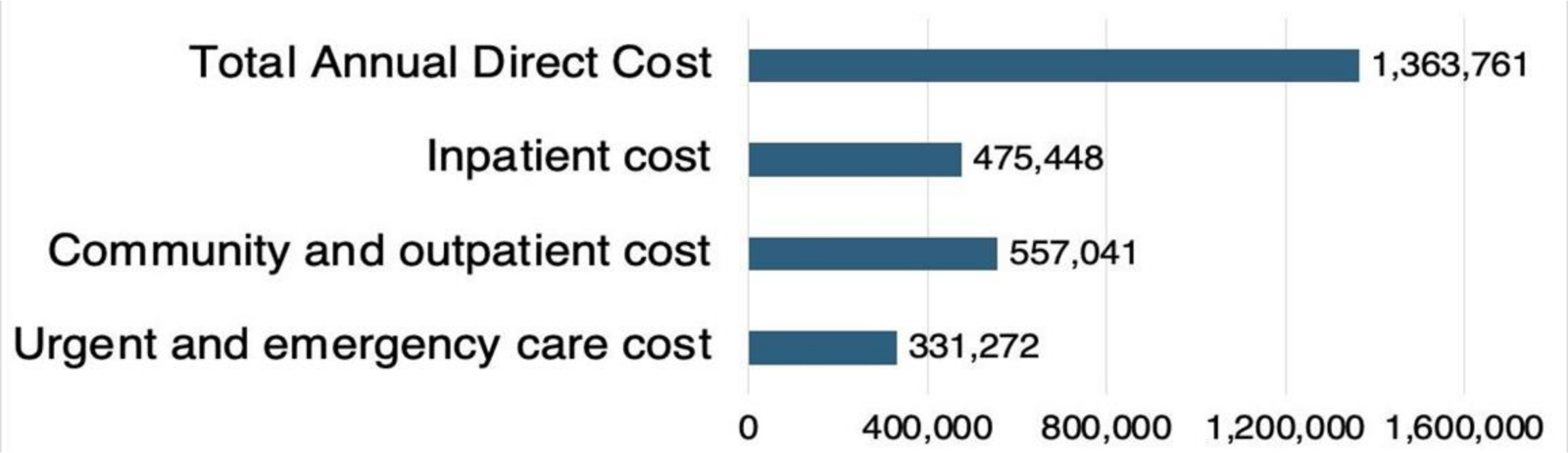
Methods

- Secondary survey data was used for this study and unit costs for each resource utilised was estimated using the Health and Social Care 2025 manual (Jones, 2026).
- Stata was used to conduct descriptive analysis to summarise the distribution of resource usage, including urgent care costs, community care costs and symptom management costs.
- One outlier with a yearlong inpatient stay was identified, and sensitivity analysis was conducted excluding this case, which reduced direct care costs by 24.1%

Results

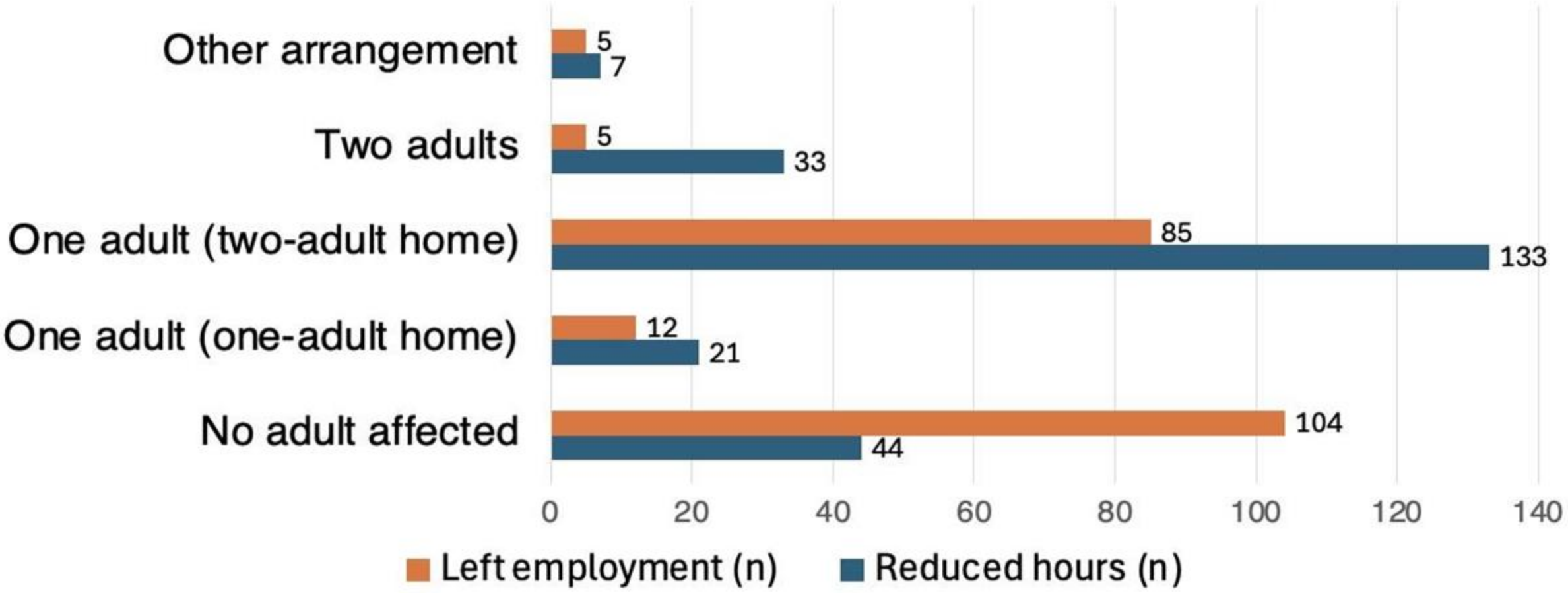
- The median age of onset was 7 years (IQR 4-10). For 309/411 of the children, symptoms were severe at their worst. Children were primarily diagnosed by private medical professionals (n = 194).
- 287 caregivers reported delays in treatment and 167 went without any treatment for more than a year.

Annual Direct Cost of PANS and PANDAS



- Financial impact did not differ between families whose child began treatment within a year of symptom onset and those who waited longer (median annual direct cost £1,026 vs £1,008, p=0.56).

Impact on Employment



Limitations

- The evidence from this study 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.

THANK YOU !

Research in progress…

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Exploring Parents' and Carers Experiences of the Diagnostic Journey and Psychosocial Impact of Caring for a Child with PANS/PANDAS in the UK.

Tia Chahal
Doctorate in Clinical Psychology, University of Leeds
Supervised by Dr David Turgoose and Dr Nicolo Zarotti

The Study:

- 12 participants: 11 mothers & 1 father (data collection now complete)
- Semi-structured interviews via Microsoft Teams
- Thematic Anlalysis (Braun & Clarke, 2006) for accessibility
- Data analysis underway

Psychological Frameworks:

a) Epistemic Injustice (Fricker, 2007)

b) Transactional Model of Stress and Coping (Lazarus & Folkman, 1984)

Being Disbelieved and Unheard:

“But then everybody was telling us there was nothing wrong. So you have nowhere to go at all.”

“I've had basically my oldest friends say, you're making it up, basically. There's nothing wrong with him.”

Epistemic Injustice (Fricker, 2007) : exploring whose knowledge is recognised

Please note these are provisional findings

Daily Strain, Validation and Connection:

"Every day is survival, surviving."

- Diagnosis: offers validation, relief, alongside guilt
- Peer Support: Facebook groups and speaking with other parents helpful
- Uncertainty, Anxiety
- Grief & a sense of loss
- Trauma remains an area for further exploration

Transactional Model of Stress and Coping (Lazarus & Folkman, 1984): how do parents/carers understand the demands and what resources are available to cope?

Please note these are provisional findings

What early accounts suggest:

- Being heard, listened to and validated matters, alongside the search for diagnosis
- Possible implications for NHS professionals e.g. listening, communicating uncertainty and supporting parents
- Highlight need for support for parents/carers!
- Interpretation is ongoing…
- **Next Step:** Refine themes across the full dataset, write up, pass, publish!

Please note these are provisional findings

Thank You!

Clinical symptom profiles in PANS: Differences by age group and family history from the PPUK Lived Experience Survey



Hayley Gilfillan

University of Dundee



Megan Parks

University of BRISTOL

Introduction and Methods

What was the purpose of our research?

- The clinical presentation of PANS and PANDAS can vary considerably between children
- This can make recognition and diagnosis challenging.
- However, UK-specific data on symptom profiles remain limited.

Aim: To characterise the symptom profiles of children with PANS and PANDAS in the UK.

How did we carry out our research?

Data source: "Speak Up: A national survey for PANS and PANDAS" by PANS PANDAS UK

Survey respondents:

422 parents/ carers

7 young adults

Survey question example:

Which of the following symptoms has your child or young person experienced since onset?

Data analysis:

Descriptive statistics and categorical analysis

Results and Discussion

1 PANS symptom prevelance

- **Most common symptoms since onset:** anxiety (90%), OCD (83%) and emotional lability (82%)
- **Most common obsessions since onset:** Perfectionism (54%) and contamination (51%) obsessions
- **Most common compulsions since onset:** Repeating (56%) and mental (57%) compulsions

2 Differences by age group

More common in younger onset (≤7 years)	More common in older onset (≥8 years)
Enuresis/ urinary frequency	Depression
	OCD
	Contamination obsessions
	Checking compulsions

3 Differences by family history

Children with a family history of…	We're more likely to experience…
Neurological condition	Vocal tics, intrusive thoughts, aggression, motor abnormalities
Psychiatric condition	Anxiety, emotional lability, depression, irritability, insomnia
Autoimmune condition	Depression, irritability, mental compulsions
Inflammatory condition	Perfectionism-related and mental compulsions

Results and Discussion

Strengths

- One of the **largest UK-specific lived-experience surveys** in PANS/PANDAS to date
- National **geographic representation**

Limitations

- **Recall bias**
- Predominantly White British sample (85.9%) limits **generalisability**
- Diagnostic **heterogeneity**
- No non-PANS **comparison group**

Clinical Implications

- Supports **age-tailored** and **history-informed** clinical recognition
- Age-atypical presentations **should not be used to rule PANS in or out**

Conclusion



Future directions

- Explore "Other" free-text responses
- Structured diagnostic assessment
- Longitudinal follow-up
- Test predictive value of family history and comorbidity for symptom trajectory and treatment response

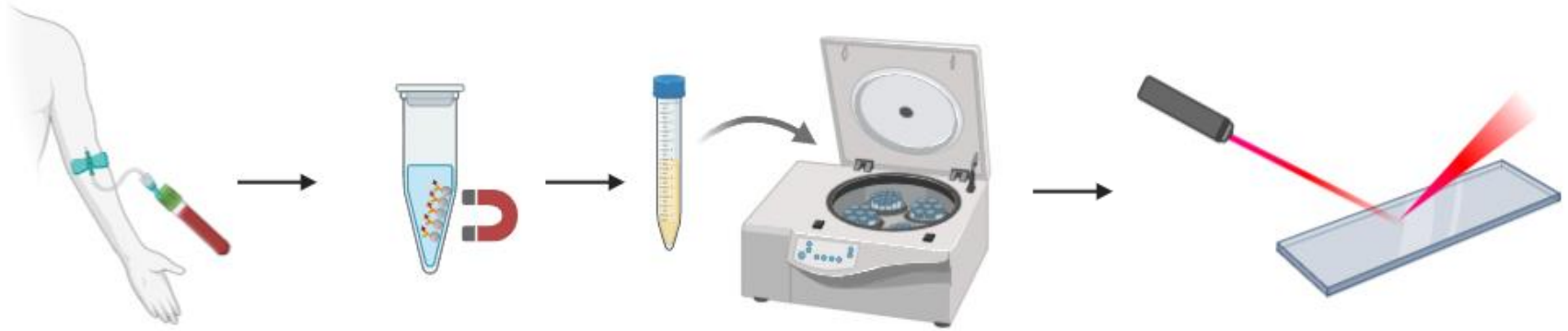
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Investigating abnormal immune responses in post-infection conditions using Raman microscopy

Maisy Higgs,
NDWRH, Reuben College, University of Oxford

Methodology

- Negative selection
  - Confirmation of the effectiveness of negative selection kits for immune cell isolation



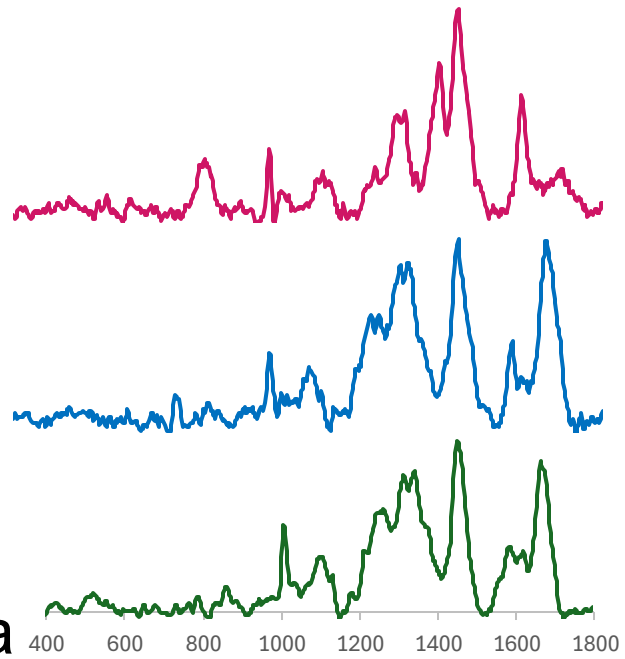
- Single spectra were acquired for each cell with an integration time of 0.5s and 10 accumulations with a 532nm laser

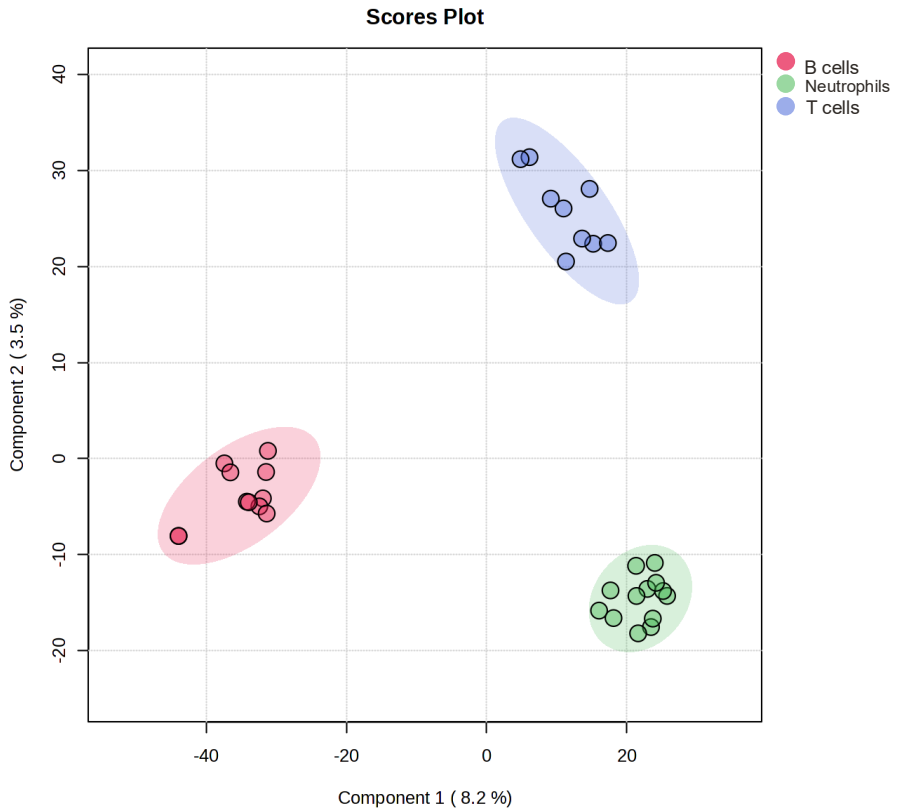
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Successful separation of immune cell spectra

- PLS-DA was able to differentiate healthy immune cell types with an $R^2 = 0.87$ and $Q^2 = 0.62$
- 830–850 cm^{-1} repeatedly appears as a high-VIP region in the B cell spectra





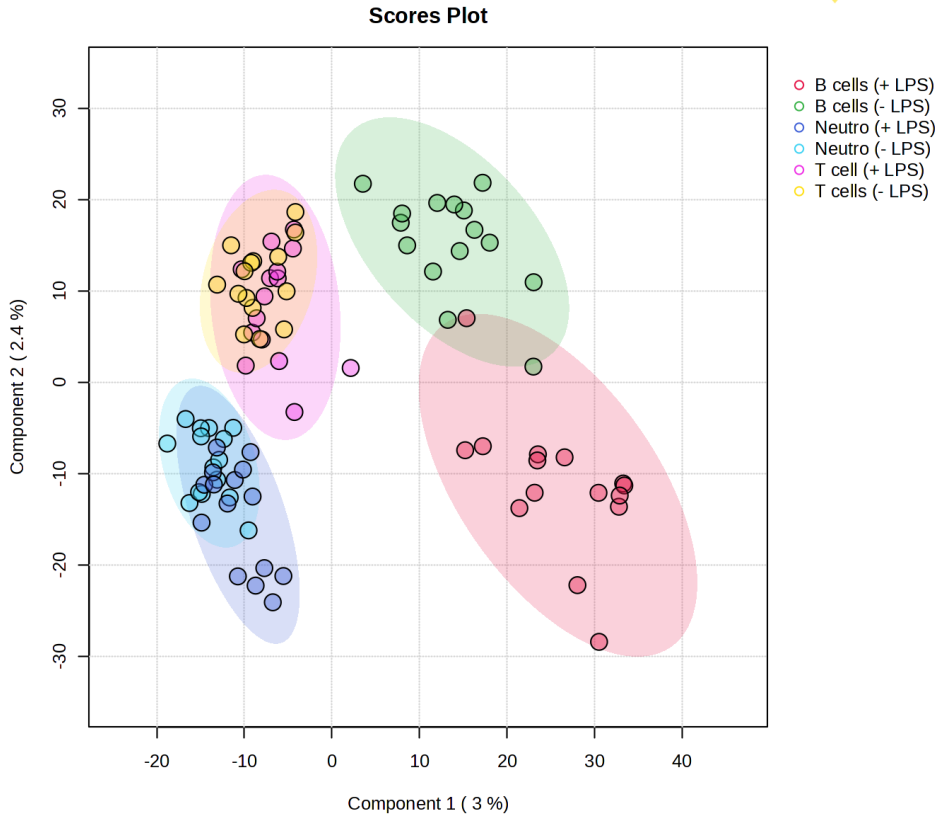
Data associated with B cells (pink), Neutrophils (green) and T cells (blue). (a) Average fingerprint regions (400-1800 cm^{-1}) of each blood cell type. (b) PLS-DA 2D Scores Plot (created using MetaboAnalyst.com).

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B cell spectra differences when stimulated with LPS

- LPS-associated spectral changes were detected in all cell types, but separation was only achieved with B cell spectra
- Additional data needed to develop these findings ($R^2 = 0.58$, $Q^2 = 0.35$)



PLS-DA 2D Scores Plot of LPS treated and untreated immune cells. Cells were kept in RPMI medium for 3 hours, with the treated cells in media at a concentration of 2 µL/mL of LPS (created using MetaboAnalyst.com)

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Conclusions and future directions

- Raman microscopy can distinguish immune-cell populations.
- Longitudinal spectral profiling could reveal immune changes associated with PANS symptom flares
- Larger datasets are now needed to validate and develop this approach

Acknowledgements
Professor Karl Morten and Dr Isabela Pedroza-Pacheco

Thank you for listening

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Increasing Paediatric Acute-Onset Neuropsychiatric Syndrome/ Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANS/PANDAS) Awareness in the UK

PANS/PANDAS UK Conference

8th October 2026

PANS PANDAS UK

University of Dundee

Introduction

PANS is characterised by the abrupt onset of OCD symptoms, tics or eating restrictions, alongside at least two additional neuropsychiatric symptoms such as:

- Anxiety
- Emotional lability
- Irritability or aggression
- Enuresis

PANDAS is a *subset* of PANS infections, specifically linked to Group A streptococcal infections

Why Recognise It?

- Whilst the categorisation and pathophysiology of the conditions require *further elucidation*,
- PANS/PANDAS UK's **"Speak Up" National Survey** explored the struggles of patients with PANS/PANDAS
- PANS/PANDAS have a long-term and significant impact on patient's lives and permeates into:
  - their social and family life,
  - education,
  - Physical and mental health
- As healthcare professionals, we have a **duty** to improve awareness of these conditions for the betterment of the affected children

Data Collection

1

The **Speak Up Survey** was created by PANS/PANDAS UK and refined with the help of a group of healthcare students to formulae the questions to get to the crux of each question.

2

The Survey was shared onto the PANS/PANDAS Social Media sites and Community Group Chats to increase engagement. A total of **429 respondents** completed the Survey.

3

I carried out 2 1-hour group discussions with **parents and guardians** of children with PANS/PANDAS to better understand the familial, social and educational impact of these conditions.

4

I carried out 2 interviews with children from the Youth Board Group with PANS/PANDAS to familiarise myself with the message that they wanted to share and put the **patient voice** at the centre.

What Does the Data Show?

92% of parents report that symptoms were "*at their worst*" during the initial onset of PANS/PANDAS

51% of parents report that behavioural regression was the initial trigger for seeking medical support

75% of parents report that the clinician suspected a **streptococcal infection** as the trigger

88% of parents report that their child has talked about harming or killing themselves

PANS/PANDAS Diagnosis

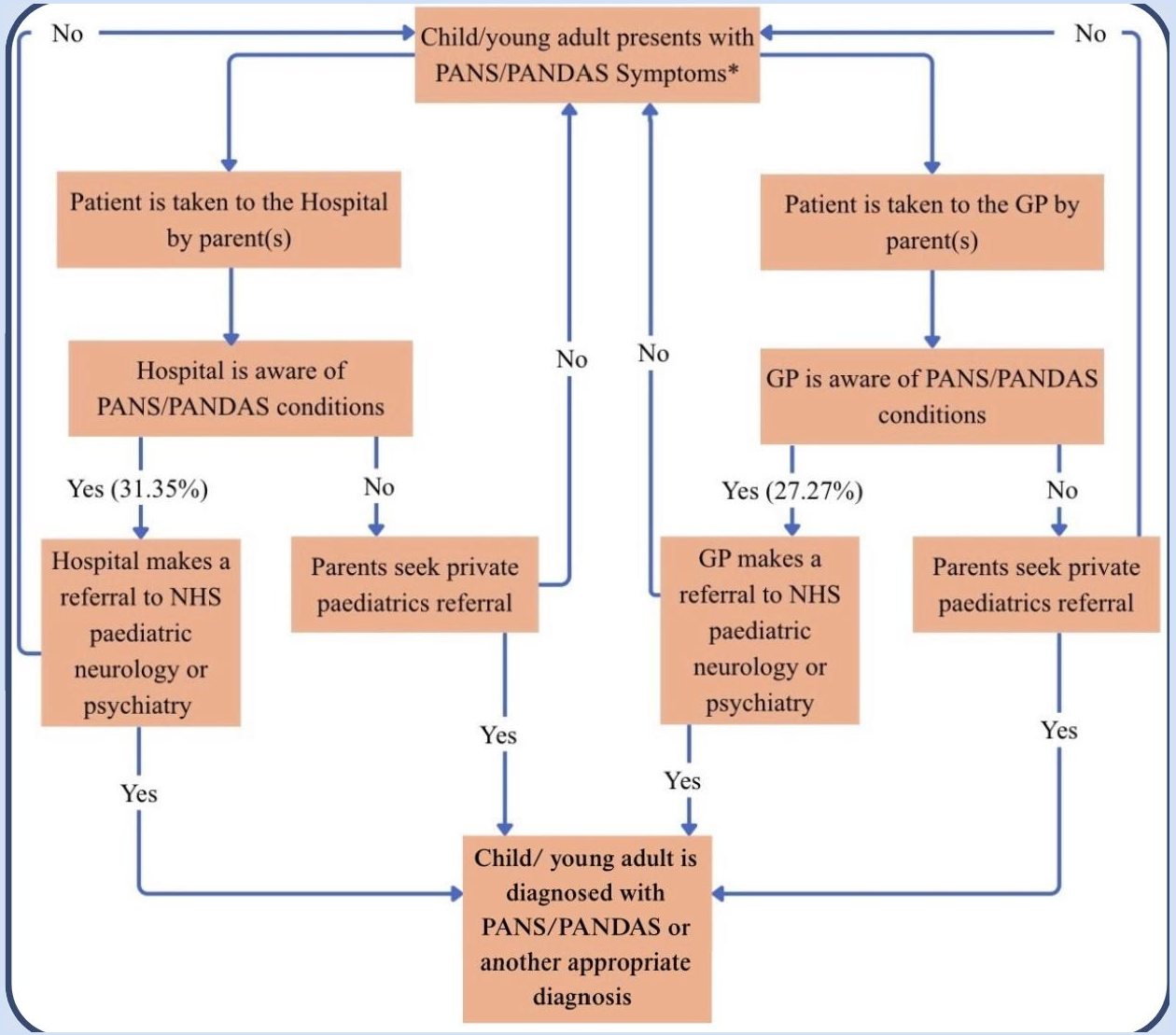


Figure 3: Diagnostic Process Map

- The **most common symptoms** identified from the survey included:
  - Anxiety (**90%)**
  - OCD (**83%)**
  - Emotional lability (**82%)**
- **63%** of parents reported that their GP did not undertake *any* tests
- **67%** of parents reported that their child had a formal diagnosis of PANS/PANDAS from a **private** healthcare professional
  - Only **15%** received a diagnosis from an **NHS** healthcare professional

PANS/PANDAS Management

- The ISCA Evidence research team is a, **NIHR-commissioned**, University-of-Exeter based group, gathering the most up-to-date evidence via the “PANS/PANDAS Unveiled Project”
- **Current** treatments include:

1. Antibiotics
2. Intravenous Immunoglobulin Therapy (IVIG)
3. Therapeutic Plasma Exchange (TPE)

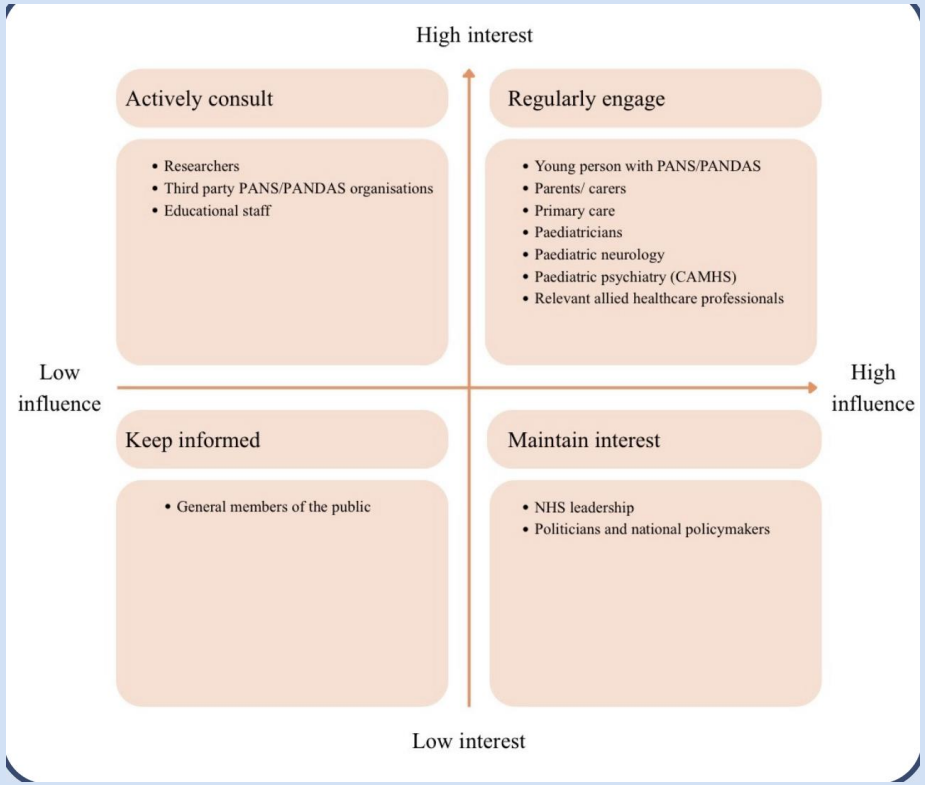


Figure 4: Stakeholder Matrix

What Can Clinicians Do?

Consider

- Approach your patient with a **holistic** approach

Discern

- Think ***"could this be PANS/PANDAS?"***
- If so, what evidence can I use to include or exclude this diagnosis?

Advocate

- Put your patient at the **centre** of the challenge posed
- Advocate for your patient so that they receive the treatment they need to thrive

Take Home Messages

- PANS/PANDAS conditions have significant negative impacts on patients both in the **personal and community setting**
- Patients want to be **listened to and acknowledged**
- Research is ongoing and *continuously* evolving
  - We should be **ready** to put the correct pathways into place once we are more robustly supported by the new guidelines
- You are a stronger voice for change than you think- use it!

Thank you!

Steven Malcherczyk

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