Themed Session 2
Management

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Chair: Professor Ming Lim

Management and Care

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Management/Care for a child/young person with PANS

Who needs to be involved?

How do they best work together?

Complex PANS presentations require multidisciplinary care

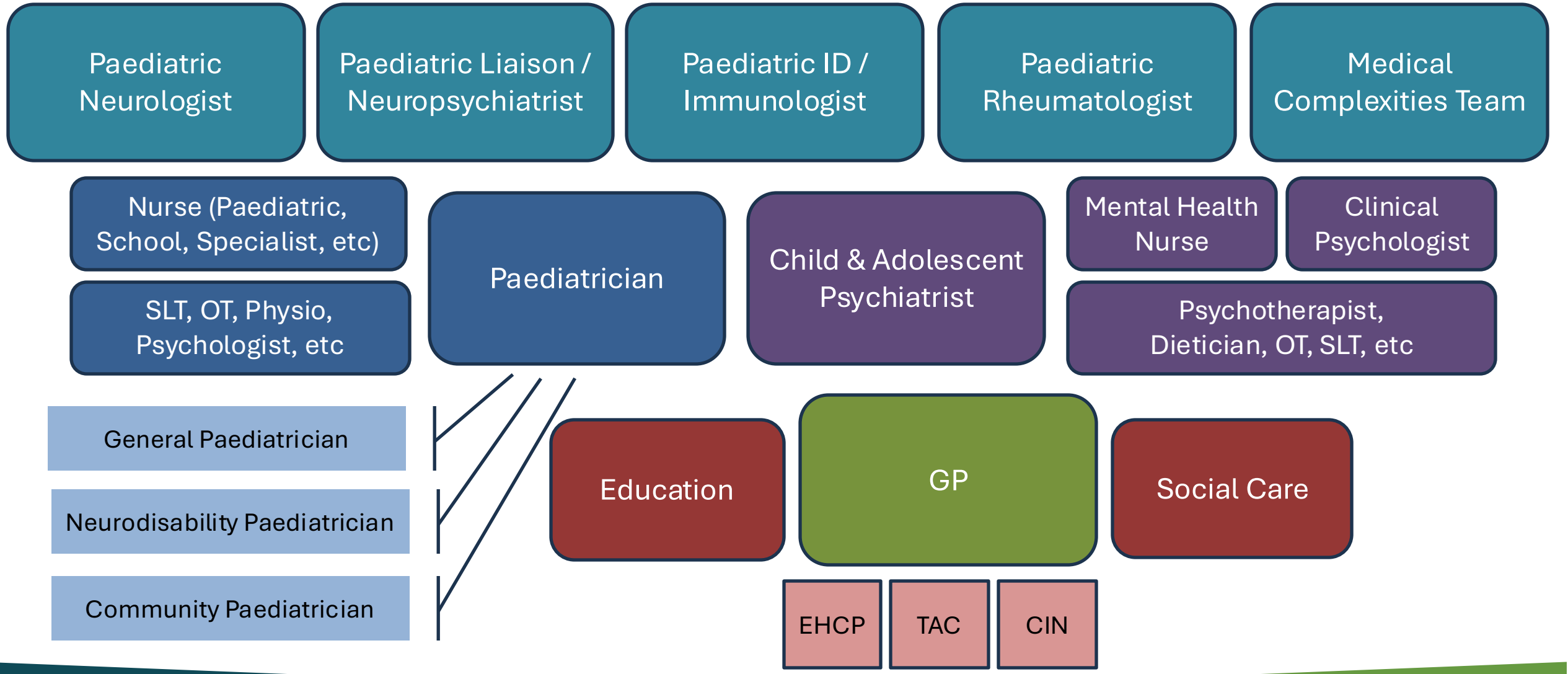
Current centers of excellence

- Stanford (Frankovich et al, 2015)
- Karolinska Institutet (Gromark et al, 2019)

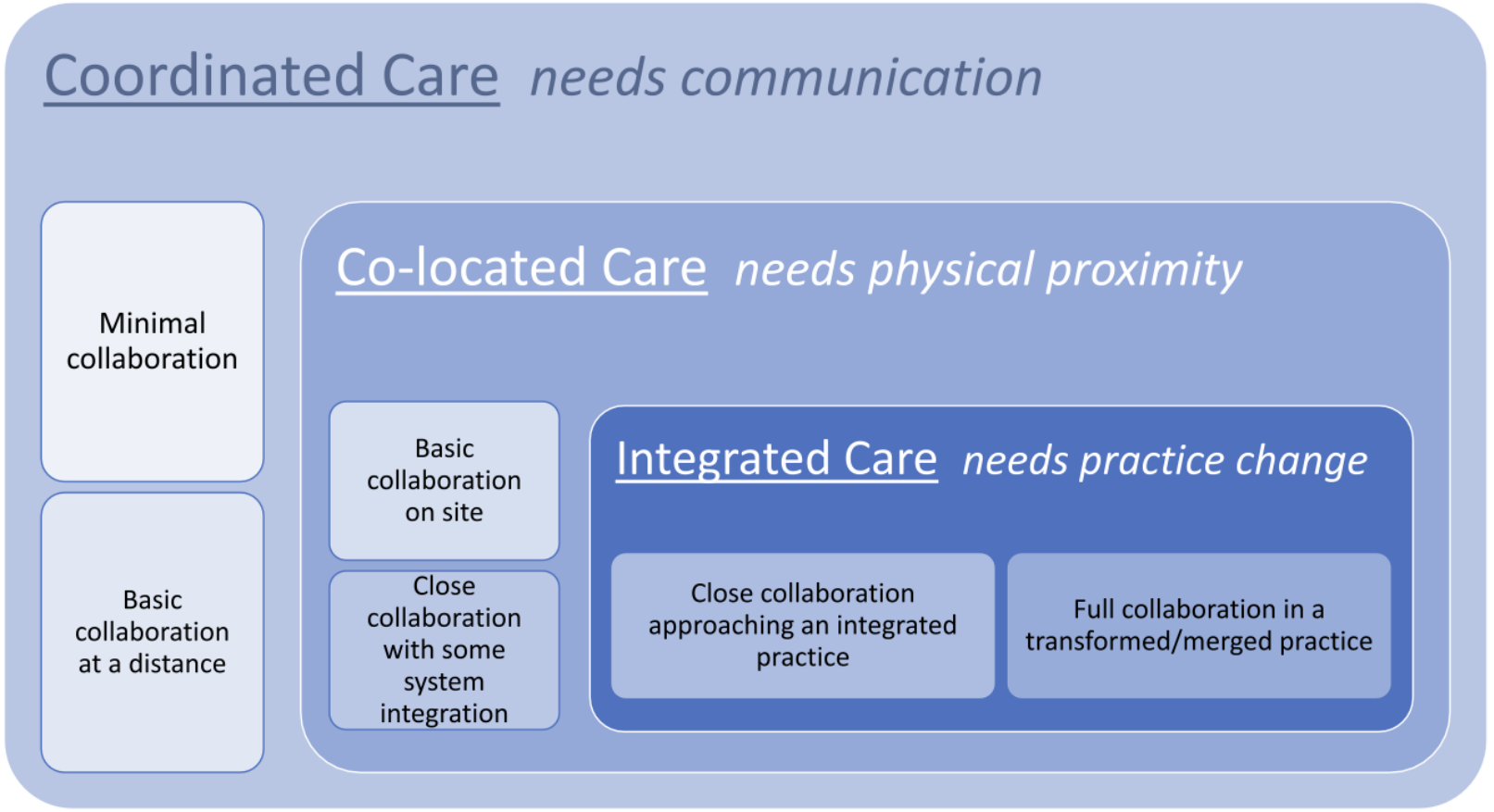
As recommended by international guidelines

- PANS Research Consortium (Frankovich et al, 2019)
- Nordic Guidelines (Pfeiffer et al, 2021)

Possible members of a multidisciplinary care network in the UK



Models of multidisciplinary care



Fazel, M., et al. (2021) Integrated care to address child and adolescent health in the 21st century: A clinical review. *JCPP Advances*. 1 (4), e12045.

Examples of integrated multidisciplinary care in the UK

Which informs a complex clinical formulation to help guide treatment, and shared decision-making

- Paediatric Neurosciences @ Evelina London Children's Hospital
- Rare genetic disorder clinics eg. Tuberous Sclerosis

Which guides decisions on complex and scarce treatments, and sets national standards

- Children's Epilepsy Surgery Service (CESS)
- Spinal Muscular Atrophy clinical network

Which provides holistic care with integrated biopsychosocial treatments

- Treatment and rehabilitation of adolescents and children with complex conditions service (TRACCS) @ University College London Hospital
- Post-Covid Service

Future of integrated multidisciplinary care in England







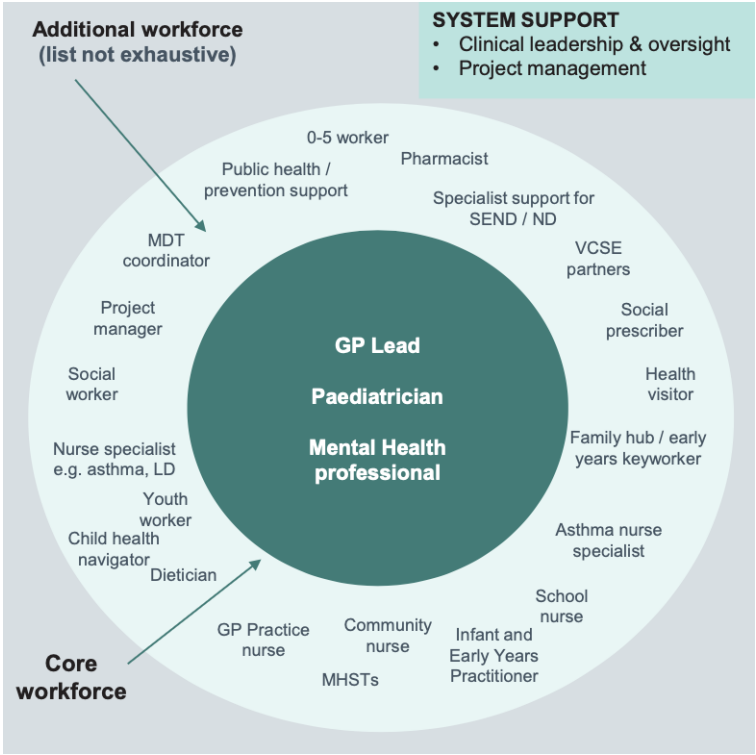


Future of integrated multidisciplinary care in England

NHS England

Guidance on neighbourhood multidisciplinary teams for children and young people

- Earlier identification of health needs
- Earlier access to appropriate interventions
- Reduce fragmentation across agencies
- Address inequalities in access and outcomes



Summary

Treatment of PANS is best coordinated by a multidisciplinary and multiagency care network

There are multiple UK models of integrated multidisciplinary care across children's neurosciences which serve as exemplars for a PANS treatment service / network

Integrated multidisciplinary care:

- Informs a complex clinical formulation to guide treatment and shared decision-making
- Guides decisions on complex and scarce treatments, and sets national standards
- Provides holistic care with integrated biopsychosocial treatments

Future funded models of integrated neighborhood MDTs hold promise for earlier and more accessible PANS care and treatments

Treatment of acute cases

Professor Rajat Gupta
Consultant Paediatric Neurologist
Birmingham Children's Hospital

CORE THERAPEUTIC MODEL

The Three-Pronged Acute Strategy

1. Antimicrobials

Eradicate underlying bacterial infectious triggers immediately upon presentation.

2. Immunomodulation

Control post-infectious neuroinflammation with NSAIDs, steroids, *(IVIG, or plasmapheresis).*

3. Symptomatic Relief

De-escalate severe OCD, anxiety, and distress via CBT and other behavioural therapies, low-dose psychotropics, and support.

PHASE 1 • INFECTION ERADICATION

First-Line Acute Treatment

Empiric Antimicrobial Initiation

- **Immediate Start:** Treat upon clinical suspicion; do not delay for culture results.
- **PANDAS First-Line:** Beta-lactams (Amoxicillin / Augmentin, Penicillin V, or Cefaclor).
- **Macrolide Options:** Azithromycin or Clarithromycin for penicillin-allergic patients.
- **Duration:** Standard 10–14 day acute therapeutic course.

Early Anti-Inflammatory Support

- **NSAID Trial:** Ibuprofen or Naproxen to reduce mild-to-moderate neuroinflammation.
- **Antihistamines:** If allergy trigger suspected

SEVERITY-BASED ESCALATION

Immunomodulatory Stepped Ladder

TIER 1 • MILD

NSAIDs & CBT

Ibuprofen or Naproxen trial combined with psychoeducation and supportive behavioral therapy.

TIER 2 • MODERATE

Steroid Burst

5-day oral Prednisolone (1-2mg/kg) burst to rapidly halt/reduce neuroinflammatory cascade.

TIER 3 • SEVERE

High-Dose IVIG

Immunomodulatory dose (1.5–2.0 g/kg split over 2 days) for severe OCD, anorexia, or disability.

TIER 4 • EXTREME

TPE

Therapeutic Plasma Exchange (5–6 volumes) for severe or refractory cases.

Please note – IVIG and TPE are not routinely available in the NHS for treating PANS PANDAS

SYMPTOMATIC INTERVENTIONS

Psychiatric Support & Dosing Cautions

SSRI "Start Low, Go Slow"

- **Extreme Sensitivity:** PANS brain is hypersensitive to psychotropics; side effects occur easily.
- **Micro-Dosing:** Start at 1/4 to 1/8 of standard pediatric starting dose (e.g., Sertraline 6.25 mg).
- **Behavioral Activation:** Watch closely for akathisia, motor agitation, or disinhibition.

Acute Rescue & CBT Adaptation

- **Acute Rescue:** Benzodiazepines for severe panic.
- **ERP / CBT:** Exposure and Response Prevention must be modified during acute encephalopathy.
- **Family Accommodation:** Educate parents to reduce OCD participation without triggering rage.

MONITORING & OBJECTIVE METRICS

Measuring Treatment Response

1. Validated Scales & PTEC

Utilize **CY-BOCS** (OCD severity), **YGTSS** (tics), and the digital **PTEC Checklist** weekly to quantify progress.

2. Handwriting & Fine Motor

Daily handwriting samples

3. Functional Restoration

Track oral caloric intake (if restrictive eating present), sleep duration, urinary frequency, and school attendance and performance.

4. Bespoke Measures

CY-BOCS Children's Yale-Brown Obsessive Scale
YGTSS Yale Global tic Severity Scale
PTEC PANS/PANDAS and Related Inflammatory Brain Disorders Treatment Evaluation Checklist (Neuroimmune Foundation)

MANAGEMENT OF NON-RESPONDERS

What To Do If Initial Response Is Poor

1. Re-evaluate Occult Triggers

- **Screen Contacts:** Check asymptomatic family members/siblings for strep carriers.
- **Expand Infections:** Test for Mycoplasma, Lyme/co-infections, EBV, HHV-6, Sinusitis, or Dental Abscess.
- **Environmental:** Evaluate for mold exposure, heavy metals, or toxic ingestions.

2. Immunomodulatory Escalation

- **Antibiotic Switch:** Shift from Penicillin to Augmentin or Cefaclor to cover intracellular organisms.
- **Prophylactic Antibiotics:** if concerned about recurrent infections
- **Steroid:** Oral burst
- **Repeat IVIG / TPE:** Not routinely available in the NHS for treating PANS PANDAS

CLINICAL DECISION MAKING

Risks & Benefits

Therapy Tier	Key Clinical Benefits	Key Clinical Risks
Antibiotics	Rapid clearance of triggering infection; low cost; highly effective in early presentation.	Gut microbiome disruption, C. diff risk, bacterial resistance with long-term prophylaxis.
Corticosteroids	Rapid reduction of acute neuroinflammation; diagnostic response marker within 24–48h.	Transient behavioral flare during burst, insomnia, appetite spike, immunosuppression.
High-Dose IVIG	*Restores immune homeostasis; long-term durability; rescue in moderate-to-severe cases.*	*Aseptic meningitis, severe post-infusion headache, high cost, IV access requirement.*
Plasmapheresis (TPE)	*Immediate physical removal of autoantibodies; life-saving in extreme/refractory cases.*	*Invasive central line required, ICU admission trauma, fluid shift, infection/bleeding risks.*

Liaise with colleagues –
Multidisciplinary Approach to Management



Consideration

Early Rapid Intervention Appears to Drive Long-Term Remission

Guidelines

JCAP (Journal of Child and Adolescent Psychopharmacology)

Part 1 – Psychiatric and Behavioural Interventions

Thienemann, M., Murphy, T., Leckman, J., Shaw, R., Williams, K., Kapphahn, C., Frankovich, J., Geller, D., Bernstein, G., Chang, K., Elia, J., Swedo, S. (2017) Journal of Child and Adolescent Psychopharmacology. V27(7) pp1-8

Part 2 – Use of Immunomodulatory Therapies

Frankovich, J., Swedo, S., Murphy, T., Dale, R. C., Agalliu, D., Williams, K., Daines, M., Hornig, M., Chugani, H., Sanger, T., Muscal, E., Pasternack, M., Cooperstock, M., Gans, H., Zhang, Y., Cunningham, M., Bernstein, G., Bromberg, R., Willett, T., Brown, K., Farhadian, B., Chang,K., Geller, D., Hernandez, J., Sherr, J., Shaw, R., Latimer, E., Leckman, J., Thienemann, M., PANS PANDAS Consortium (2017) Journal of Child and Adolescent Psychopharmacology. V27(7) pp1-16

Part 3 – Treatment and Prevention of Infection

Cooperstock, M., Swedo, S., Pasternack, M., Murphy, T.; for the PANS PANDAS Consortium (2017) Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Journal of Child and Adolescent Psychopharmacology. V27(7) pp1-13

Nordic Guidelines

Clinical guidance for diagnosis and management of PANS in the Nordic Countries In 2021 a Nordic-UK working group published peer-reviewed clinical guidelines for the diagnosis and management of suspected PANS in the Nordic countries [39]. These guidelines, co-authored by British Paediatric Neurology Association members, recommend a comprehensive medical history work-up which includes symptom assessment related to infectious, autoimmune and rheumatic diseases as well as psychiatric, neurologic and neurodevelopmental diseases. The treatment aims outlined in the Nordic countries guidelines are threefold: treating ongoing verified infections, suspected inflammation and mental health symptoms.

Pfeiffer, H., Wickstrom, R., Skov, L., Sørensen, C., Sandvig, I., Gjone, I., Ygberg, S., de Visscher, C., Nordstrom, S., Herner, L., Hesselmark, E., Hedderly, T., Lim, M., Debes, N., Acta Paediatrica. 2021;110:3153–3160.

Treatment of chronic cases

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