



Integrated
Care System
Nottingham & Nottinghamshire

Research updates

Nottingham
Neurodiversity
Network





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Research update

- Economic evaluation of undiagnosed ADHD/autism
- Waiting well, INTEND and EXPAND projects
- National and international links
 - French institutions
 - International organisations
 - Uk Institutions



ADHD review

French, B., Nalbant, G., Wright, H., Sayal, K., Daley, D., Groom, M. J., & Hall, C. L. (2024). The impacts associated with having ADHD: an umbrella review. *Frontiers in psychiatry*, 15, 1343314.

Impact of ADHD risks beyond the symptoms

Attention Deficit Hyperactivity Disorder (ADHD) affects up to 5% of the population and is characterised by symptoms of impulsivity, hyperactivity and inattention. These symptoms are significantly impairing and ADHD carry additional costs for children and adults, including negative mental health, physical health, and societal outcomes.

Physical health

Around
50% of people with ADHD have increased risk of sleep and/or teeth issues



increased risk of:

accidents or injury

higher instances of eating disorders or obesity

greater risk of drug or alcohol abuse (a means of self-medicating)



Mental health

Around
30% of people with ADHD have risk of addiction to gaming or the internet



increased risk of:

depression, anxiety, suicide

low self-esteem and increased experience of gender dysphoria

risk-taking behaviour



Other impacts

Around
44% of people in prison have undiagnosed ADHD and are at a higher risk of criminal and violent behaviour



increased risk of:

joblessness and unemployment

relationship difficulties and divorce

unwanted pregnancy

difficult social skills with peers



Autism review

French B, Newell V, Nalbant G, Wright H, Daley D and Cassidy S (2026) Adverse outcomes for autistic people: an umbrella review of mental health, physical health, social and lifestyle domains. Front. Psychiatry 17:1702822. doi: 10.3389/fpsy.2026.1702822



Outcomes of autistic people

Autism is a common condition that affects both children and adults. Being autistic can come with many challenges, including increased risk of poor mental health, physical health and social outcomes.

Our umbrella review identified the most extensively researched outcomes in autistic people, summarising over 130 reviews and 1,000 studies.

Physical health

55% more gut and digestive system problems

compared to the general population



Higher rates of:

poor oral health



epilepsy (**12% compared to 1%** for general population)



asthma and diabetes

sleep issues

early death

Mental health

3x the odds of self-injurious behaviour and suicidality



Higher rates of:

mood disorders – depression, bipolar, schizophrenia, psychosis and paranoia



anxiety disorders – OCD, social anxiety



eating disorders particularly anorexia nervosa

Other impacts



Around

44% of autistic individuals experience victimisation

including bullying, interpersonal, and sexual



Higher rates of:

loneliness



challenges forming and maintaining friendships



lower quality of life outcomes

transgender or gender non-conforming identities

The power of words: respectful language in ADHD research

Greater social awareness of ADHD is stimulating a much-needed shift towards the use of compassionate and respectful language. This has positive impact on individuals with lived experience of ADHD. It strengthens our clinical practice and research outcomes. The language we use affects and shapes our understanding of the difficulties people face and the paradigms in which researchers and clinicians operate.

Disorder or
condition?

Deficits or
challenges?

Abnormal or
neurodivergent?

Illness or
difference?

Disease or
traits?



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The power of words: respectful language in ADHD research

French, Blandine; Dekkers, Tycho J.; Barclay, Isabella; Black, Melissa H.; Bølle, Sven; Daley, David; Ernst, J.; Kaiser, Anna; Kerner Auch Koener, Julia; Kurtsi, Janna; Michelini, Giorgia; Price, Anna; Purper-Ouakil, D.; Joanna

Abstract

Language is powerful. It reflects and shapes our understanding of the world. It influences the paradigms in which researchers and clinicians operate. The language we use affects and shapes our expectations of those with lived experiences of ADHD. This paper explores the power of language in ADHD research and the impact it has on the lives of individuals with ADHD.

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Authors

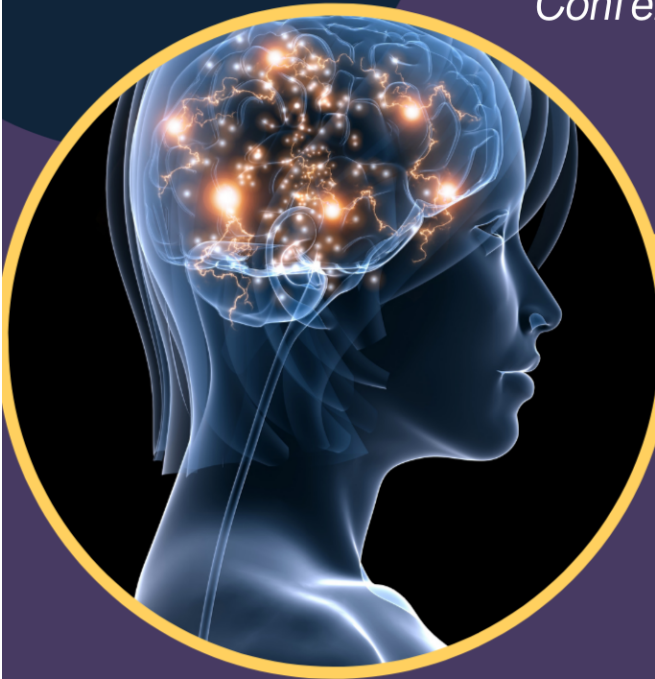
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SENIOR RESEARCH FELLOW

NNN

SIGHT: RESEARCH AND CLINICAL UPDATE ON ADHD IN GIRLS & WOMEN

Conference for academics and clinicians

*Hosted by Dr Blandine French
and Dr Jessica Agnew-Blais*



25th of March 2026
9.30AM-3PM

In person at The University
of Nottingham Jubilee
Conference Centre

International speakers
from a wide range of
clinical & research backgrounds



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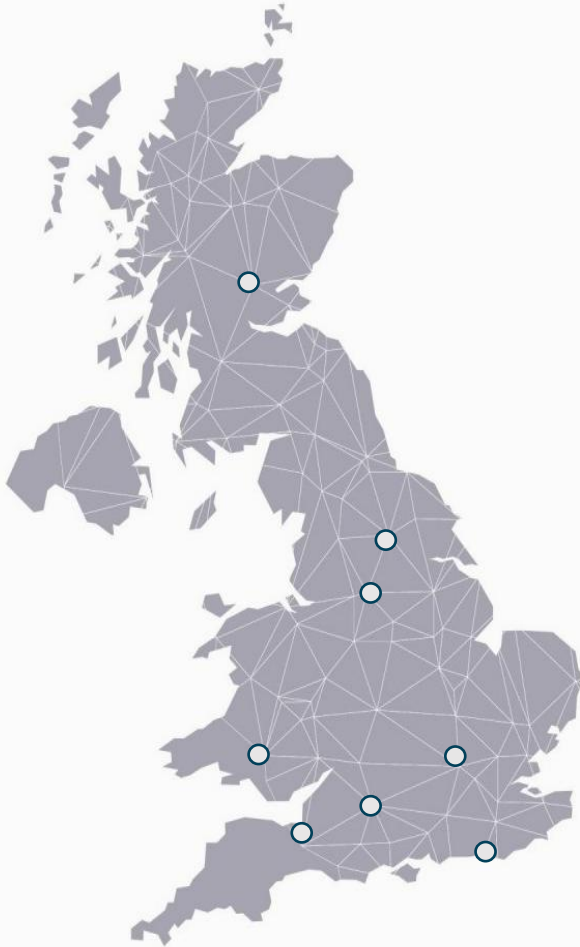
UK research group

Ongoing communication
with local researchers

Collaboration opportunities

Ongoing exchange of good
practice, implementation
etc.

Link with international
network

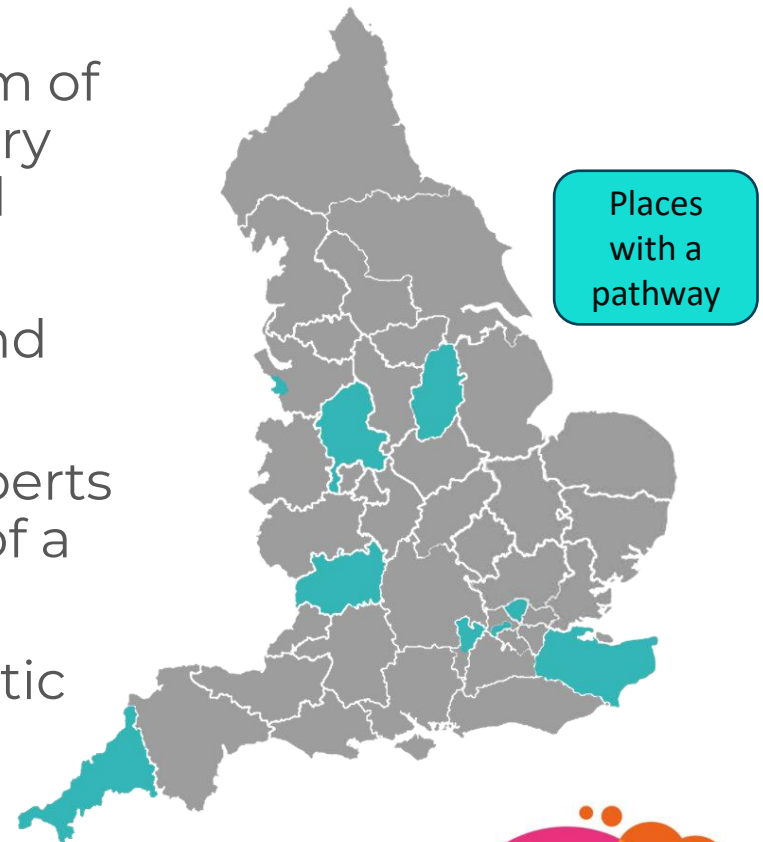




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improviNg Tic services in EnglanD

- Evidence gathered from freedom of information requests showed very few pathways for tics in England
- Surveys and workshops with professionals showed barriers and facilitators to change
- Delphi (consensus) survey of experts identified the key components of a care pathway for tics
- -> **Integrated Care Protocol** for tic disorders in children and young people in England



A recommended service pathway for the referral, assessment, treatment and management of tic disorders in children and young people



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Referral

Referrals from GP or via appropriate secondary/specialist services using a standardised electronic referral process

Referral Criteria

If the answer to ANY of the following questions is yes, then refer:

- i** Have the tics been present for 12 months or more?
- i** Are the tics causing psychological / physical distress or harm?
- i** Are the tics causing functional impairment?

In all cases, signpost the young person and family to Tourettes Action for guidance and support

If no criteria are met, advise to watch and wait and come back if symptoms persist or worsen

Assessment

- Physical and neurological examination
- Interview with child/young person and parent/carer
- Yale Global Tic Severity Scale
- Parent Tic Questionnaire
- Screen for Neurodevelopmental Disorders and mental health difficulties

Diagnostic decision in accordance with DSM-5 or ICD-11 criteria

Liaise with other services

- If ADHD/ASD assessment required, refer to/liaise with Neurodevelopmental Disorder (NDD) service
- If mental health difficulties are severe, refer to/liaise with Child & Adolescent Mental Health Services (CAMHS)
- If tics are likely to be functional, refer to/liaise with CAMHS
- If medication is required for tics, ADHD, or mental health condition, consult with/refer to a medically trained professional (Psychiatrist, Paediatrician, Nurse Prescriber)

Treatment, Management and Support

Depending on tic severity, impact & child's/young person's preferences:

- Psychoeducation for child/young person and family and other relevant services/agencies (e.g., school)
- Evidence-based psychological therapies (e.g., Exposure Response Prevention, Habit Reversal Training, Comprehensive Behavioural Intervention for Tics) delivered in group or one-to-one format, in-person or remotely if clinically appropriate
- Pharmacotherapy alone or in conjunction with psychological therapy

Report summarising diagnosis and treatment plan shared with referring clinician, young person & appropriate agencies in accordance with service protocols & data protection regulations

Monitoring, Review and Follow-up

- Discharge from tic disorder pathway when the tics are well-managed (based on clinical symptoms and discussion with CYP and family)
- Patient Initiated Follow-Up (PIFU) within specified time-frame (discharge letter should detail how to re-engage and the PIFU time-frame)
- Shared care arrangements, if applicable, must be specified in the discharge letter
- The service should have an upper age limit with structured support for transition into adult services

NIHR | National Institute for Health and Care Research

University of Nottingham
Academic Research

NHS
Nottinghamshire Healthcare
NHS Foundation Trust

THE VOICES OF MENTAL HEALTH
Nottingham

**Tourettes
action**

Read more about the INTEND study and download the care protocol here:





Developing digital psychoeducation for adults referred for ADHD



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Aim: to work with a range of stakeholders to create an initial design for a digital psychoeducation tool aimed at adults referred for ADHD assessment

Progress so far:

- Created advisory panel of lived experience, clinical, research, and digital health experts
- Completed a systematic review of published evidence on psychoeducation for ADHD
- Completed interviews with people with lived experience of the ADHD waitlist, and clinical specialists in ADHD services





Developing digital psychoeducation for adults referred for ADHD



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Emerging findings – systematic review of the literature:

- Mixed evidence on psychoeducation for ADHD with most studies evaluating group interventions or psychoeducation as part of a broader package
- Wide variation in content and delivery of psychoeducation interventions, small proportion are digitalised
- Measured outcomes are rarely those that matter to people with lived experience





Developing digital psychoeducation for adults referred for ADHD



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Emerging findings – stakeholder interviews:

- Emergent themes from the interview data centre around complexity
 - Complexity of presentation
 - Complexity of knowledge/information
 - Complexity of support
 - Complexity of systems

Next steps:

- Guide design of initial wireframe
- Prepare funding application to develop and evaluate the digital intervention in clinical practice





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EXPAND

**Exploring the
EXPeriences of
Accessing services and
understanding
Neurodevelopmental
Disorders for ethnic
minorities in England**

Led by Dr Charlotte Hall,
Dr Camilla Babbage, and
Dr Shireen Patel

Funded by the NIHR

