Integrated Care System
Nottingham & Nottinghamshire

Improving pathways to care for neurodevelopmental conditions in Nottingham(shire)

Dr Blandine French

Nottingham Neurodiversity Network

Agenda

9.30 Welcome, NNN and research updates

- Blandine French and Maddie Groom-Research update from UoN
- Charlotte Reading – Nottingham and Nottinghamshire ICB, ADHD and autism adult pathways
- Sarah Birch, Vicky Romilly - Neurodiversity awareness in Adult Local Mental Health Team Quality Improvement Project.

11.15 Presentations on local initiatives

- Amelia Draper – Changing Futures Nottingham, Neurodivergence and Severe and Multiple Disadvantages
- Danny Donelly - Carers and Neurodiversity: How We Can Better Support Them
- Tracey Jackman, Beth Askey – Health Innovation Network, Expanding Access and Support for Adults with ADHD through Innovation

Key Questions

- What is the ideal pathway to care for neurodevelopmental conditions?
- What are the barriers in achieving this pathway?
- What do you think should be avoided in creating this pathway?
- How are we doing locally?
- What are the tangible solutions to these problems?
- Who are the key stakeholders who can make this happen?

Steering group

Nottingham University Researchers

Nottingham & Nottinghamshire ICB

Neurodevelopmental Pathway Support Team (NPST-City Council), Neurodevelopmental Support Team (NST-County Council)

Neurodevelopmental Pathway Bassetlaw (NPB)

Clinicians - Community Paediatrics, GPs, Speech and Language Therapy, CAMHS,

Neurodevelopmental Specialist Service (NeSS) - Adults

Health Innovation Network

Parents and Carers

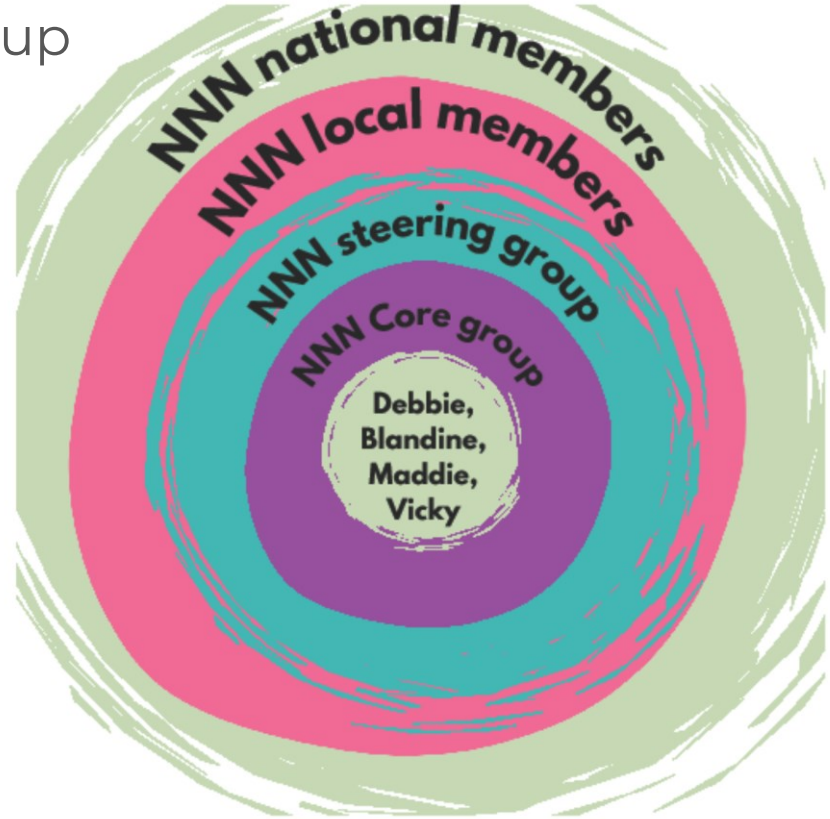
Education leads

Charities: APTCOO (Bassetlaw)

- Adult ADHD group
- Autistic Nottingham
- Tourettes Action

NNN - structure

- Bi- monthly meetings - core group
- Online meetings- steering group
- Conferences in person
- Newsletters
- Terms of reference



Developing the ideal pathway to care for neurodiversities

Our network worked together to assess what the ideal pathway to care looks like

Support

Ongoing, throughout the journey and into adulthood. Flexibility, being able to dip in and out. One key person as point of contact. Waiting well.

Clarity

About the process, the pathway.

Knowledge and education

For parents and all other stakeholders.

Holistic approach

Less siloed thinking, not being passed around different services. Have a ND point of access. Need-led service rather than diagnosis led.

Nottingham Neurodiversity Network

The Nottingham Neurodiversity Network is a network of local charities, academics, commissioners, healthcare professionals and service users that aims to support access to care for neurodiversity.

www.nottsneurodiversitynetwork.org.uk

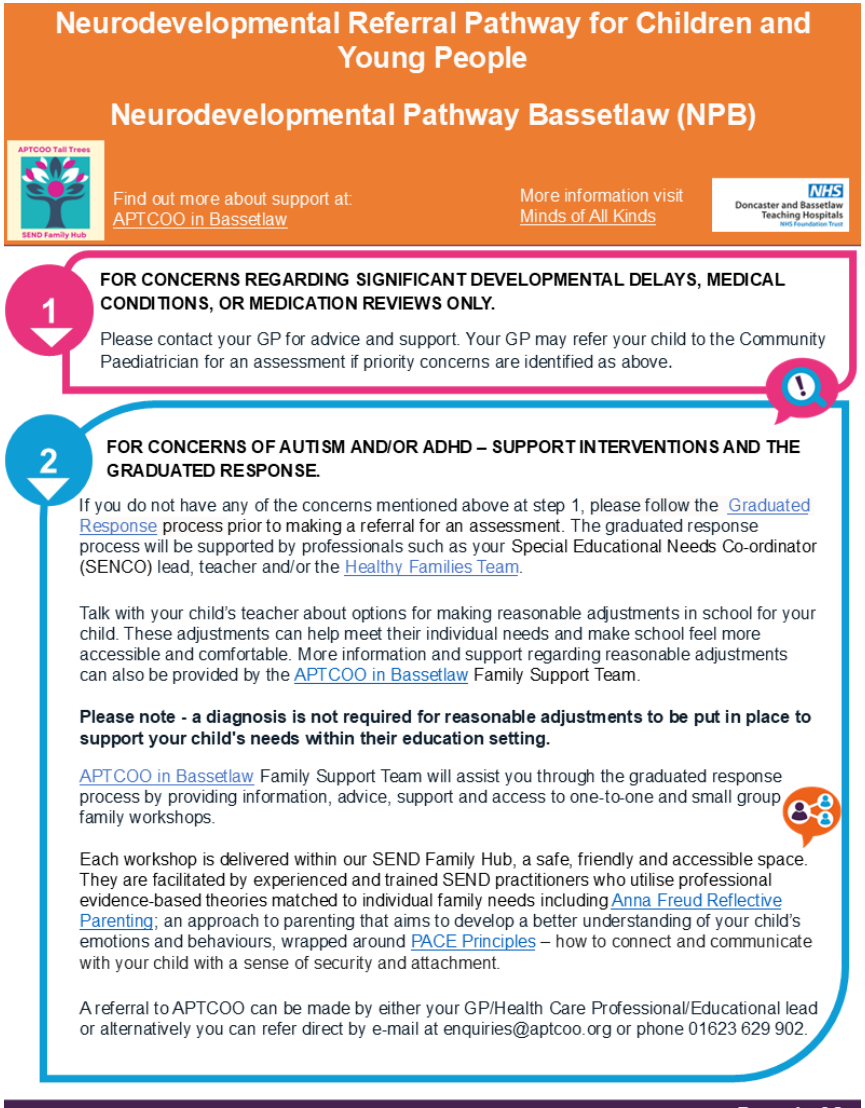
Nottingham and Nottinghamshire ADHD/Autism Assessment Pathways

	Children and Young People Pathway			Adult Pathway
1st step: Graduated Response	Discuss your concerns/child's needs with your child's health visitor or education setting to agree a support plan that can be regularly reviewed and adapted. Also, speak to the Healthy Family Team or 0-19 Early Support Services for further help and advice. This process is often referred to as the graduated response. More information can be found here: Graduated Response			Not applicable
2nd step: Referral (based on location of GP practice)	**Nottinghamshire County**	**Nottingham City**	**Bassetlaw**	**Any**
	Education, Health Professional/GP	Self-referral, Education, Health Professional/GP	Education, Healthy Family Team	GP
3rd step: Screening	Neuro-developmental Support Team (NST)*	Neurodevelopmental Pathway & Support Team (NPST)*	Neurodevelopmental Pathway Bassetlaw (NPB)*	↓
4th step: Specialist Assessment Services (subject to screening outcome)	Community Paediatrics*	AND /OR	other specialist services depending on needs*	Neuro-development Specialist Service (NeSS)*

*While these pathways reflect the majority of referrals, some cases may be referred to other Nottingham(shire) based services. This is an overview of the pathway and does not include details of support services that are offered along the way. For more detailed information, please scan the QR code at the top of the page.

Version 14/10/2025

Pathways documents



Neurodevelopmental Referral Pathway for Children and Young People

Neurodevelopmental Pathway Bassetlaw (NPB)

Find out more about support at: APTCOO in Bassetlaw

More information visit Minds of All Kinds

1

FOR CONCERNS REGARDING SIGNIFICANT DEVELOPMENTAL DELAYS, MEDICAL CONDITIONS, OR MEDICATION REVIEWS ONLY.

Please contact your GP for advice and support. Your GP may refer your child to the Community Paediatrician for an assessment if priority concerns are identified as above.

2

FOR CONCERNS OF AUTISM AND/OR ADHD – SUPPORT INTERVENTIONS AND THE GRADUATED RESPONSE.

If you do not have any of the concerns mentioned above at step 1, please follow the Graduated Response process prior to making a referral for an assessment. The graduated response process will be supported by professionals such as your Special Educational Needs Co-ordinator (SENCO) lead, teacher and/or the Healthy Families Team.

Talk with your child's teacher about options for making reasonable adjustments in school for your child. These adjustments can help meet their individual needs and make school feel more accessible and comfortable. More information and support regarding reasonable adjustments can also be provided by the APTCOO in Bassetlaw Family Support Team.

Please note - a diagnosis is not required for reasonable adjustments to be put in place to support your child's needs within their education setting.

APTCOO in Bassetlaw Family Support Team will assist you through the graduated response process by providing information, advice, support and access to one-to-one and small group family workshops.

Each workshop is delivered within our SEND Family Hub, a safe, friendly and accessible space. They are facilitated by experienced and trained SEND practitioners who utilise professional evidence-based theories matched to individual family needs including Anna Freud Reflective Parenting; an approach to parenting that aims to develop a better understanding of your child's emotions and behaviours, wrapped around PACE Principles – how to connect and communicate with your child with a sense of security and attachment.

A referral to APTCOO can be made by either your GP/Health Care Professional/Educational lead or alternatively you can refer direct by e-mail at enquiries@aptcoo.org or phone 01623 629 902.

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University of Nottingham UK | CHINA | MALAYSIA

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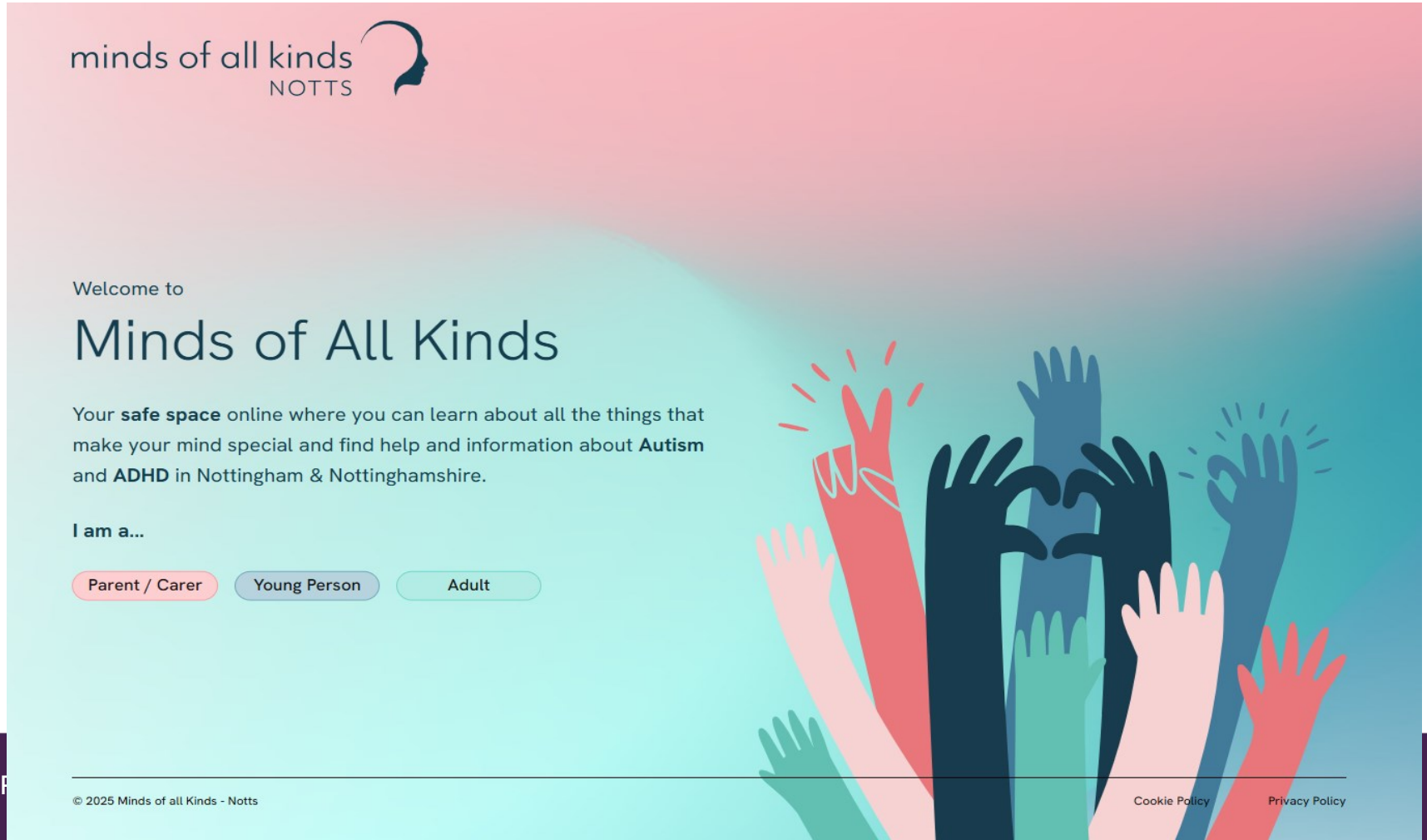
NNN update

Nottingham Neurodiversity Network

Minds of All Kinds

Debbie Bickley

https://mindsofallkindsnotts.co.uk/pathway-guidance



Other outputs

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- Working closely with providers to identify and implement service improvements and better outcomes for our local population.

  - Videos
  - Guidelines
  - Transitions
  - SENCO training on ADHD
  - Parents workshop and survey
  - Adult survey

Regional Neurodiversity Network (RNN)

Shared Learning Session:

- **Leicestershire Model:** Pilot of training pharmacists to take on ADHD prescriptions and reviews for (CYP).
- **Derbyshire Model:** Early years neurodiversity pilot focused on peer support and collaboration between health visitors, SLT, and paediatrics, resulting in reduced referrals to the SPA
- **Lincolnshire Model**: Established a specific pathway for adults with ADHD who have an addiction
- **Nottinghamshire/UoN**: Highlighted the "Notts Autism Safety Plan" and the reasonable adjustment toolkit for autism.
- **Birmingham and Solihull:** Relationship with parent carer forum
- **Northamptonshire:** Star award GP, SEND Dad's group

Business plan

Michael Rose

- **Sustainability**
  - Letter of support
  - Funding applications
- **Principles**
  - *Evidence based*
  - *Co-produced*
  - *Positive and inclusive*
  - *Takes a societal perspective of neurodiversity*
  - *Open to challenge*
  - *Scalable*
  - *Live document*

Evidence workshop

- Improved services
- Better working across the system
- Improved support and relationships that would otherwise only happen by chance

Next steps

- Funding
  - Letter of support
  - Plan of action
  - Lobbying letter
- Adult survey
- Teacher workshops and ongoing training

Dates for the diary

- May conference – **13th of May**
  - National examples of care pathways
- ADHD in women and girls conference – **25th of March**
  - International speakers
  - For clinicians and researchers
  - CPD accredited

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Research update

Nottingham
Neurodiversity
Network

ADHD taskforce report

https://www.england.nhs.uk/long-read/report-of-the-independent-adhd-taskforce-part-1/

1. Shift Care from Specialist to Community

- Urgent Waiting List Action
- Decouple Support from Diagnosis
- Holistic, Stepped Care
- Interim Support Mandate

2. Cross-Sector Collaboration & Prevention

- Whole-Person Approach
- Invest-to-Save Model
- Workforce Training

3. Data, Digital, and Efficiency

- Digitise Services
- Improve Data Quality
- NICE Review

ADHD language

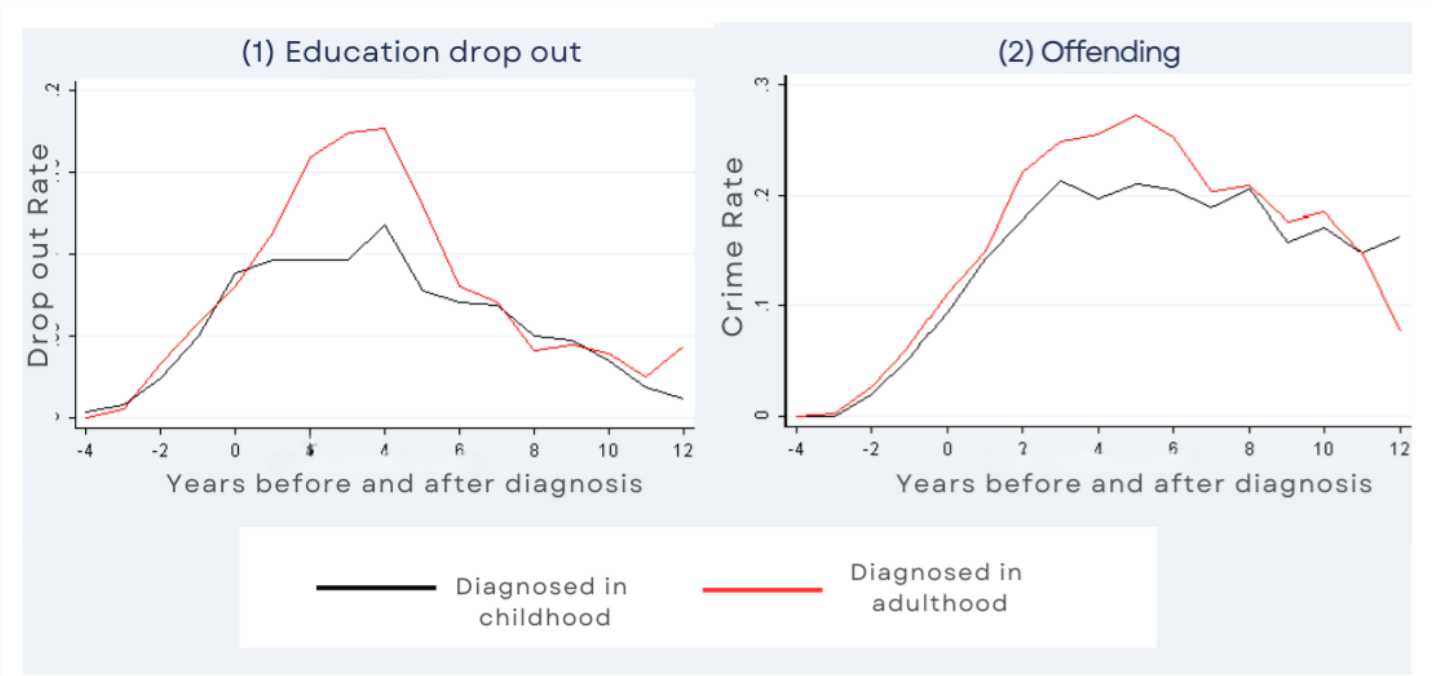
Danish study

The cost of earlier versus later access to care

(French, B., Smith. L., Lange. A.M., Sorenson, A. Jacobson, R.H., Waldorf, J & Daley, D. in preparation)

- Analysis of Danish National patient Register
- Outcomes
  - Dropout of education rate
  - Crime rate
- Educational dropout and crime rates are similar between the diagnosed in child and diagnosed in adult groups up until the diagnosed in c**hildhood group receive their diagnosis**
- **After diagnosis**, the diagnosed in childhood group improves **on educational dropout** and **criminal offending**, whereas the same aged children who are not diagnosed until adulthood continue to deteriorate.

Results
(childhood diagnosis at 0 and adult at 5)



Recount

RECOUNT

Economic evaluation of the cost of undiagnosed ADHD/autism

- Risks identified in Study 1 and 2
  - Education, Mental health, Relationships, Criminal justice system, Finances, Work, Risky behaviours, Physical health
- Three groups:
  - Adults diagnosed in childhood/ over 10 years
  - Adults diagnosed within 10 years
  - Undiagnosed adults
- Four domains
  - Health and social care
  - Public sector
  - Societal
  - Non-health and social care

Adults with an ADHD and/or autism diagnosis had significantly greater costs than those undiagnosed for three out of the four of our cost perspectives.

Generalized linear regression models on four cost perspectives.

Controlled for **age, sex, ethnicity, relationship status, and ASRS & AQ-10 clinically significant scores.**

Cost perspective	Diagnosis coef. (SE)
Health and social care	**0.360** (0.130)**
Public sector	**0.276** (0.088)**
Societal	**0.327** (0.121)**
Non-health and social care	0.445 (0.302)
** p<.01	

Findings consideration

Under powered?

Recruitment bias? (support group)

Function (undiagnosed milder, diagnosed in childhood manage better)

Self selection

Group representation (female vs male, criminal justice)

Screening questionnaires?

Difficult to quantify?

How do you cost difficulties

Capturing softer factors in health economics

Self-report reliance

Different methodologies

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Waiting well grant

AIM: To explore the potential for a digital psychoeducation tool to support adults awaiting ADHD assessment and scope its initial design

Funding secured from the NIHR for 15 months of work

Leading into a larger-scale funding application to develop and evaluate the tool

Longer-term aims: to improve outcomes for adults awaiting ADHD assessment

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Objectives 1-4:

1.Engage Patient and Public Involvement (PPI) throughout

- Recruit a Lived Experience Advisory Panel (LEAP) of adults with experience of waiting for ADHD assessment

2. Evidence discovery & synthesis

- Review evidence for psychoeducation via a systematic literature review
- Explore relevant currently available digital resources

3. Explore stakeholder views and experiences

- Interview adults referred for ADHD assessment and healthcare professionals working in adult ADHD services

4. Team building

- Create an advisory group including key stakeholders from industry, healthcare, clinical trials and evaluation, and PPI

Objectives (5-7):

5. Technology & Research Design:

Co-design:

a) A low-fidelity specification of the digital psychoeducation tool that will be further developed in the future Programme Grant

b) A research methodology to evaluate the digital tool

6. Design the Programme Grant

- Prepare an application for NIHR Programme Grants for Applied Research (PGfAR)

7. Dissemination

- Disseminate findings via academic and healthcare conferences and to the lived experience community via charities, support groups, and social media

The INTEND study

improviNg Tic services in EnglaND

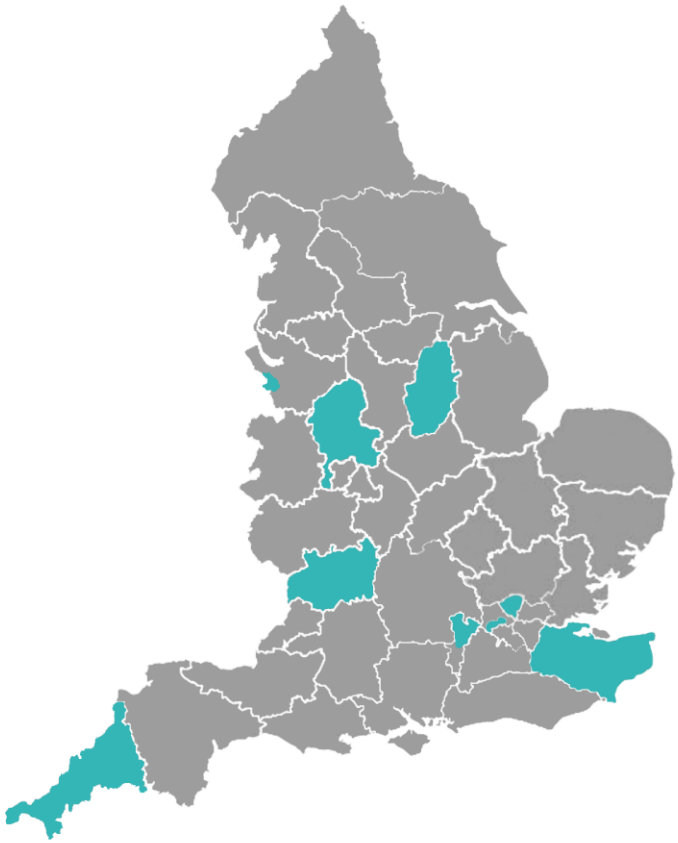
Aim: to establish an evidence-based, co-produced service model for the referral, assessment and treatment of tics in children and young people

1	2	3	4
Understand current service provision	**Barriers and facilitators to tic service provision**	**Developing an effective service model**	**Guideline development**
Freedom of Information Requests Nov 23-July 24	Survey of healthcare practitioners Nov 23-July 24	Delphi survey and consensus workshop Nov 23-Jul 24	Engagement with stakeholders to shape the guidelines Feb 2024-Jan 2025

Patient & Public Involvement
National steering group for Tourette Syndrome - UK

FUNDED BY
NIHR | National Institute for Health and Care Research

Work package 1: FOI requests



Evidence of a postcode lottery

- Full pathway provision was mostly concentrated in the region of London
- Minimal provision in the West Midlands, South East and North West
- No full pathway providers in the upper North or the East of England

Rattu et al., 2025, *BMJ Mental Health:* ImproviNg Tic services in EnglaND: a multi-method study to explore existing healthcare service provision for children and young people with tics and Tourette syndrome | BMJ Mental Health

Resources and guidance needed

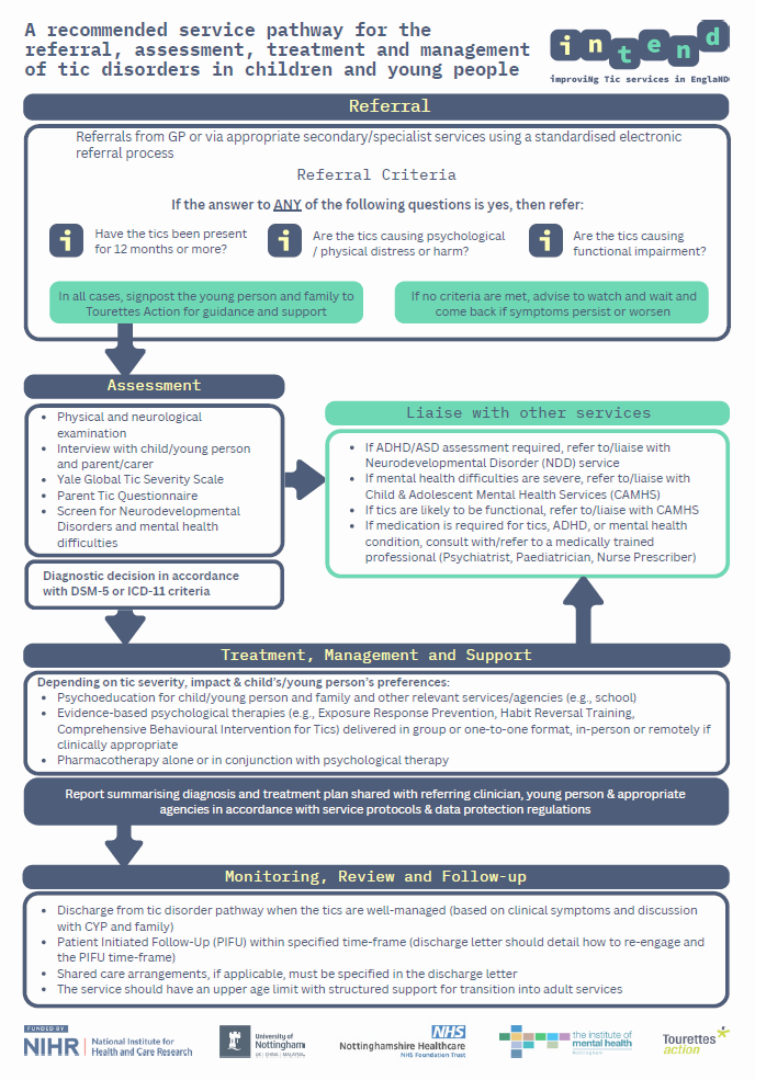
Need for further resources

	Assessment	Treatment
Yes	81.5%	79.3%
No	5.4%	5.4%
Maybe	13.0%	15.2%

Clinicians **need more guidance** and **support**

WP4: Guideline development

INTEND Integrated Care Protocol (ICP) with accompanying written guidelines



Next steps: evaluating the INTEND ICP

- Further explore barriers and facilitators to ***implementation***
- Strengthen links between ***primary care*** and secondary care
- Co-produce a ***training & development*** *toolkit* for professionals
- Measure the ***effect*** of the pathway on an aspect of patient care (e.g. rates of referrals accepted/declined, time to referral/time to initial assessment)
- Gather ***health economics*** data to build the evidence case for pathway implementation
- Longer term national ***adoption*** through the Health Innovation Networks

To find out more about other research taking place in the Centre for ADHD and Neurodevelopmental Disorders, visit our website