



Integrated
Care System
Nottingham & Nottinghamshire

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

Nottingham
Neurodiversity
Network



Agenda



9.30 Welcome, introduction and NNN update

9.45 Research and pathway updates

- Debbie Bickley -Parent workshop and survey: you said, we did
- Vicky Romilly and Kathy- Adult health pathway for autistic people

10.45 Break

11.15 Presentations on local initiatives

- Rachel Chatwin and Blandine French -ADHD in local schools
- Louise Ann Whitehead - The PINs project
- Richard Flewitt and Jennine Fox - The Wolfpack Project



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

ICB

Children: SPA: BEH Team (City), NBS (County)

Community Paediatrics

Adults: NeSS

GPs

Researchers

Parents

Education

Charities: APTCOO (Bassetlaw)

ADHD adult group

Autistic Nottingham



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Nottinghamshire Healthcare
NHS Foundation Trust



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.





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NNN update

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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)*	Behavioural & Emotional Health Team (BEH)*	General Developmental Assessment (GDA)*	↓
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.

Pathways documents



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Neurodevelopmental Referral Pathway for Children and Young People – APTCOO

(A place to call our own) Bassetlaw
Tel: 01623 629902

Find out more at: [APTCOO in Bassetlaw](#) Find out more at: "Minds of All Kind's" link to be added here

1

FOR CONCERNS REGARDING NEURODEVELOPMENT BEHAVIOURS

Contact your GP/Health Care Professional/Educational Senco Lead to be referred via the General Development Pathway (GDA) for consideration for referral to the Community Paediatrician for a neurodevelopmental assessment.

Information about the GDA pathway can be found [here](#)

Information about the role of the Community Paediatrician can be found [here](#)

2

FOR NEURODEVELOPMENT SUPPORT WHILST WAITING FOR AN ASSESSMENT OR FOR SUPPORT IN GENERAL

A referral to APTCOO for support can be made by either your GP/Health Care Professional/Educational Senco Lead or alternatively you can refer direct by e-mail at enquiries@aptcoo.org or phone 01623 629902

3

APTCOO SOCIAL PRESCRIBING TEAM

The APTCOO social prescribing team will then contact you to discuss your referral and signpost you to non-clinical support services, dependant on your child's individual need

4

PRE & POST ASSESSMENT SUPPORT

Support can be offered with one-to-one sessions, the Family Learning Programme, Anna Freud Reflective Parenting Programme, Relationships Really Matter online workshop, sensory therapy, communication & language skills, challenging behaviour support, and transition to adulthood and peer support



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ICS

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**University of
Nottingham**
UK | CHINA | MALAYSIA





Nottingham Neurodiversity Network



UNDERSTANDING THE DIFFERENT ROLES WITHIN THE NEURODIVERSITY CARE PATHWAY



SCHOOL

PRIMARY SCHOOLS
No NURSERY = **HUGE** Difference!

Specific strands of diagnosis need their own interventions & Process

FURTHER EDUCATION

Information SHOULD be Shared from Secondary School - NOT ALWAYS THE CASE!

16 to 19 Year olds generally have a longer wait time to be assessed

Work with external agencies = CAMHS & PAEDIATRICS

Learner profiles for all staff is **IMPORTANT!** due to range of conditions

Smaller classes to help students cope in classrooms
Eg- Vocational Subjects

FOCUS ON THE LEARNER
NOT ON THE LABEL

SECONDARY SCHOOLS
SHOULD receive information from Primary School prior to transition
Movement breaks in classrooms



GP

RESPONSIBILITY = To refer Patients to **SHARED CARE PATHWAY**

We tend to be a **1st POINT OF CALL**

We DO NOT diagnose - we collate information & send on for referral

Once diagnosed, we can RE-REFER if needed

Once assessed - NHS will do further detailed assessments

CHALLENGES

Referrals can be delayed if there is not enough information

10-15min APPOINTMENT TIME for Neurodiverse Patients is NOT LONG ENOUGH!

WAIT LIST = knock-on effect for families

Patients could be moved to the back of the queue

MOST CONCERNED about Mental & behavioural Patients who can ESCALATE when waiting longer

Most Patients can give their own evidence to get referred sooner



SINGLE POINT OF ACCESS

We support Parents/carers who's children have behaviours indicative of Autism/ADHD

OR who already have a diagnosis of Autism/ADHD

We provide support for **PRE & POST DIAGNOSIS**

We complete Neurodevelopmental Assessments - **NON CLINICAL**

Behaviour concern has been identified by a professional or parent / carer

We deliver programmes & support groups to Parents/carers

We **PRIORITISE** certain categories of children / young people

UNDER 5s **16+**
ALL GET A 12 WEEK ACCELERATION

WE DO NOT
• Work directly with children / young people
• Provide diagnosis

WE ARE NOT:
• A crisis service
• A mental health service
• An education service

Regular meetings with CAMHS colleagues to work out best support

Doing all we can to **REDUCE** wait & Assessment times

CHALLENGES

UNDERSTANDING OF THE SERVICE / ROLES

CAPACITY
GP's can not gather ALL the information we need!

FUNDING
MISCONCEPTION that a GP referral holds more weight = **DELAY IN PROCESS**

TIER 1 Support has been completed
if child / young person is between 0-17yrs 9mends
if child / young person is registered with a Nottinghamshire GP

GRADUATED response has been put in place & reviewed

START **STARTING POINT** for REFERRAL PROGRAMME



CHILDREN & ADOLESCENT MENTAL HEALTH SERVICE

CAMHS

We work with a range of Young People & Parents

Creating a **BRIDGE** between Mental Health & Neurodiversity to help practitioners

Multi-agency work for the best process

DYNAMIC SUPPORT REGISTER
Run by IEB for young people diagnosed with Neurodevelopmental disorders & who are at risk

HOME VISITS help get a better understanding
Sensory check-list with young people

We try to **HELP SERVICES**

When we get referrals for Autism, we are NOT commissioned for Assessments

CHALLENGES

Helping people to understand the difference between **MENTAL HEALTH** & **AUTISM**



COMMUNITY PAEDIATRICIAN

Most referrals come from GPs = long wait list

We do all sorts of Paediatrics

Picking up more **RARE** conditions & Supporting those

ALL Patients are treated the same no matter the Pathway

We see to complex Neurodisabilities as well as medical

IMPORTANT to examine child at 1st appointment as may be the only chance

ALL get follow up appointment

THEN referred to Single Point of Access & other services to help families

RED FLAG REFERRALS
When we have concerns about something else medical (eg neurodevelopmental regression)

DIAGNOSIS may be given after a few assessments

KEY MESSAGE

Neurodevelopmental Assessments are only a part of what we do!

We try to look at medical reasons behind conditions

Statutory responsibilities of children in care

We are **NOT** a MENTAL HEALTH SERVICE

We are **NOT** Behaviour Specialists

NOT formally a Neurodevelopmental Disorder Service

We have no access to Educational Assessments

Number of referrals are **INCREASING**

Funding & resources are **NOT**

BUT we support what we can

CHALLENGES
Struggling with increasing number of patients requesting 2nd opinions

NATIONAL shortage of PAEDIATRICIANS



ADULT SERVICES

NESS

NOTTINGHAMSHIRE VERY FORTUNATE
A lot of places DO NOT have access to Adult Services

We accept referrals for assessment & short term support for Autism / ADHD

CHALLENGES

Service originally commissioned to see **600** cases a year

BUT Demand is **10x HIGHER!**

We are a **MULTIDISCIPLINARY** TEAM
We assess where there is diagnostic uncertainty & / or additional needs

InkyThinking.com



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UNDERSTANDING THE DIFFERENT ROLES NEURODIVERSITY CARE PATHWAY

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PRIMARY SCHOOL
No NURSERY = HUG DIFFERENCE

Specific strands of diag need their own intervention & Process

SECONDARY SCHOOLS

SHOULD receive information from Primary School prior to transition

Movement breaks in classrooms

Information SHOULD be shared from Secondary School - NOT ALWAYS THE CASE!!

16 to 19 Year olds generally have a longer wait time to be assessed

Work w/ agencies & PEDIA

Learner for all sth IMPORT due to conditions

Smaller classes to help students cope in classrooms

Eg- Vocational Subjects

FOCUS ON THE LEARNER NOT ON THE LABEL

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SINGLE POINT OF ACCESS

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STARTING POINT for REFERRAL PROGRAMME

WHEN TO REFER / CRITERIA

We provide support for PRE & POST DIAGNOSIS

We complete Neurodevelopmental Assessments - NON CLINICAL

Behaviour concern has been identified by a professional or parent / carer

Providing tools, Strategies & confidence to manage!

We PRIORITISE certain categories of children / young people

UNDER 5s

16

ALL GET A SHARED ASSESSMENT

TIER 1 Support has been completed

Graduated response has been put in place & reviewed

616 child / young person is between 0-17yrs 9months

616 child / young person is registered with a Nottinghamshire GP

CHALLENGES

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Other outcomes



- Website – “Minds of All Kinds” to launch March 25.
- Working closely with providers to identify and implement “quick wins”
 - Videos
 - Resources
 - Guidelines
 - Transitions
 - Pilot of direct referral to Community Paediatrician.





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Research update

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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

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



Mental health

3x the odds of self-injurious behaviour and suicidality



Other impacts

Around

44% of autistic individuals experience victimisation

including bullying, interpersonal, and sexual



Higher rates of:

poor oral health



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



asthma and diabetes

sleep issues

early death



Higher rates of:

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



anxiety disorders – OCD, social anxiety



eating disorders particularly anorexia nervosa



Higher rates of:

loneliness



challenges forming and maintaining friendships



lower quality of life outcomes

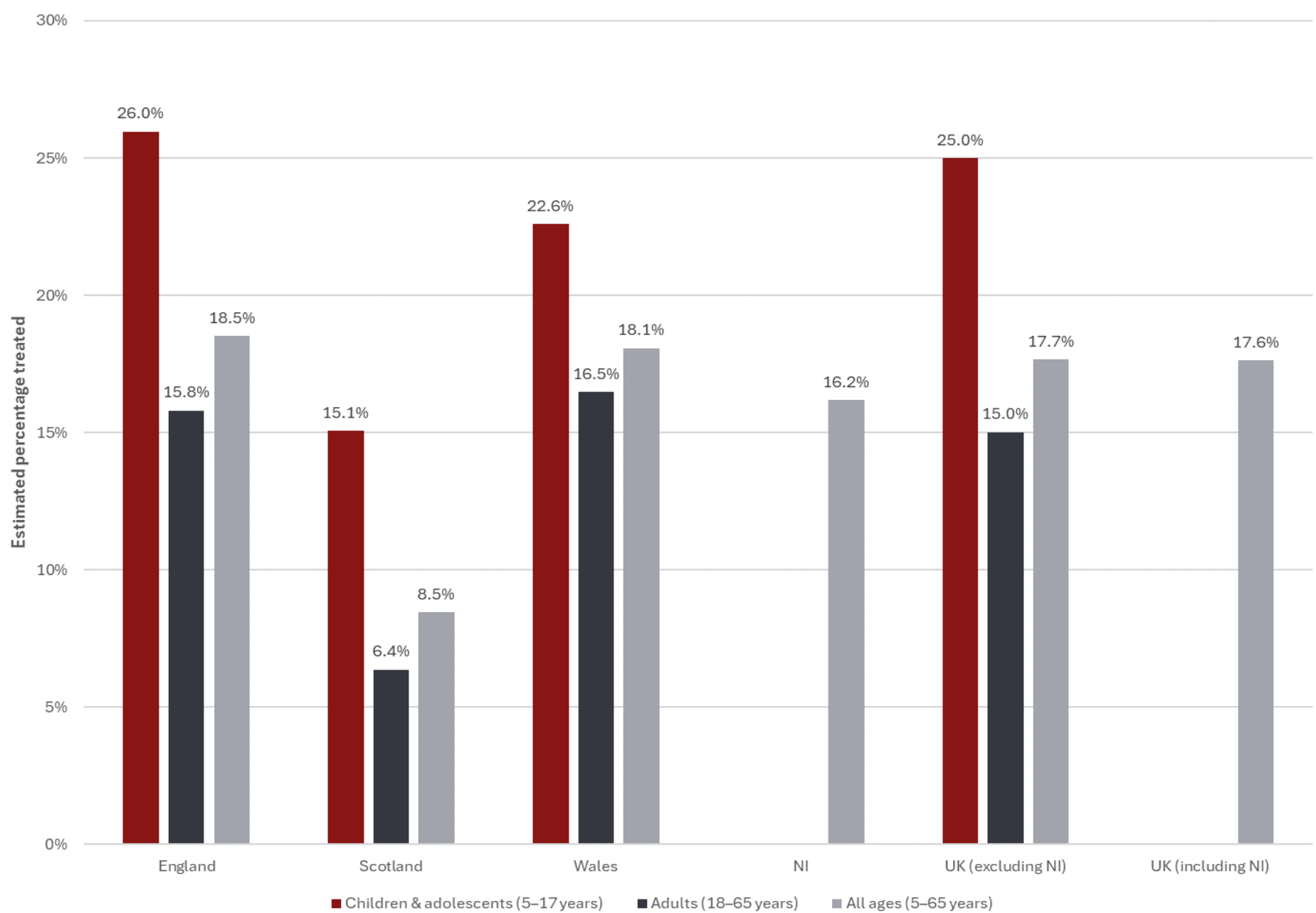
transgender or gender non-conforming identities

ADHD variation model

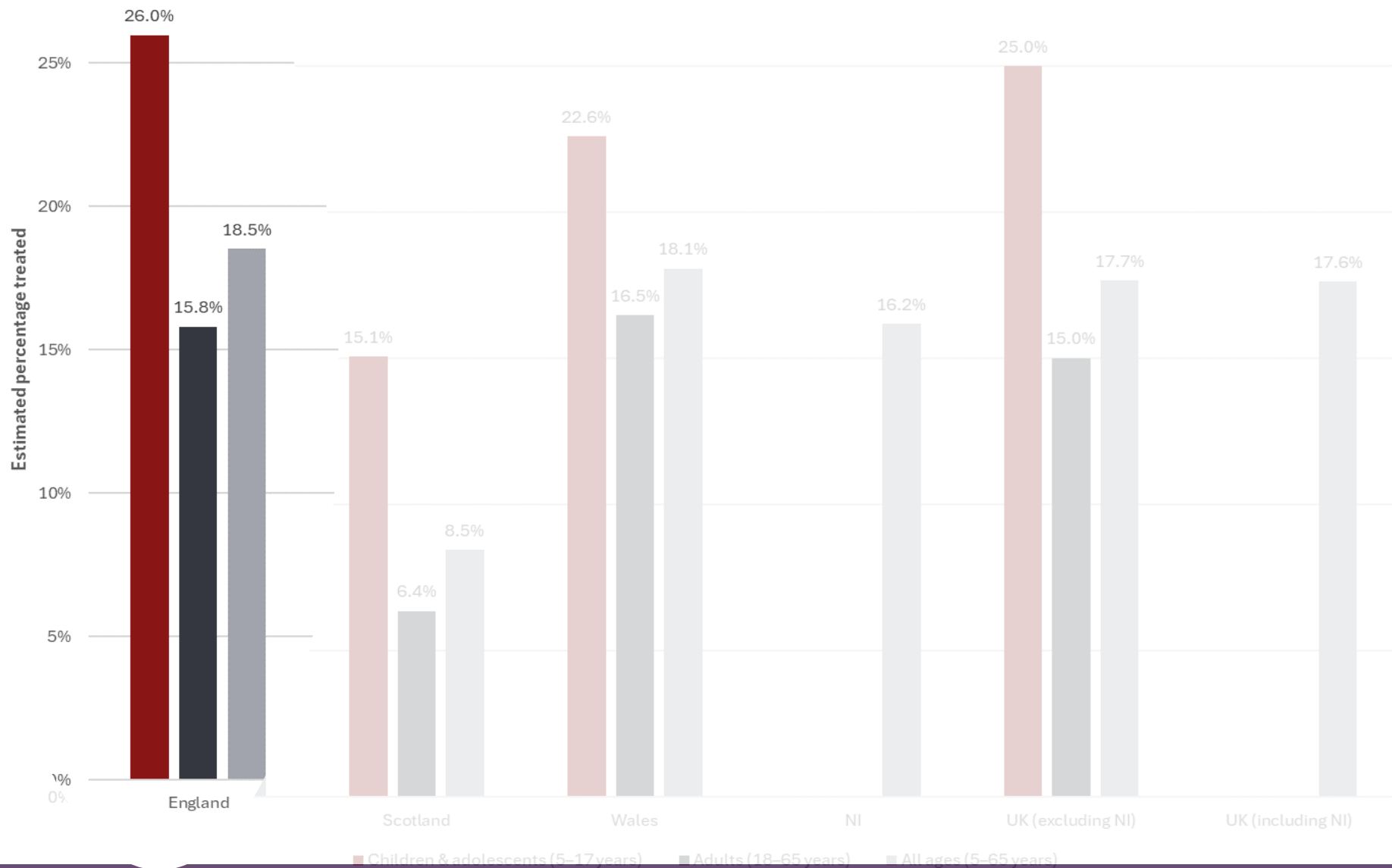


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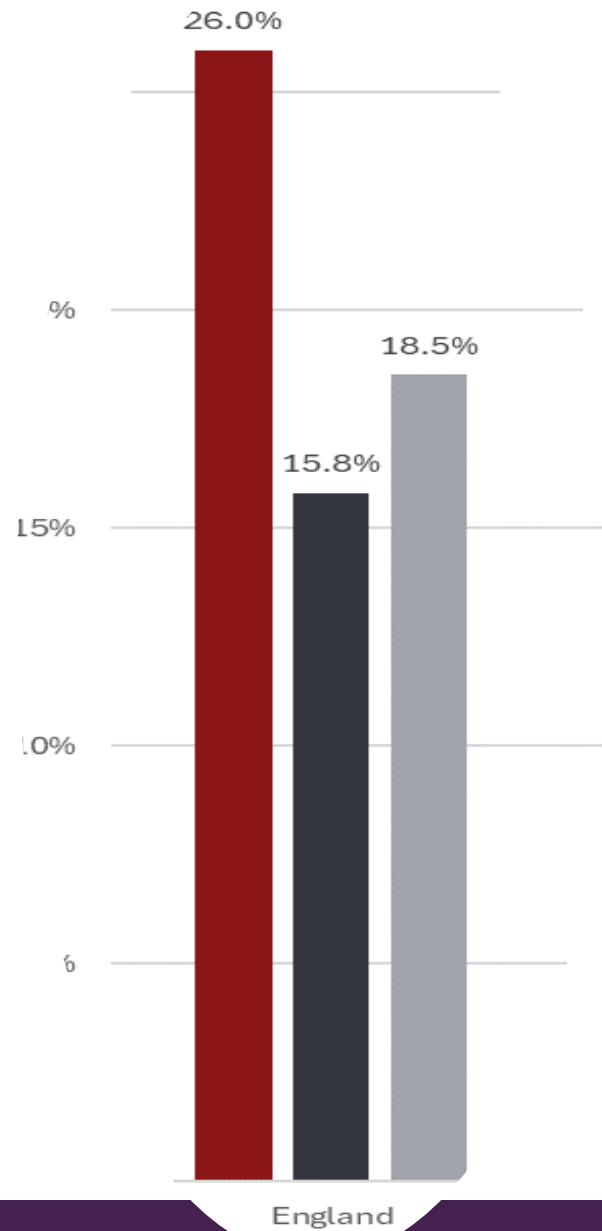
Country	Estimated ADHD population			Estimated number of treated patients		
	CYP (5-17 years)	Adult (18-65 years)	Overall (5-65 years)	CYP (5-17 years)	Adult (18-65 years)	Overall (5-65 years)
England	442,692	1,209,739	1,652,431	114,958	191,135	306,094
Scotland	38,156	120,610	158,766	5,748	7,673	13,421
Wales	23,220	65,120	88,340	5,244	10,722	15,966
Northern Ireland	16,169	40,374	56,542	N/A*	N/A*	9,155
Great Britain	504,068	1,395,469	1,899,537	125,950	209,531	335,481
UK	520,236	1,435,843	1,956,079	N/A†	N/A†	344,636



Estimated percentage of patients treated with licenced ADHD medicines in the UK



Estimated percentage of patients treated with licenced ADHD medicines in the UK



Estimated percentage of patients treated with licenced ADHD medicines in the UK



Waiting well grant

Prof Maddie Groom

- NIHR funding to explore the potential for a digitalised psychoeducation resource to support adults referred for ADHD assessment while they are on the waitlist
- This will be a 15-month project to:
 - explore stakeholder views (including those with lived experience & healthcare providers)
 - review the literature on psychoeducation for ADHD
 - work with a tech company to begin designing a resource
- We aim for this to lead to a full programme grant (e.g. 4-5 years) to develop the resource and evaluate it
- This news is still confidential at the moment





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Fellowship proposal

Support for local services in care pathway

Evaluating existing solutions from other NHS trust for services:

Atmos

Anathem

Mayden

And service users:

Portsmouth profiler

Dimensions



Dates for the diary

- May conference – **22d of May**
 - National examples of care pathway
 - NHSE autism team
 - Other pathways
- ADHD in women and girls conference – **27th of March**
 - International speakers
 - For clinicians and researchers
 - CPD accredited

