Implementing a local care pathway for children and young people with Tic Disorders and the INTEND study

Dr Maddie Groom
Associate Professor in Applied Developmental Cognitive Neuroscience

Joseph Kilgariff
Advanced Clinical Practitioner – Developmental Neuropsychiatry

What we do and Where we do it

Professor Chris Hollis leads the CAMHS Developmental Neuropsychiatry tics disorder service based at the Queen's Medical Centre in Nottingham.

We support children and young people aged 5-18 to manage conditions such as Chronic Motor Tic Disorder and Tourette Syndrome. We provide both pharmacological and non-pharmacological options as one of only a handful of centres across the UK specialising in the treatment of tics.

We offer advice/consultation/ and clinical input to our young people and their referrers such as, Paediatric and CAMHS services in relation to all aspects of treatment including assessment, psycho-education and management of tic disorders and common co-morbidities (e.g. ADHD, ASD, emotional disorders).

We currently have 203 children and young people open to our service.

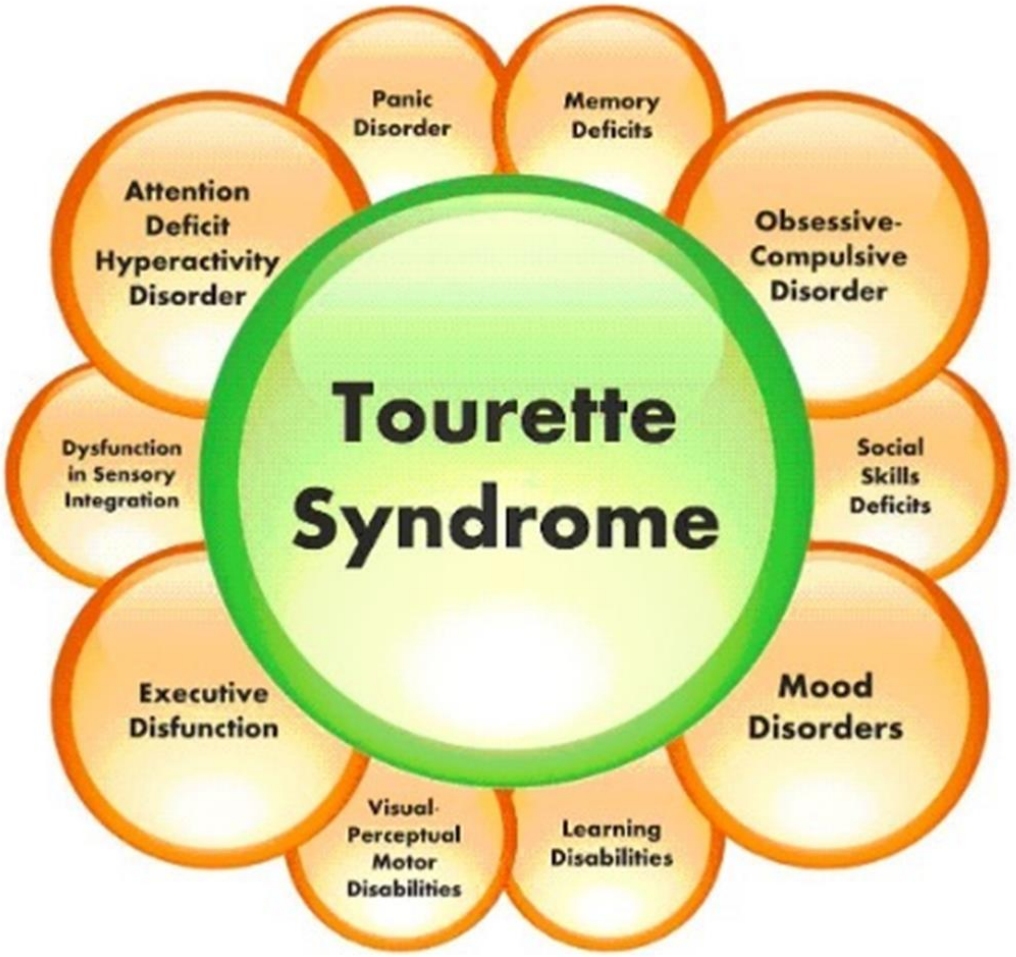
Capacity currently is 0.4WTE consultant psychiatry, 0.6WTE Nursing and 0.9WTE admin.

Tic Disorders

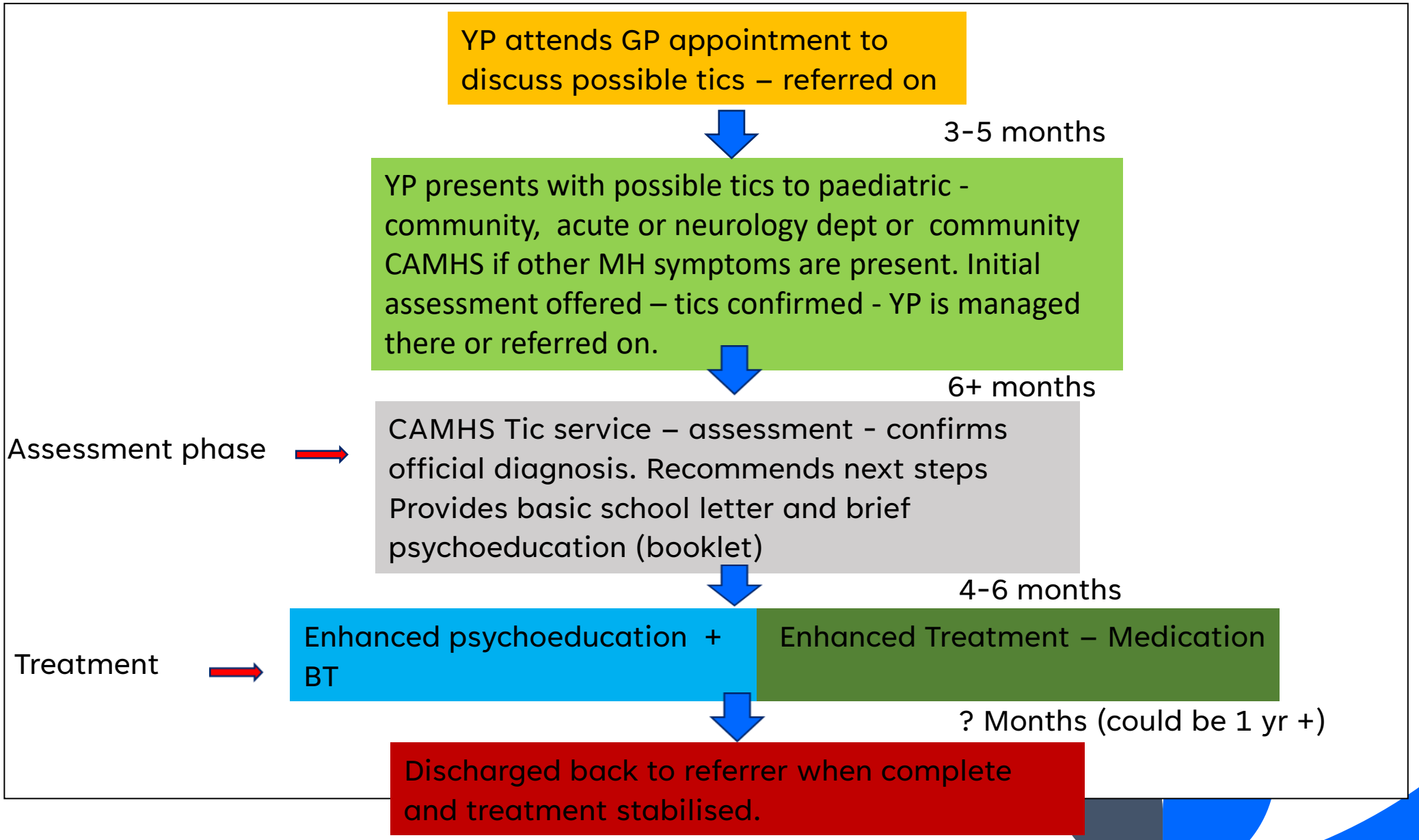
Tic disorders range from mild to severe and can have a profound impact on the young person and their families. If supported these difficulties have a greater chance to be effectively treated and limited.

- <u>Co – existent symptoms</u>
- ADHD / ASC / OCD
- Difficulties with self-esteem and self-concept
- Depression / Anxiety
- Sleep difficulties
- Substance use
- Oppositional / Conduct disorders

- Self harm
- Suicide (4x general population)



Local existing pathway (under review)



Limitations

As typical – clinic was originally a special interest of clinical academic staff – not formally / diagnostically commissioned

No Nice Guidelines to describe minimal recommended service offer and who/what service is best for YP to see at each stage.

Tic disorders seen as rare, difficult to treat, hard to disentangle from more well-known disorders, changing and unpredictable in nature.

Hardly any examples of existing good quality services

improviNg Tic services in EnglaND

Centre for ADHD and Neurodevelopmental Disorders (CANDAL)

The INTEND study

Maddie Groom, Study Lead
University of Nottingham

University of Nottingham
UK | CHINA | MALAYSIA

FUNDED BY
NIHR | National Institute for Health and Care Research

the institute of mental health
Nottingham

The background to this project

- In September 2021, we formed a national steering group with the aim of improving services for tics and Tourette Syndrome, and campaigning for the development of NICE guidelines
- The steering group includes healthcare professionals, academics, charity and support group leads, clinical leads, adults with tics/TS, and parent/carers
- The group meet quarterly to discuss challenges and to develop expert-led solutions
- The INTEND project was generated by these discussions and the team was formed from steering group members
- The steering group will continue to contribute to and steer the INTEND study

Aims & Objectives

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

To achieve this, we will:

- Assess how services are currently organised for children & young people with tics in England
- Explore barriers & facilitators experienced by healthcare practitioners when assessing or treating tics, and any training needs/gaps they have
- Through expert consensus, establish the key features of an effective service model
- Develop guidelines for the implementation of an effective service model and engage with stakeholders to identify barriers, facilitators, and regional context
- Prepare a future study for implementation and evaluation of the recommendations

Work packages & timeline

1

Understand current service provision

Freedom of Information Requests

Nov 23-May 24

2

Barriers and facilitators to tic service provision

Survey of healthcare practitioners

Nov 23-May 24

3

Developing an effective service model

Delphi survey and consensus workshop

Nov 23-Jul 24

4

Guideline development

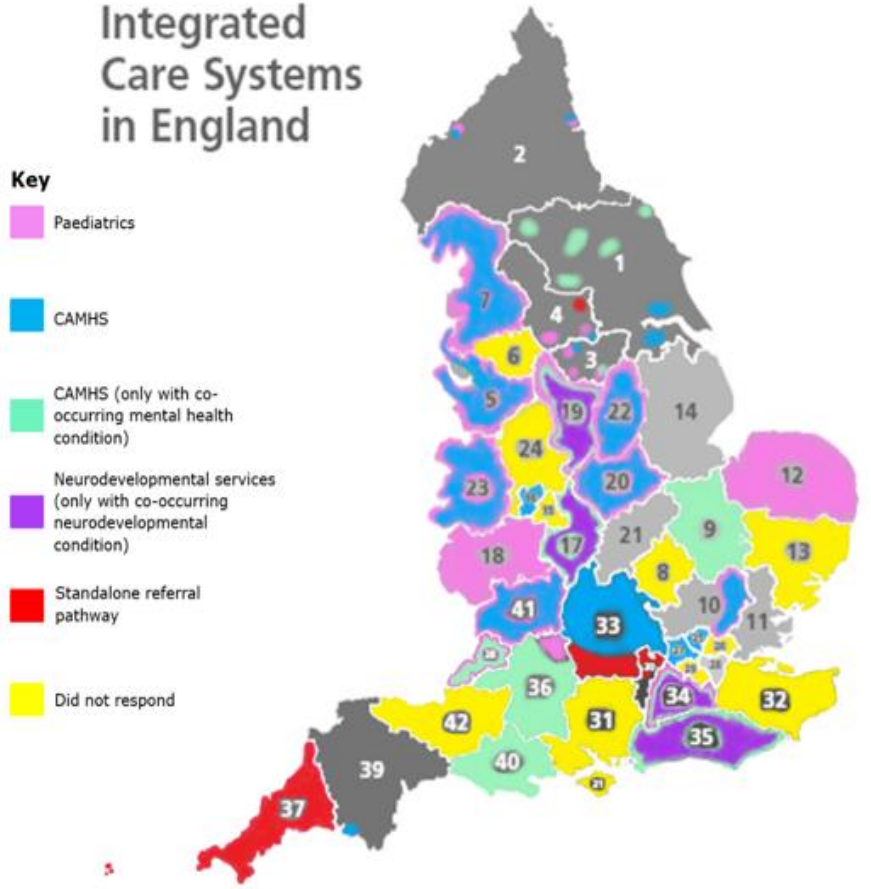
Engagement with stakeholders to shape the guidelines

Feb 2024-March 2025

Patient & Public Involvement throughout

Freedom of Information requests

- We gathered information from ICBs to describe and evaluate their current provision for tics and TS in children and young people.
- 234/295 Places provided information (34/42 ICBs)
  - Of those
    - 3% (7 Places) offer a clear pathway for tics/TS
    - 8.5% (16 Places) report no provision
- 73% (172 Places) reported 'other' provision
  - Of these, 30.8% see children & young people with tics **only** if they have a co-occurring mental health
  - 20.3% **only** if they have a co-occurring neurodevelopmental condition



Guideline development & local context

- We will engage with key stakeholders in regions of England to understand the local context to service delivery
- This will enable us to understand challenges to introducing change
- And potential solutions to overcomes those barriers
- These challenges and solutions will be reflected in our draft recommended service model

LOOKING AHEAD

How will we take this forward?

After the study ends, we aim to:

- Share our recommendations with ICBs and Places
- Work with them to develop an implementation plan, addressing barriers to implementation
- Monitor the implementation and adjust the recommendations if necessary
- Host our recommendations online
- Steering group meeting in May 2024 to develop a Policy Brief

Thank you!

Any questions?

University of Nottingham
UK | CHINA | MALAYSIA

the institute of mental health
Nottingham