A co-designed pathway for the referral, assessment, treatment and management of tic disorders in children and young people: Guidelines for implementation

These guidelines accompany the recommended service pathway developed by the 'Improving tic services in England' (INTEND) study led by the University of Nottingham. The pathway and all materials relating to the development of the pathway and guidelines are available here institutemh.org.uk/intend-study.

Pathway section	Supporting Guidance
PATHWAY SETTING	The tic disorder pathway should be offered within neurodevelopmental or children and young people's mental health services (e.g., Paediatrics or CAMHS), depending on local service configuration, to ensure the best fit with local services for children and young people. This is to ensure that provision for tic disorders is embedded within a wider service model whereby additional co-morbidities can be assessed and treated. Furthermore, professionals working within these services have the relevant expertise in child development and/or mental health. These services should add tic disorders to their standard operating procedures with appropriate funding by the Integrated Care Board. Specifically, tics must be accepted as a primary referral reason (not only secondary to another mental health or neurodevelopmental condition) as per the referral criteria specified below.
REFERRAL Referrals should be made by a GP or via appropriate secondary/specialist services using a standardised electronic referral process	Referral from Primary Care is recommended: GP teams have the appropriate medical expertise and training to ensure potential medical emergencies are correctly identified and appropriate urgent action is taken. Examples may include sudden onset chorea, symptoms or signs suggestive of brain tumour, emerging ataxia or dystonia, or other urgent medical or neurological problem. In very rare cases, tics may be a sign of another neurological abnormality and require immediate and urgent referral to A&E/Emergency Department or on-call specialist acute services. Please see NICE guideline NG127: Recommendations for children aged under 16 | Suspected neurological conditions: recognition and referral | Guidance | NICE Referral into the tic pathway from other secondary services is recommended for cases where tics are identified during screening or assessment of a neurodevelopmental, mental health, or other health condition. Referrals should be made via a standardised electronic referral process, aligned to the process for referrals of other neurodevelopmental or mental health conditions, as per the service standard operating procedures. Examples are available from the INTEND team (see **Extra Resources** section below).

REFERRAL CRITERIA If any of the below questions are true, then refer: • Have the tics been present for 12 months or more? • Are the tics causing psychological or physical distress or harm? • Are the tics causing functional impairment? **If 'Yes' to any of these questions, refer immediately** If child does not meet any of the criteria, advise them to watch and wait and come back if symptoms persist or get worse.	Referrers are required to consider the level of psychological or physical distress or harm to the child, OR whether the tics are functionally impairing (even if mild) (e.g., school absence), OR the chronicity of the tics. **If Referral Criteria Met** A referral must be made if **any** of the individual criteria are met. Practitioners should signpost the family and young person to the national charity Tourettes Action to provide support while waiting for an initial assessment. Tourettes Action offers psychoeducation materials and additional resources to support families: Tourettes Action **If Referral Criteria Not Met** If there is not enough evidence to support referral, practitioners should signpost the family and young person to the national charity Tourettes Action, which offers psychoeducation materials and additional resources to support families. Tourettes Action Primary care practitioners should also encourage the family to return if the tics worsen or become more functionally impairing/harmful. **Please note – families should be advised that signposting to Tourettes Action is not a referral to a healthcare service. The charity is not a medical service and cannot offer diagnostic assessment or therapy.**
ASSESSMENT Assessment of tics should include: • Physical & neurological health screen • Interview with child/young person and parent/carer • Assessment of tic frequency, severity and impact, using a standardised scale if possible • Screen for neurodevelopmental disorders and mental health difficulties ➢ **Reach a diagnostic decision in accordance with DSM-5 or ICD-11 criteria**	Diagnostic assessment of tics should include measures to assess the chronicity, severity and impact of the tics, including: • Physical and neurological screening is advised to assess overall health and to ensure the tics are not a sign of another neurological condition. • An interview with the child or young person and parent/carer to establish developmental history, time-course of tics, and their impact at home, school and other areas of life. • Standardised assessment scales are helpful to provide a quantitative measure of tic type and severity and to provide a baseline from which to assess change over time. Examples include the Yale Global Tic Severity Scale (YGTSS) which has the strongest evidence base, the Parent Tic Questionnaire (PTQ) which is shorter and quicker to complete and the Premonitory Urge for Tics Scale (PUTS) to assess the premonitory urge that often accompanies tics. See **Extra Resources** section below for further information about these measures). • Screening questions for mental health and other neurodevelopmental conditions which commonly co-occur with tics, including ADHD, autism spectrum disorder, OCD, anxiety and other mental health conditions. ➢ The information should be combined to reach a diagnostic decision and determine whether referral to/liaison with another service is required for co-occurring symptoms and difficulties.

TREATMENT, MANAGEMENT AND SUPPORT • All cases: Offer psychoeducation for young person and family and other relevant parties (e.g., school) • First-line treatment when treatment is needed: Offer evidence-based psychological therapies (e.g., ERP, HRT, CBIT) online, group or one-to-one format, in-person or remotely via teleconference if clinically appropriate • When therapy hasn't helped **or** isn't feasible/appropriate **or** symptom severity means medication may facilitate engagement with therapy: Offer pharmacotherapy alone or in conjunction with psychological therapy	**ALL CASES:** All CYP should be offered signposting and advice, for example, the support and resources offered by Tourettes Action for the CYP, their family or school. Psychoeducation is an essential component of care and should be offered to all children and young people with Tourette syndrome and their families, ideally at the point of diagnosis. If it is not possible to offer this immediately at the time of the assessment, then this could be delivered in group format, online or in person. If psychoeducation cannot be delivered due to lack of capacity or resource, then provision of leaflets or websites and advice to consult Tourettes Action is recommended. Tourettes Action can also be commissioned to provide these psychoeducational sessions on your behalf. **IF THERE IS A TREATMENT NEED:** Psychological (behavioural) therapies have the strongest evidence base as first line interventions for treating tics. There are two behavioural therapies (Habit Reversal Training and Exposure with Response Prevention) with a similar level of evidence. At least one of these interventions should be offered by the service and delivered by a trained therapist, either in-person/remotely, in group or individual format, depending on the preferences of the child/young person and resources available within the service. (Training for professionals in these techniques is available - see **Extra Resources** section below). Pharmacotherapy should be considered in cases where tics are causing significant psychological or physical distress, harm, or functional impairment, and behavioural therapy has been ineffective, is not clinically appropriate, or the child/young person is unable to engage with or complete therapy. Pharmacotherapy may also be considered alongside behavioural therapy where tic severity is likely to prevent meaningful engagement with treatment, or where a reduction in tic severity may support participation in and completion of the programme. Behavioural therapy and pharmacotherapy should only be offered where there is a treatment need, i.e., if there is physical/psychological harm/distress caused by the tics, or functional impairment, or where the child/young person actively want support to help manage their tics. Some children and young people may be confident in managing their tics in daily life, not want therapy or medication or may have their needs met solely with psychoeducation.

LIAISON WITH OTHER SERVICES • If ADHD/ASD assessment required, refer to/liaise with NDD service • If mental health difficulties are severe, refer to/liaise with CAMHS • If tics likely to be functional, refer to/liaise with CAMHS • If pain needs management refer to/liaise with specialist • If medication is required for tics, ADHD, or mental health, refer to/liaise with a medically trained professional (Psychiatrist, Paediatrician, Nurse Prescriber)	When screening indicates there may be a co-occurring mental health or neurodevelopmental difficulty, liaison between neurodevelopmental and mental health services is essential to facilitate assessment and management of symptoms. This should include diagnostic assessment and development of an appropriate treatment plan for the tics and co-occurring conditions. Liaison can take the form of a regular multidisciplinary team meeting OR a clear, well-specified arrangement for communication and consultation between professionals working in each service. Examples from services in England include: i) a monthly MDT to review several neurodevelopmental cases (including tic cases). The panel includes a specialist nurse (who holds primary responsibility for the tic cases), a psychiatrist and a psychologist. Tic cases with additional comorbidities which may impact upon diagnostic assessment and/or treatment are reviewed at the MDT. ii) a consultation clinic for healthcare professionals in the service to review tic cases with two tic experts in the team. Guidance is provided on assessment and management of tics in the context of comorbidities and where medication is required in addition to/instead of behavioural therapy. iii) Single Point of Access team refer complex cases held by Community Paediatrics to a specialist (tertiary) service for neurodevelopmental disorders where tics are assessed and treatment is offered. In cases where there is a need for specialist intervention not held by the service (e.g., pain management, physiotherapy, sleep problems), a referral should be made to the appropriate service.
Report summarising diagnosis and treatment plan shared with referring clinician, young person & appropriate agencies in accordance with service protocols & data protection regulations	The report should include the name of the clinic and team, the diagnosis made, treatment (if any) and contact details of the clinic for further information. The report should be shared with appropriate agencies including the Special Educational Needs Coordinator at the child's school, if consent has been given by the parent/carer (in accordance with the service's existing protocols for data sharing).

MONITORING, REVIEW & 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 timeframe (discharge letter should detail how to re-engage and the PIFU timeframe). • Shared care arrangements, if applicable, must be specified in the discharge letter.	Discharge from the service should only be considered once the child/young person and family have been provided with effective treatment (at least psychoeducation) and the tic symptoms or acceptance have improved (assessed by changes in scores on a standardised assessment tool such as the YGTSS, or other standardised assessment tool). The outcome of the intervention should be about 'living with the tics' rather than a cure or almost full remission of symptoms. Due to the waxing and waning nature of tics, the child/young person and parent/carer should be informed of the service's approach to PIFU. They should be encouraged to re-engage if further support is needed (e.g., if tics worsen or become more impairing) and how this can be achieved. This process must not be contingent on whether previous treatment options were declined or ineffective. Shared care protocols must be followed when the child/young person is discharged from the service, particularly when pharmacotherapy has been prescribed. If shared care agencies are unwilling to accept the transfer of care, the child/young person must remain within the tic service.
WORKFORCE, TRAINING & SERVICE EVALUATION	**Primary care:** To ensure primary care practitioners can identify and recognise tics, make appropriate referrals, and monitor the child/young person's outcomes, these professionals must have sufficient training in tic disorders and knowledge of referral into the pathway. As CYP with tics may be prescribed medication (including medication for co-occurring ADHD), primary care practitioners should be able to support them if they have concerns about symptoms and side effects (which may be part of medication review at regular intervals) and liaise with specialists in the tic pathway if co-prescribing as part of a shared care agreement). **Secondary/tertiary care:** The delivery of a tic pathway relies on the expertise of professionals trained within relevant disciplines of medicine, nursing and psychology. At a minimum, a tic service should include: 1) A medically trained professional (because of the need to identify neurological red flags/medical emergencies at assessment, conduct physical and neurological examination at initial assessment, and the potential for prescribing medication) 2) A professional with training in psychological models and therapies (in order to provide tic therapies such as ERP, HRT and CBIT). **Medically trained professionals include:** Paediatricians, Paediatric Neurologists, Child & Adolescent Psychiatrists/Neuropsychiatrists, Mental Health or Paediatric Nurses with advanced training in a relevant area. **Psychologically trained professionals include:** Psychologists, CBT Therapists and other allied health professionals. The service should be audited to identify areas of improvement, to align with the NICE Quality Standards Framework. Quality Network for Care Quality Commission (CQC) inspections and ratings of local health services should include consideration of tic services for CYP.

	Clinicians working in the service should be allocated time for continuous professional development (CPD) and to engage in activities related to audit, service evaluation and clinical research. Professional accrediting organisations (e.g., the Royal Colleges, British Psychological Society, the Health and Care Professions Council) should include training in mandated topics on tic disorders in CYP.

CAMHS = Child and Adolescent Mental Health Services; CBIT = Comprehensive Behavioural Therapy for Tics; CBT = Cognitive Behavioural Therapy; CQC = Care Quality Commission; CYP = Children & Young People; ERP = Exposure Response Prevention; GP = General Practitioner; HRT = Habit Reversal Training; NICE = National Institute of Health & Care Excellence; PIFU = Patient Initiated Follow-up; PTQ = Parent Tic Questionnaire; PUTS = Premonitory Urge for Tics Scale; YGTSS = Yale Global Tic Severity Scale

Extra Resources

INTEND study team:

For guidance and advice on tics, psychoeducation and clinical training:

- Tourettes Action website
- Tourettes Action eLearning Modules:
- Understanding Tourette Syndrome: this course is for anyone wanting to learn more about Tourette syndrome. It covers what Tourette syndrome is, co-occurring features and differences that accompany TS, how it affects an individual and what can be done to help and understand. The course is available in both English and Welsh.
- Understanding Tourette syndrome for GPs: this course provides clinical information, also covering the aetiology of Tourette's, other movement disorders and the current diagnostic pathway
- Great Ormond Street Hospital Tic Service: The Tic Service | Great Ormond Street Hospital

Available clinical guidelines

- NICE guidelines on neurological disorders: Recommendations for children aged under 16 | Suspected neurological conditions: recognition and referral | Guidance | NICE
- British Medical Journal Best Practice Guidance on Tic Disorders: Tic disorders - Symptoms, diagnosis and treatment | BMJ Best Practice
- European Guidelines on Tic Disorders: European clinical guidelines for Tourette syndrome and other tic disorders: summary statement - PubMed
- American Academy of Neurology guidelines on tic disorders: Practice Guideline Recommendations: Treatment of Tics in People with Tourette Syndrome and Chronic Tic Disorders

Tic Assessment Tools:

- Yale Global Tic Severity Scale

- Parent Tic Questionnaire: Chang, S., Himle, M. B., Tucker, B. T. P., Woods, D. W., & Piacentini, J. (2009). Initial psychometric properties of a brief parent-report instrument for assessing tic severity in children with chronic tic disorders. *Child & Family Behavior Therapy, 31*(3), 181–191. https://doi.org/10.1080/07317100903099100
- Premonitory Urge Scale

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