



NHS

Great Ormond Street
Hospital for Children
NHS Foundation Trust

Tics disorders: a MDT Perspective and Pathways for care

Tara Murphy, Consultant Clinical Psychologist

Tourette syndrome Clinic

Great Ormond Street Hospital NHS Trust, London

Tara.Murphy@ucl.ac.uk

Overview of Talk

- Why an MDT?
- What would an MDT look like?
- Pathways
- Current and future work



- Can you put your professional background in the chat please.

DSM – 5 Classification

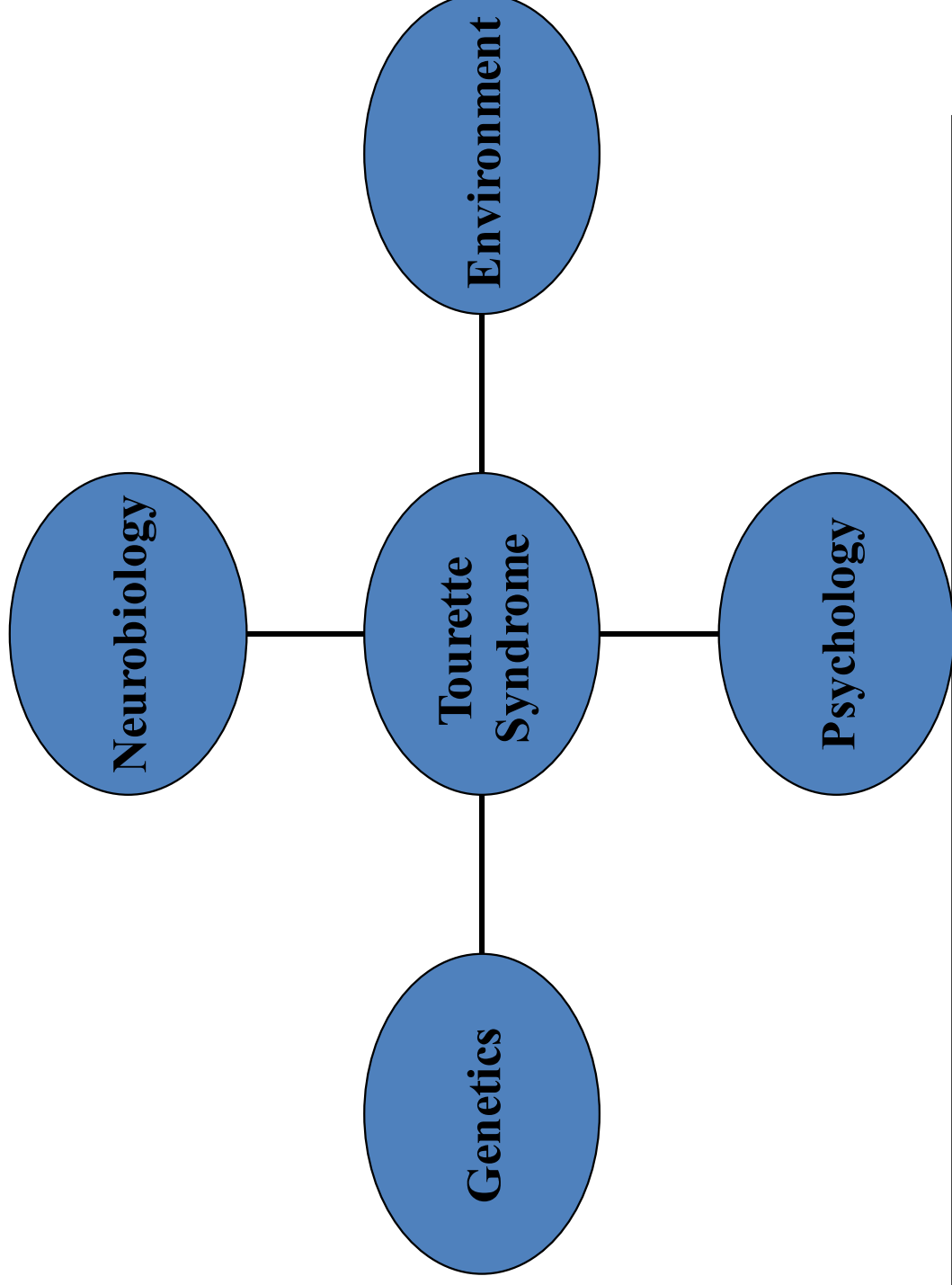
- **Neurodevelopmental disorders** – motor disorders
- Onset before age 18 years, not due to any other medical condition/substance
- **Provisional tic disorder**
 - Tics less than one year
- **Persistent motor/vocal tic disorder**
 - Either motor or vocal tics for more than one year
- **Tourette’s disorder (TS)**
 - At least two motor tics and one or more vocal tics at least one year
 - Often other symptoms and comorbidity
- **Tic disorder not otherwise specified**
 - ~~Criteria are not met for one of the specific tic disorders~~
 - E.g., onset >18 years



ICD – 11 Classification

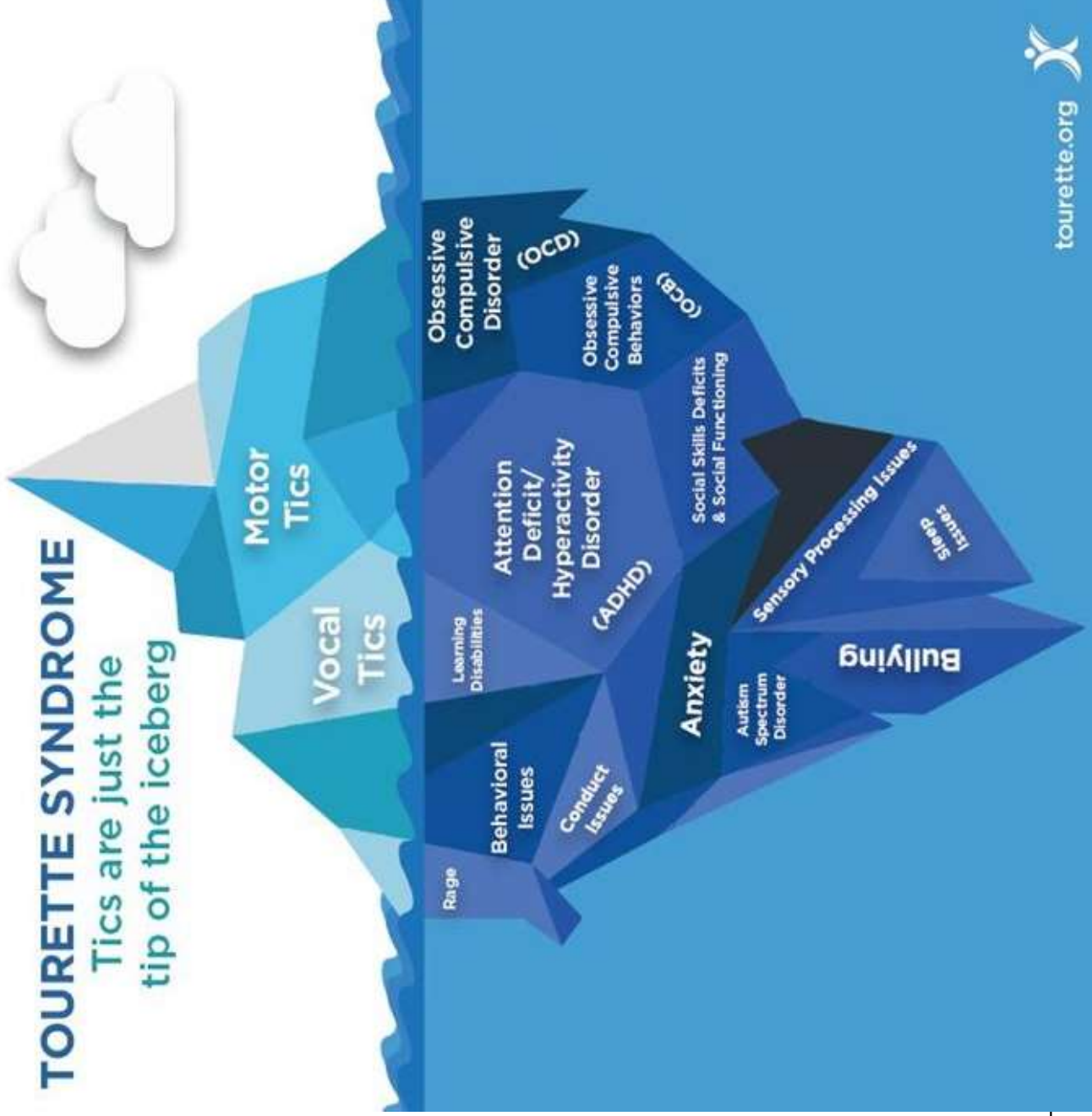
- **Disease of the Nervous system**
 - Motor Disorders**
 - **8A05.0 Primary tics or tic disorders**
 - In order to be diagnosed as Tourette syndrome, both motor and vocal tics must have been present for at least one year, although they may not manifest concurrently or consistently throughout the symptomatic course.
 - Kept the terms ‘chronic’ and ‘transient’
-

What is Tourette Syndrome?

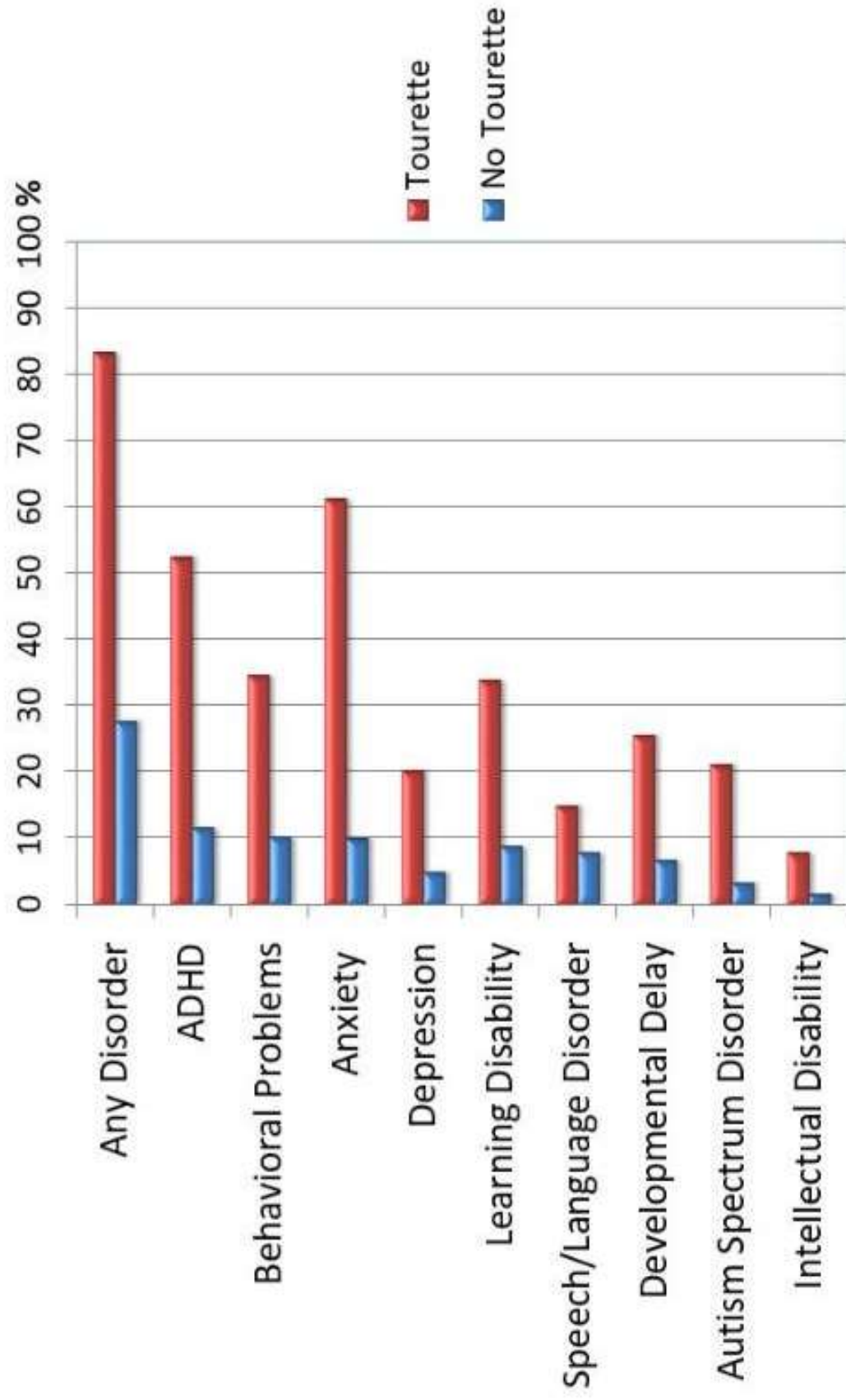


TOURETTE SYNDROME

Tics are just the tip of the iceberg



Percentage of children with and without Tourette syndrome and another mental, behavioral, or developmental disorder



Data on 51,001 US children aged 6–17 years from the 2016–2017 National Survey of Children's Health

Compulsive tics/tic-like behaviours and impulsive tics

Self-injurious behaviours

Quality of life in TS

OCD and ADHD

Autism spectrum disorder

Rage attacks

Neuropsychological impairments

Other hyperkinetic movements (e.g. dystonia, myoclonus and chorea)

Stereotypies

Functional movement disorders and vocalisations

Somatic conditions

PANS/PANDAS

Functional tics (FND)



Review | [Open Access](#) | Published: 18 October 2021

European clinical guidelines for Tourette syndrome and other tic disorders—version 2.0. Part I: assessment

Natalia Szejko, Sally Robinson, Andreas Hartmann, Christos Ganos, Nanette M. Debes, Liselotte Skov, Martina Haas, Renata Rizzo, Jeremy Stern, Alexander Münchau, Virginie Czernecki, Andrea Dietrich, Tara L. Murphy, Davide Martino, Zsanett Tarnok, Tammy Hedderly, Kirsten R. Müller-Vahl & Danielle C. Cath 

European Child & Adolescent Psychiatry **31**, 383–402 (2022) | [Cite this article](#)

3465 Accesses | **4** Citations | **24** Altmetric | [Metrics](#)

Other areas to consider

- Sleep (Ricketts et al, 2018)
 - Pain (Malek et al, 2022)
 - Headache (Ghosh, 2015)
 - Allergies (Huang et al, 2022)
 - High rates of psychopathology in mothers (25%) and fathers (18%) (Leivone et al, 2017)
-

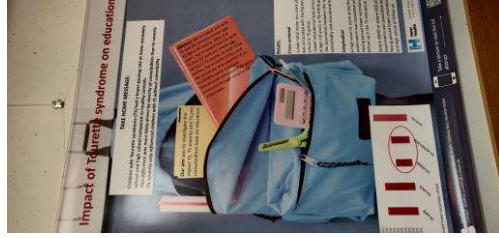
What is the impact?

How tics effect:

> BMC Psychiatry. 2016 Jan 20;16:14. doi: 10.1186/s12888-016-0717-9.

Difficulties experienced by young people with Tourette syndrome in secondary school: a mixed methods description of self, parent and staff perspectives

Ruth Wadman¹, Cris Glazebrook², Charlotte Beer³, Georgina M Jackson⁴



Driving with Tic Disorders: An International Survey of Lived Experiences

Lorena Fernández de la Cruz, PhD,¹ Helene Ringberg, MSc,² Seonaid Anderson, PhD,³ Jeremy S. Stern, PhD,⁴ and David Mataix-Cols, PhD⁵

Calidad de vida y comorbilidades psiquiátricas en pacientes pediátricos con síndrome de Gilles de la Tourette

J. Solís-García, A. Jové-Blanco, A. Chacón-Pascual, M. Vázquez-López, P. Castro-De Castro, J.J. Arballo, L. Pina-Camacho, M.C. Miranda-Herrero

Association of Tourette Syndrome and Chronic Tic Disorder With Subsequent Risk of Alcohol- or Drug-Related Disorders, Criminal Convictions, and Death: A Population-Based Family Study

Suvi Virtanen¹, Antti Latvala², Anna Sidorchuk³, Lorena Fernández de la Cruz⁴, ... Paul Lichtenstein⁵, Antti Latvala⁶, David Mataix-Cols⁷ • Show all authors
Published: September 21, 2020 • DOI: <https://doi.org/10.1016/j.biopsych.2020.09.014>

Association of Tourette Syndrome and Chronic Tic Disorders With Objective Indicators of Educational Attainment

A Population-Based Sibling Comparison Study

Ana Pérez-Vigil, MD, Lorena Fernández de la Cruz, PhD, [...] and David Mataix-Cols, PhD

Calidad de vida y comorbilidades psiquiátricas en pacientes pediátricos con síndrome de Gilles de la Tourette

J. Solís-García, A. Jové-Blanco, A. Chacón-Pascual, M. Vázquez-López, P. Castro-De Castro, J.J. Arballo, L. Pina-Camacho, M.C. Miranda-Herrero

Association of Tourette Syndrome and Chronic Tic Disorder With Violent Assault and Criminal Convictions

David Mataix-Cols, PhD, Suvi Virtanen, PhD, [...], and Antti Latvala, PhD

The effects of Gilles de la Tourette syndrome and other chronic tic disorders on quality of life across the lifespan: a systematic review

Joel Evans, Stefano Seri, and Andrea E. Cavanna

Correspondence information about the author: Erika Augustina, MD, MS

Published: December 26, 2019 • DOI: <https://doi.org/10.1016/j.pediatrneurol.2019.12.003>

Tic Disorders are Associated With Lower Child and Adolescent Family Functioning

Jennifer Vermillion, MD, Erika Augustina, MD, MS, Heather R. Adams, P, Edwin van Wijngaarden, PhD, Tanya K. Murphy, J

Correspondence information about the author: Erika Augustina, MD, MS

Published: December 26, 2019 • DOI: <https://doi.org/10.1016/j.pediatrneurol.2019.12.003>

Suggested management algorithm for children with tic disorders.

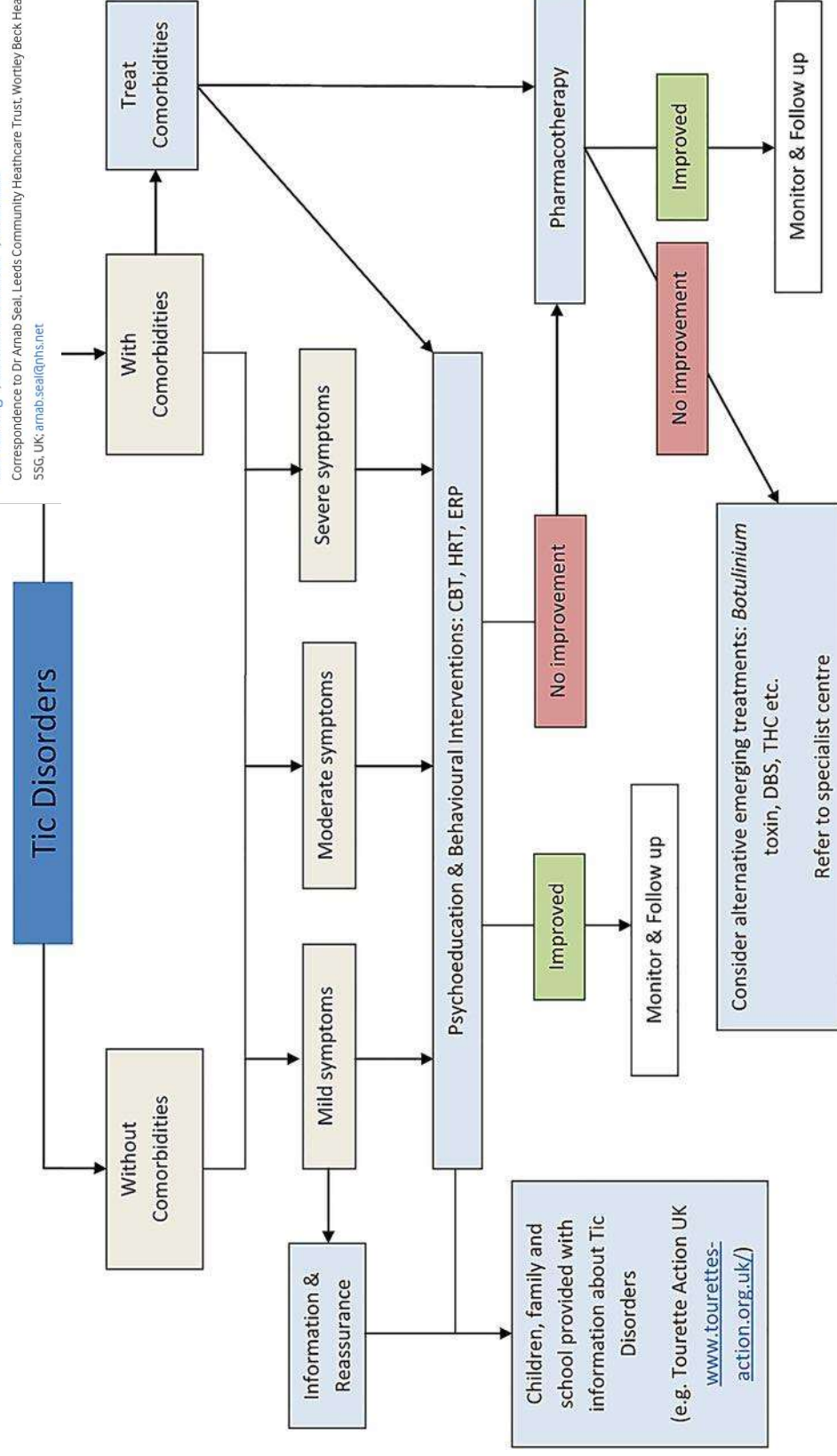
Best practice

Fifteen minute consultation: tics and Tourette syndrome

FREE

Min Tsui Ong¹, Santosh R Mordekar¹, Arnab Seal²

Correspondence to Dr Arnab Seal, Leeds Community Healthcare Trust, Wortley Beck Health Centre, Leeds LS12 5SG, UK; amab.seal@lchs.net



Min Tsui Ong et al. Arch Dis Child Educ Pract Ed 2016;101:87-94

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European clinical guidelines for Tourette syndrome and other tic disorders—version 2.0. Part II: psychological interventions

Per Andrén ^{# 1}, Ewgeni Jakubowski ^{# 2}, Tara L Murphy ³, Katrin Woitecki ⁴, Zsanett Tarnok ⁵, Sharon Zimmerman-Brenner ⁶, Jolande van de Griendt ⁷, Nanette Mol Debes ⁸, Paula Viefhaus ⁴, Sally Robinson ⁹, Veit Roessner ¹⁰, Christos Ganos ¹¹, Natalia Szejko ^{12 13 14}, Kirsten R Müller-Vahl ², Danielle Cath ¹⁵, Andreas Hartmann ¹⁶, Cara Verdellen ¹⁷

Affiliations + expand

PMID: 34313861 PMCID: PMC8314030 DOI: 10.1007/s00787-021-01845-z

Review > Eur Child Adolesc Psychiatry. 2022 Mar;31(3):425–441.

doi: 10.1007/s00787-021-01899-z. Epub 2021 Nov 10.

European clinical guidelines for Tourette syndrome and other tic disorders—version 2.0. Part III: pharmacological treatment

Veit Roessner ¹, Heike Eichele ², Jeremy S Stern ⁴, Liselotte Skov ⁵, Renata Rizzo ⁶, Nanette Mol Debes ⁵, Péter Nagy ⁷, Andrea E Cavanna ⁸, Cristiano Termine ⁹, Christos Ganos ¹⁰, Alexander Münchau ¹¹, Natalia Szejko ^{12 13 14}, Danielle Cath ¹⁵, Kirsten R Müller-Vahl ¹⁶, Cara Verdellen ^{17 18}, Andreas Hartmann ^{19 20}, Aribert Rothenberger ², Pieter J Hoekstra ²², Kerstin J Plessen ^{23 24}

European clinical guidelines for Tourette syndrome and other tic disorders—version 2.0. Part IV: deep brain stimulation

Natalia Szejko ^{1 2 3}, Yulia Worbe ^{4 5}, Andreas Hartmann ⁶, Veerle Visser-Vandewalle ⁷, Linda Ackermans ⁸, Christos Ganos ⁹, Mauro Porta ¹⁰, Albert F G Leentjens ¹¹, Jan-Hinmerk Mehrkens ¹², Daniel Huys ¹³, Juan Carlos Baldermann ¹³, Jens Kuhn ^{13 14}, Carine Karachi ^{5 6 15}, Cécile Delorme ⁶, Thomas Foltynie ¹⁶, Andrea E Cavanna ¹⁷, Danielle Cath ^{18 19}, Kirsten Müller-Vahl ²⁰

Affiliations + expand

PMID: 34605960 PMCID: PMC8940783 DOI: 10.1007/s00787-021-01881-9

Psychoeducation

(Wu & McGuire, 2018)

Causes of tics

Clinical course of tic disorders

Factors that expression

Common problems with tics

Psychoeducation -intervention

The Neurobehavioral Model

Myths and misconceptions

School, workplace, extended system.....

UK Opinions (Cuenca et al, 2015)

Online survey in UK N= 295 & N= 42 interviews

Difficulties in receiving specialist treatment:

- Delays
- Cancellations
- Insufficient funding
- little information about tics diagnoses from health professionals

“...After I got diagnosed two years after that, that's when I started to get information about it. ...I would have liked it to have been just more of a frequent

Thing when I actually needed the help more. Some sort of like guidance on

things I could do, instead of just finding out that I had to deal with it all on my own.”

Lack of understanding

- Health professionals have insufficient knowledge
- Health professionals have limited training
- Families had to attend different health services to receive treatment

“...most of the places we have been to about my Tourettes like it seems like no one actually knows about it, like we know more than them... when we go there they usually ask us about it more than we ask them”

UK Opinions

- Medication was common and young people / parents described benefits.
 - Adverse effects were described and meds stopped
 - Access to behavioural interventions for tics was limited
 - 76% of parents wanted this for their child
 - young people had reservations about about BTs
 - effectiveness
 - practicality
-

Positive experiences

- Young people who had behavioural interventions felt that it helped them to recognise, control and / or manage their tics
- The treatment involved learning and practising behaviours similar to some of the behaviours they have used to control their tics, and they were described as “natural”.

“ ...it took me a while but now it works more... I don't have to think oh I must bite my lip I just do it without thinking, but at the time I was just like oh this isn't going to work but it got better.”

Working together



- GP
 - Medical consultant (Paediatrician, Neurologist, Psychiatrist)
 - Psychologist
 - Speech and language therapist
 - Occupational therapist
 - Nurse
 - Educators
 - Mental Health Specialist
 - Family therapists
-

Home > Our services > Hospital services > TANDeM

• Our hospital services
 > **TANDeM**
 • Patients
 • Referrals
 • Team

Tics and neuro-developmental movements (TANDeM)

Caring for children and young people with tics and neuro-developmental movements

What is the TANDeM service?

The Tic and Neuro-Developmental Movements (TANDeM) team provides services for children and young people, up to the age of 18, with tics and other movement difficulties.

Our clinic is part of the children's neurosciences centre at St Thomas' Hospital, the largest children's neurosciences service in Europe.

We provide a 'stepped care' approach to treatment, meaning that your child's treatment will be matched to their needs. We offer a range of treatment options, including:

- child and parent/carer therapy groups (habit reversal, mindfulness)
- psychoeducation ev
- school liaison
- medication reviews
- individual psychology
- neuropsychology as



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The Tic Disorder Service

The Tic Disorder Service at Great Ormond Street Hospital (GOSH) is a multi-disciplinary clinic headed by Dr Holan Liang (Child and Adolescent Psychiatrist), Dr Sara Shavel-Jessop (Consultant Paediatric Neuropsychologist) and Dr Tara Murphy (Consultant Paediatric Neuropsychologist).

The Tourette syndrome clinic is a national specialist service that cares for children and young people up to 17 years of age. We have a specialist multi-disciplinary team that works closely with other departments within GOSH, and with neurology, in particular. The care of children is always shared between local services and the specialist service here at GOSH.

There is a strong research collaboration between GOSH and the other Tourette syndrome clinics in the UK, and we have an international reputation for clinical research into psychological treatments for Tourette syndrome, including cognitive (learning) profiles as well as studies of the genetics of tic disorders and the role of infection.



Multidisciplinary Telemedicine Care for Tourette Syndrome: Minireview

Shan-shan Cen^{1,2†}, Jun Yu^{1†}, Qiao Wang³, Wissam Deeb^{1,4}, Kai-liang Wang³, Aparna Wagle Shukla¹, Irene Malaty¹, Adolfo Ramirez-Zamora¹, Jian-guo Zhang³, Wei Hu^{1*} and Fan-gang Meng^{3,5*}

¹ Program in Movement Disorders and Neurorestoration, Department of Neurology, Fixel Institution for Neurological Diseases, University of Florida, Gainesville, FL, United States, ² Department of Neurology, Xuanwu Hospital of Capital Medical University, Beijing, China, ³ Department of Functional Neurosurgery, Beijing Neurosurgical Institute, Beijing Tiantan Hospital, Capital Medical University, Beijing, China, ⁴ Department of Neurology, University of Massachusetts, Worcester, MA, United States, ⁵ Chinese Institute for Brain Research, Beijing, China

Tourette syndrome (TS) is a childhood-onset, chronic neuropsychiatric disorder characterized by multiple motor and vocal tics. TS poses a considerable burden on both patients and health care providers, leading to a major detriment of educational success, occupation, and interpersonal relationships. A multidisciplinary, specialist-driven management approach is required due to the complexity of TS. However, access to such specialty care is often dramatically limited by the patients' locations and the specialists' geographic clustering in large urban centers. Telemedicine uses electronic information and communication technology to provide and support health care when distance separates participants. Therefore, we conducted this mini-review to describe the latest information on telemedicine in the assessment and management of TS and discuss the potential contributions to care for TS patients with a multidisciplinary approach. We believe that telemedicine could be a revolutionary method in improving medical access to patients with TS.

OPEN ACCESS

Edited by:
Takashi Morishita,
Fukuoka University, Japan

Reviewed by:
Davide Martino,
University of Calgary, Canada
Xiantun Zhu,
The Chinese University of
Hong Kong, China

***Correspondence:**
Wei Hu

BUT....

Pathways are complicated & inconsistent

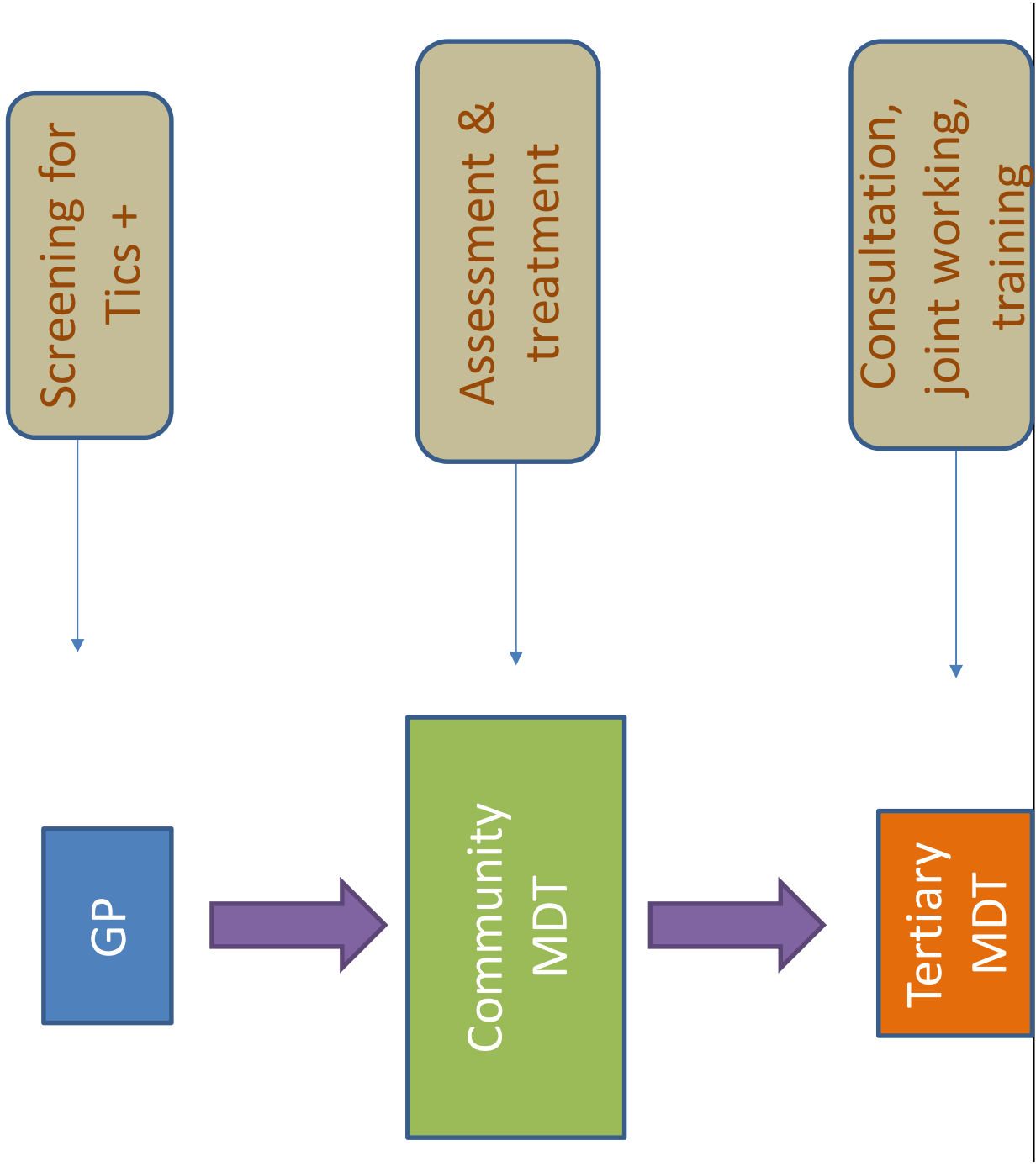
Many regions:

- have no pathway for tics

- won't / cannot accept referrals

- either seen in paediatrics or psychiatry

Limited access to behavioural therapy for tics, psychological care for commonly co-occurring conditions



Gold Standard

- Clear referral pathway from primary to tertiary care
 - Framework such as NICE guidelines
 - Assessment within a multi / interdisciplinary team
 - Emphasis on evidence-based intervention
 - Clear commissioning routes
 - Links between health and education and social care
-

Currently

- Pathways being developed in St Helens, Merseyside, Cornwall CCGs
- Consultation with MPs
- Tourette Action

Parliamentary Debate

Posted on 31 January 2022 by Fiopa McChouan

For the first time in 10 years, TS is debated in the Houses of Parliament.



Thanks to the tireless efforts of TA CEO Emma McNally, the lack of services and funding for TS is now being discussed at the highest level.

Following on from last year's petition, which gained over 71,000 signatures, Emma's local MP, Conor McGinn bought the issue to parliament where it was discussed last week.

This is a monumental step towards improved awareness and support for the TS community.

If you missed the live debate, we have the recording for you below. Simply scroll along to the start of the discussion at 11:00am to watch the full 23 minute debate.

[Watch the debate here](#)

The screenshot shows the Tourette Action website interface. At the top, there is a navigation bar with the logo 'Tourette action' and a search bar. Below the navigation bar, there is a main content area with a green header that says 'Contact the Helpdesk' and 'The Tourette Action Creativity Awards for Young People'. The main content area features a large image of a group of people in a meeting room, with a man in the foreground looking at a laptop. To the right of the image is the article title 'Welsh Senedd debate TS services' and a sub-headline 'Thanks to the tireless efforts of Helen Devere-Graham, the lack of services and funding for TS in Wales is now being discussed at the highest level.' Below the article text, there is a small video player with a play button icon. At the bottom of the page, there is a footer with social media icons and a 'Donate' button.

Future Survey

- Associate Professor Maddie Groom, UoN
 - Experiences of healthcare professionals
 - Consult experts to develop a recommended service model
 - Invitation in next 12-24 months
 - Survey requests to recruit a representative sample from across specialities
-


Summary

- Children with TS rarely just have needs with TS
- MDT for assessment and intervention
- Telemedicine

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Articles

Therapist-supported online remote behavioural intervention for tics in children and adolescents in England (ORBIT): a multicentre, parallel group, single-blind, randomised controlled trial

Prof Chris Hollis FRCPsych^{a, b, c, d, e, f, g, h, i, j, k, l, m, n, o, p, q, r, s, t, u, v, w, x, y, z}, Charlotte L Hall PhD^{a, c, e, f, g, h, i, j, k, l, m, n, o, p, q, r, s, t, u, v, w, x, y, z}, Rebecca Jones MSc^{a, c, e, f, g, h, i, j, k, l, m, n, o, p, q, r, s, t, u, v, w, x, y, z}, Louise Marston PhD^{a, c, e, f, g, h, i, j, k, l, m, n, o, p, q, r, s, t, u, v, w, x, y, z}, Mairee Le Novere MSc^{a, c, e, f, g, h, i, j, k, l, m, n, o, p, q, r, s, t, u, v, w, x, y, z}, Rachael Hunter MSc^{a, c, e, f, g, h, i, j, k, l, m, n, o, p, q, r, s, t, u, v, w, x, y, z}, Beverley J Brown PhD^{a, c, e, f, g, h, i, j, k, l, m, n, o, p, q, r, s, t, u, v, w, x, y, z}, Charlotte Sanderson DClinPsy^{a, c, e, f, g, h, i, j, k, l, m, n, o, p, q, r, s, t, u, v, w, x, y, z}, Per Andren MSc^{a, c, e, f, g, h, i, j, k, l, m, n, o, p, q, r, s, t, u, v, w, x, y, z}, Sophie D Bennett PhD^{a, c, e, f, g, h, i, j, k, l, m, n, o, p, q, r, s, t, u, v, w, x, y, z}, Liam R Chamberlain BSc^{a, c, e, f, g, h, i, j, k, l, m, n, o, p, q, r, s, t, u, v, w, x, y, z}, Amber Evans MSc^{a, c, e, f, g, h, i, j, k, l, m, n, o, p, q, r, s, t, u, v, w, x, y, z}, Nadia Kourouba MSc^{a, c, e, f, g, h, i, j, k, l, m, n, o, p, q, r, s, t, u, v, w, x, y, z}, Caitlin McKenzie MSc^{a, c, e, f, g, h, i, j, k, l, m, n, o, p, q, r, s, t, u, v, w, x, y, z}, Prof Isabel Heyman PhD^{a, c, e, f, g, h, i, j, k, l, m, n, o, p, q, r, s, t, u, v, w, x, y, z}, Kareem Khan PhD^{a, c, e, f, g, h, i, j, k, l, m, n, o, p, q, r, s, t, u, v, w, x, y, z}, Joseph Kilgaff BA^{a, c, e, f, g, h, i, j, k, l, m, n, o, p, q, r, s, t, u, v, w, x, y, z} ... Prof Elizabeth Murray PhD^{a, c, e, f, g, h, i, j, k, l, m, n, o, p, q, r, s, t, u, v, w, x, y, z}

Thank you for listening

Comments, queries, questions

