

intend

improving Tic services in England

Aim:

To improve tic services in England for children and young people (CYP) by establishing an evidence-based, co-produced service pathway for the referral, assessment and treatment of tics



Many children and young people have difficulties with accessing appropriate healthcare services for tics in England

- Tics are sudden, involuntary, repetitive movements or vocalisations
- They can cause physical pain and contribute to poor mental health and quality of life
- They often first emerge during early childhood and are lifelong for many
- It's estimated that around 1% of CYP in England have tics

Methods:

1

Understanding current organisation of tic services across England

Freedom of Information requests sent to local NHS organisations across England to gather data on tic service provision for CYP, including data on:

- Referrals
- Assessment processes
- Treatments available

2

Exploring healthcare professionals' experiences of providing assessment & treatment to CYP with tics

Healthcare professionals (HCPs) (n=184) surveyed nationally to identify:

- Barriers and facilitators to providing effective care
- Training needs

3

Identifying essential features of an effective service pathway for CYP with tics

Three-round consensus survey of a panel of Tourette syndrome experts (n=48) conducted to reach agreement on the essential features of an effective service pathway

4

Developing the pathway and accompanying clinical guidelines

Combining study findings with consultation of additional stakeholders to guide design

Findings:

Only 12 service providers in England have a full care pathway, offering both assessment and treatment

- Considerable regional disparities
- 5 of 12 full pathway providers are located in London

National survey respondents shared their frustrations with a lack of resources, including funding, training and national clinical guidelines

- Majority of HCPs identified need for further resources, including training, to support with both assessing (n=150, 81.5%) and treating tics (n=146, 79.3%)

Overall, tic services need urgent improvement and HCPs require more guidance and support

The intend Pathway:

Consensus study experts rated 62 service features on level of importance to include within a care pathway

- Items related to service design; referral; assessment, treatment and monitoring; professional roles; training and funding
- 43 core features reached agreement for inclusion, which were then developed into a pathway

The pathway was further informed through additional stakeholder consultation, including:



In-person workshops with HCPs



Meetings with ten PPI panel members (parents/carers of CYP with tics)

Study lead: Maddie Groom
Maddie.Groom@nottingham.ac.uk

Next steps:

Implementing and testing the pathway within local NHS services

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