



Quarterly Update - June 2025



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Study Updates

Annual ESSTS Conference

Members of the INTEND team attended the **annual European Society for the Study of Tourette Syndrome Conference** in Athens last month.

We presented a poster on our findings from the study, which was well-received and led to international interest in the pathway!

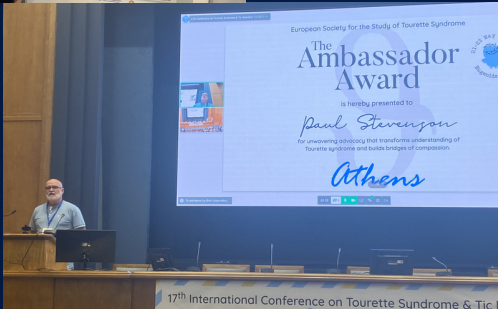


Annual ESSTS Conference

Olivia Hastings, a member of the ORBIT team, also presented a poster on the **lessons learned from working with Patient and Public Involvement (PPI) groups in tic research**. This included learnings from working with the INTEND PPI panel.

A huge well done, Olivia!

Congratulations also to **Paul Stevenson**, a member of the National Tourette Syndrome Steering Group, who received the **first ever Ambassador Award** at the conference!



Publication Papers

Our first academic paper has now been **accepted for publication** in **BMJ Mental Health**!

The paper focused on **FOI requests** that investigated tic service provision across England & our **National Survey** of healthcare professionals.

We will be submitting our second paper, detailing our **Delphi survey**, **regional workshops with healthcare professionals** and development of the **INTEND service pathway** by next month!
For a summary of our study findings, please see our new infographic on the last page.





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NICE Early Value Assessment

The National Institute for Health and Care Excellence (NICE) have released their final guidance as part of an Early Value Assessment (EVA) of **digital therapy** for chronic tic disorders and Tourette syndrome.

They recommend ORBIT (Online Remote Behavioural Intervention for Tics) for **use in clinical practice** whilst further evidence is generated. The ORBIT team have met with NICE and are planning how to fulfill the further evidence requested by NICE.

Find out more here: <https://www.nice.org.uk/guidance/hte25>



Tourette Syndrome Awareness Month

Every year, Tourette Syndrome Awareness Month takes place from May 15th to June 15th

This year, Tourettes Action's campaign for Awareness Month was called **#Misunderstood**

As part of the campaign, they created a deeply moving short film, featuring Grace, who lives with TS, and a choir of individuals with the condition.

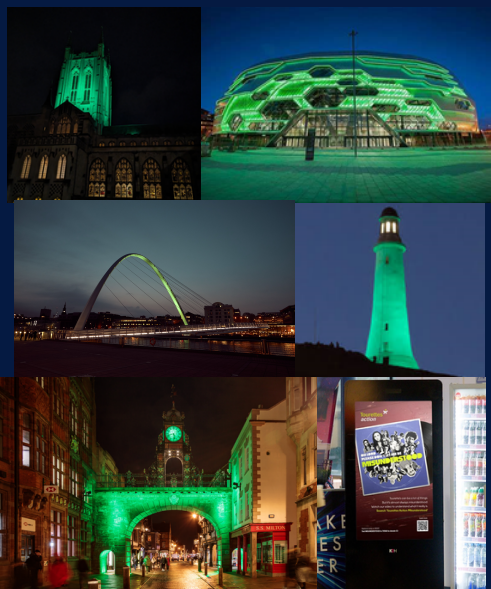


Tourettes Action's Campaign for Awareness Month

Together, they perform a stunning reinterpretation of Nina Simone's "Don't Let Me Be Misunderstood." **See the short film here**

Many places around the UK turned green to support Awareness Month!

Posters were also displayed in cinemas across the UK, raising awareness of the campaign.



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
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Next steps:

Implementing and testing the pathway within local NHS services

INTEND website



FUNDED BY

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