

ImproviNg Tic services in EnglaND – the INTEND study: understanding the current organisation of services for children and young people and identifying features of an effective care pathway

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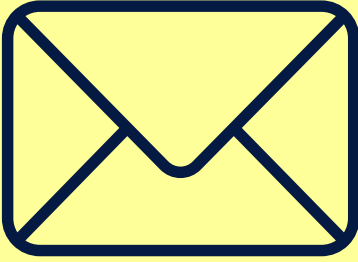
Background

- Children and young people (CYP) **struggle** to access **appropriate healthcare services** for tics and Tourette syndrome (TS) in England^{1,2,3}
- Current** local referral pathways have been described as ‘**unclear**’² in many areas in the country
- Access to **specialist clinicians** and **recommended behavioural therapies** are **limited**⁴
- To reduce the risk of poor long-term outcomes for CYP with tics, **prompt access** to care through the National Health Service (NHS) is **crucial**
- Improvements** to tic services in England are **vital** to ensure that healthcare needs of CYP with tics are met

The INTEND study had four areas of work:

1

Freedom Of Information requests




To understand current organisation of tic services across England

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

- Referrals
- Assessment processes
- Treatments available

2

National Survey




To explore healthcare professionals’ experiences of providing assessment and treatment to CYP with tics

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

- Barriers and facilitators to providing effective care
- Training needs

3

Delphi Survey

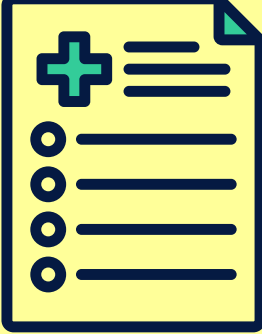


To identify essential features of an effective service pathway for CYP with tics

Three-round Delphi survey of a panel of TS experts (n=48) conducted to reach consensus on the essential features of an effective service pathway
Survey items developed based on previous study⁵ and discussions with experts from tic services

4

Pathway Development



To develop the service pathway design and accompanying guidelines

Pathway and guidelines further informed through additional stakeholder consultation, including:

- In-person regional workshops with HCPs
- Online meetings with ten Patient and Public Involvement (PPI) panel members (parents/carers of CYP with tics)


Findings

1

Freedom of Information requests

- Only 12 service providers in England have a full care pathway, offering both assessment and treatment
- Considerable regional disparities
- Five of 12 full pathway providers located in London⁶

Full care pathway providers located on a map of England




2

National Survey

Respondents shared frustrations with **lack of resources**, including:

- Funding
- Training
- 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%)⁶



3

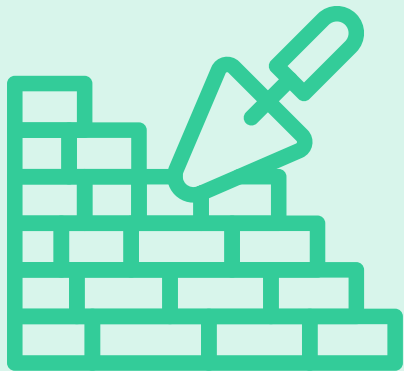
Features of the INTEND Pathway

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

Items were related to:

- Service design
- Referral
- Assessment
- Treatment and monitoring
- Professional roles
- Training and funding

Final 43 service features approved to guide pathway design



4

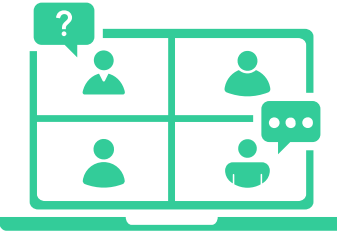

The INTEND Pathway design and accompanying clinical guidelines

PPI Panel provided input on:

- Referral criteria
- Importance of psychoeducation being available at each stage of pathway

HCPs at regional workshops facilitated development of entire pathway, including:

- Service structure
- Healthcare professionals required within pathway
- Monitoring, review and follow up
- Referral routes



Study findings and engagement with stakeholders combined to create pathway and accompanying clinical guidelines

➔ Next steps: Implementing and testing the pathway within local NHS services

Conclusion

Findings from the INTEND study have provided information on where and how improvements can be made to tic services for CYP
Further work is in development to conduct an implementation and evaluation study to implement the INTEND service pathway on a local level to ensure effective tic service delivery across England

References

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