Investigating the Current Organisation of Tic Services in England through Freedom of Information Requests

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Background
- Children and young people (CYP) with Tic Disorders do not have access to suitable NHS support in England—including effective assessment, diagnosis and treatment
- Tic services in England are critically lacking:
  - Referral pathways are unclear
  - Availability of specialist tic services is insufficient
  - No established clinical guidelines
- Freedom of Information (FOI) requests: requests that are sent to public organisations in order to access information

Integrated Care Boards
- Integrated Care Boards (ICBs): Statutory NHS organisations that bring together the NHS and local health services
- ICBs are made up of one or more geographical regions, referred to as Places
- There are 42 ICBs in England, made up of 295 Places

Aims/Method
Aims:
- To understand how tic services are currently organised in England
- To map provision of tic services in different geographical regions

FOI requests inquired:
- Do Places commission a standalone referral pathway for CYP with tics?
- If not, what services are CYP referred to?
- FOI requests sent to all 42 ICBs

Support available for CYP with tics within each ICB

Findings
3% of Places commission a standalone referral pathway
- Mostly located in South of England and Northern England; none in Midlands or East of England
- In some Places, no NHS support available for tics
- 42.8% of Places had no plans to improve tic Services
- CYP with tics most commonly referred to Paediatric services, Child and Adolescent Mental Health services and neurodevelopmental services
- Referral acceptance into services sometimes dependent on comorbid conditions being present
- The INTEND Patient and Public Involvement (PPI) panel consisting of ten parents/carers of CYP with Tic Disorders said these findings reflect their struggles to access adequate support

Conclusion
- Unclear, standardised referral pathways: available services differed considerably between Places
- Imbalance between service development and clinical need: many Places did not plan to improve services for tics

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