

Exploring Services for Tics in Children and Young People in England

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Introduction

Many children and young people with tics and Tourette Syndrome in England are unable to access services due to a lack of provision in their local area. We spoke to clinical and lived experience experts in tic disorders and they told us that there are too few professionals with appropriate training in the assessment and/or treatment of tics and that this presents a barrier to the delivery of tic services. Indeed, research suggests that there is a median delay of 2.8 years from age of tic onset to age of diagnosis in Tourette's Syndrome (Debes et al., 2008). Of those diagnosed, many are discharged without follow-on care, likely due to a lack of specialists in this area (Bhikram et al., 2021).

Aim: We conducted research to understand the current services across England. We also explored whether Integrated Care Boards (ICBs) had plans to improve services and/or provide clinicians with further training.

Methods

Freedom of Information (FOI) requests are an effective tool to access publicly held data on service information that is not otherwise disclosed (Fowler et al., 2013).

Whilst they appear to be underused by researchers, they can provide quality data at the national level (Clifton-Sprigg et al., 2020).

ICBs are responsible for coordinating and commissioning services in a particular area in the UK. They are responsible for funding services to improve health, deliver higher-quality care and improve value for money. For this reason, we targeted ICBs across England to understand which services are commissioned of services for children and young people with Tourette Syndrome.

To develop our FOIs, we consulted commissioning experts, healthcare professionals and academics. FOI items were pilot-tested first.

The FOIs asked for information on:

- whether ICBs across the United Kingdom offer stand-alone services for children and young people with tics or Tourette Syndrome
- who is the provider of this service if offered.
- how children and young people with tics are provided with services outside of stand-alone treatments.

FOIs were sent to 10 ICBs from Nov 2022 to May 2023



References:

Debes, N.M., H. Hjalgrim, and L. Skov, *Limited knowledge of Tourette syndrome causes delay in diagnosis*. *Neuropediatrics*, 2008. **39**(02): p. 101-105.

Bhikram, T., et al., *An International survey of health care services available to patients with Tourette syndrome*. *Frontiers in psychiatry*, 2021. **12**: p. 206.

Clifton-Sprigg J, James J, Vujić S. Freedom of Information (FOI) as a data collection tool for social scientists. *PLoS one*. 2020; **15**(2):e0228392–e0228392.

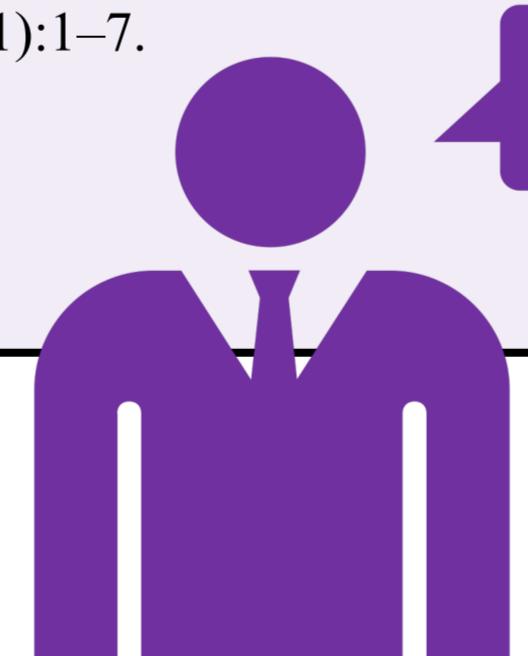
Fowler AJ, Agha RA, Camm CF, Littlejohns P. The UK Freedom of Information Act (2000) in healthcare research: a systematic review. *BMJ open*. 2013; **3**(11):1–7.

Discussion

Of 10 ICBs, only two appear to offer stand-alone services for children and young people with TS. This demonstrates the gap in access to services for young people, suggesting awareness of such a gap is pertinent to improve current services.

Considering that one ICB did not disclose information on services for children and young people with TS, and two ICBs did not disclose information on colleagues' interests, further revision of our FOI is likely required. Despite this, we believe that our initial responses identify the considerable lack of stand-alone services for children and young people with TS.

Two ICBs propose that they are open to changing their commissioning priorities if there is an indicative need for more services. This evidently shows that research is needed to highlight the current needs of the TS population.

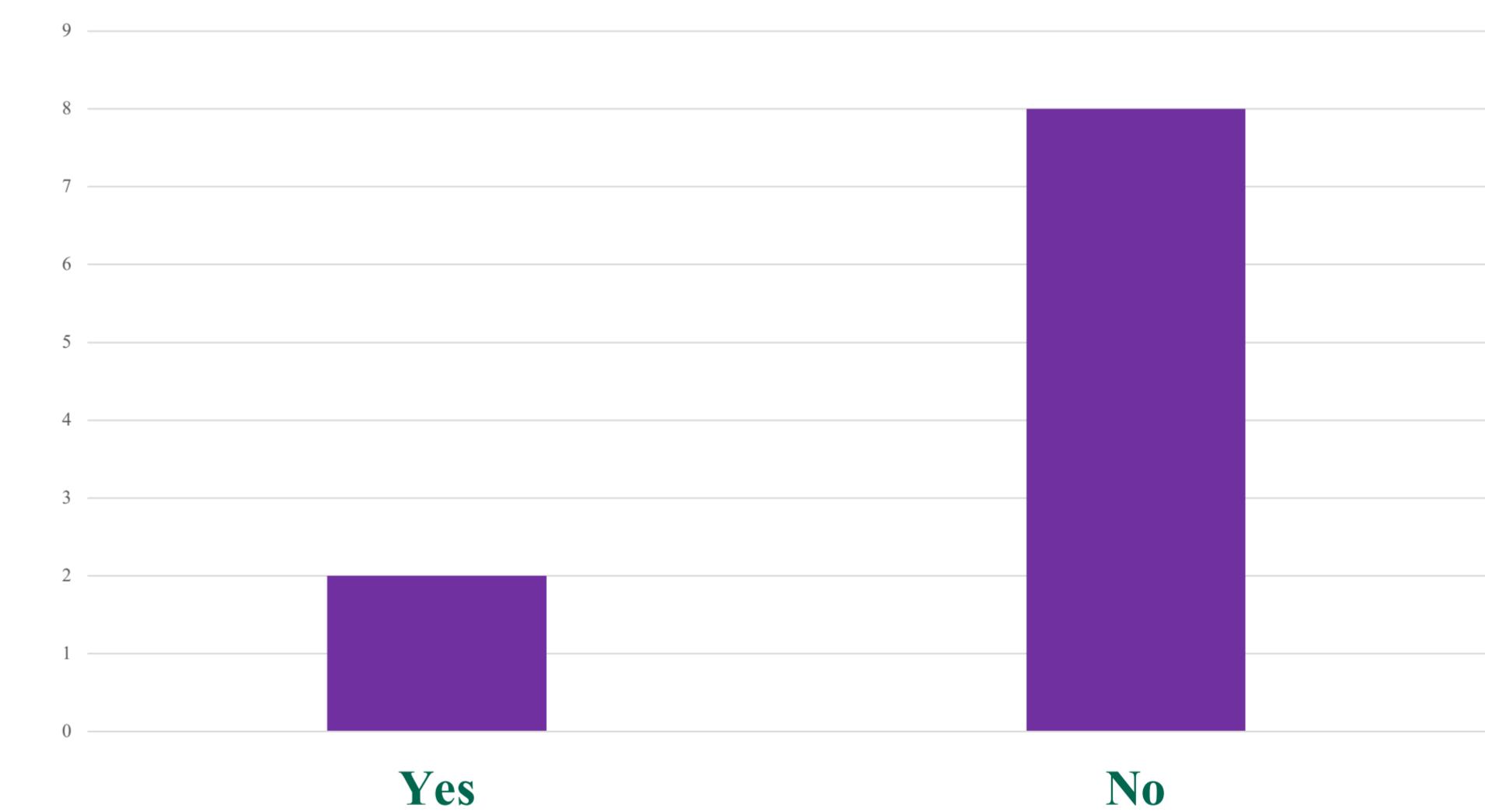


Results

What services are provided for children and young people with TS?

So far, we have received FOI responses from 10 ICBs and it appears that only 2 areas of the United Kingdom currently offer stand-alone services for children and young people with tics. Some of the remaining 8 ICBs instead offer general therapeutic support, but this is only available when the child also has a confirmed mental health disorder. Others refer them to self-help and charitable services.

Do you offer stand-alone services for tics?



Are there any plans to improve access and support for children and young people with tics?

We asked five ICBs whether there were any plans for improvement. Two ICBs stated that no improvements were planned. Another two ICBs stated that they were currently conducting a needs assessment and that if TS is identified as a specific need/gap they would consider improvements. One ICB did not disclose.

Are clinicians interested in receiving more training in the treatment and assessment of tics for children and young people?

We asked five ICBs whether colleagues at their ICB would be interested in receiving training, clinical support and guidelines advice for treating and assessing children and young people with tics. Two ICBs said they would not be interested in receiving additional information or accessing clinical support or education about tics. However, they both said that they may be willing if a current gap was established by their clinical teams. One ICB said that they would be interested, whilst two ICBs did not disclose it.