

"For the love of God just refer me"

A co-produced qualitative project into the struggles of accessing healthcare services for those living with Tourette Syndrome in the UK

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Rationale

In the United Kingdom, there are currently no medical guidelines for TS meaning there is a lack of specialist provision and no clear referral process to get access to healthcare support and/or diagnosis.

Our Aim

To explore the lived experience of children and young people, their parents, and adults with tic disorder or Tourette Syndrome, including their experiences of accessing healthcare for their tics, to inform **scientific** and **public understanding**.

Methods and Analysis

Our project is joined by educational professionals, charity representatives, researchers and lived experience advocates who have been involved throughout the project, with inclusion in grant development, data collection, analysis and dissemination.

We ran 7 online focus groups with 3 young people, 10 adults and 10 parents recruited from support groups and social media. Our focus groups were facilitated with a lived experience partner. Questions included:

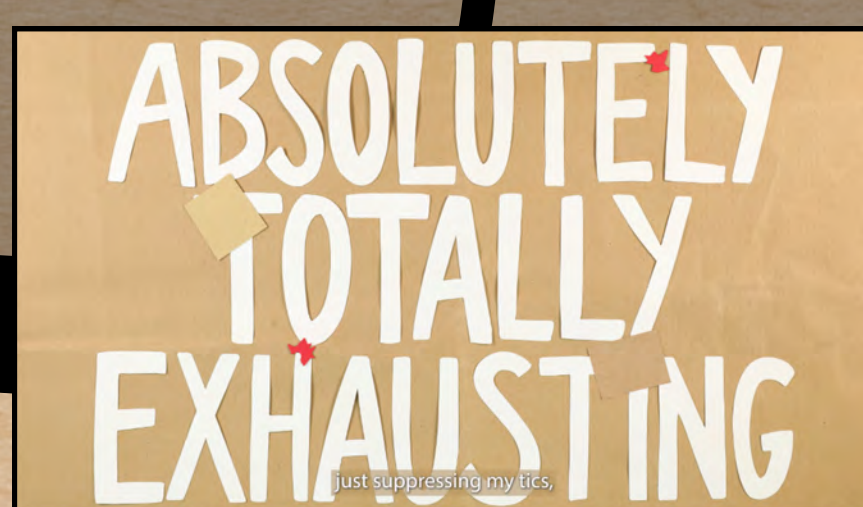
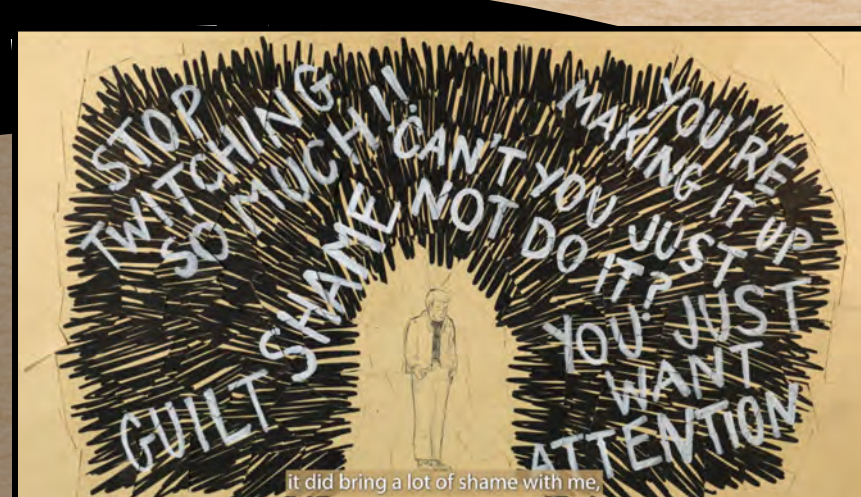
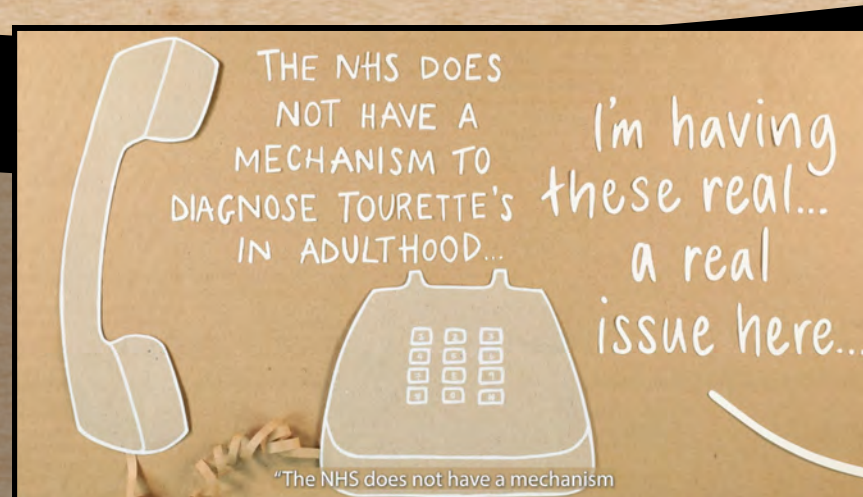
How has your journey been accessing support for your tics?

Do you think your life would have been different if your medical journey was different?

What are your experiences of living with Tourette's Syndrome or with a tic disorder?

What do you do to help with your symptoms?

We partnered with an animation company, Woven Ink, to share our findings. Spoken words from participants who consented to sharing their audio were used to develop the animation.



Reflexive thematic analysis was used to develop themes. Five themes were created:

Results

Theme 1

The healthcare system is not structured in a way that prioritises and supports Tourette Syndrome

"It needs to be like a combined service"

Theme 2

Negative experiences result from healthcare professionals having a lack of knowledge or being dismissive

"My GP didn't know, so I went off and Googled"

Theme 3

A diagnosis acts as a gatekeeper to support, acceptance and information and when withheld or delayed, can prolong difficulties

"If we had an earlier diagnosis and therefore early support and possibly earlier medication... maybe her Tourettes possibly wouldn't be as severe as it is now"

Theme 4

A lack of available treatment, limited treatment options and fragmented access to care lead to difficulties accessing treatment

"Nobody will even say well I'll put you on the waiting list"

Theme 4b

Socialising provides a space for support, sharing and learning online and in-person

"I seem to have to find more information from the people around me than I can from like looking up or talking to professionals"

Theme 5

Preventative and responsive strategies are used to support with managing TS at home

"All of my techniques have all been my own suggestion"

Implications

Posts on social media led to the animation reaching **over half a million people**, including members of parliament. Training for healthcare staff could deliver a more **compassionate and informative service** to those receiving treatment or diagnoses. Reviewing the structure of healthcare services may identify how treatment could be delivered in a more supportive manner and **improve access to care**.

Watch the animation here



and please share!