Portfolio Volume 1: Major Research Project

Functional Tics: Towards an Understanding of Young People's Lived Experiences

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Abstract

Background and Aims: Functional tics (FTs) are sudden, involuntary movements and/or vocalisations that resemble tics such as those seen in Tourette Syndrome but are thought to arise from functional neurological mechanisms. Since the COVID-19 pandemic, there has been a sharp and widely documented rise in FT presentations across the world, particularly among young people, with research linking the influence of social media platforms like TikTok to the sudden and rapid rise of what was previously a relatively rare presentation. Despite this surge, the lived experiences of young people with FTs remain significantly underexplored. This study aimed to understand what it is like for young people to live with functional tics and how they affect their daily lives, psychological wellbeing, sense of self, experiences of seeking support, and how they find ways to cope and adapt despite widespread misunderstanding and limited help.

Method: Participants were recruited through third-sector organisations and online platforms using purposive sampling. Twelve young people aged 13–24 took part in semi-structured interviews, reflecting on the onset, impact, and ongoing effects of FTs. Reflexive Thematic Analysis was used to analyse the data.

Findings: Four themes were identified from the data: *Life Upended*, which describes the sudden disruption and emotional upheaval caused by the onset of FTs; *Help that Hurts*, which explores experiences of seeking support across healthcare, education, and interpersonal systems, and how unmet needs often pushed participants toward online spaces or personal networks for understanding; *Under the Spotlight*, which captures the impact of sudden visibility on participants' psychosocial wellbeing and sense of identity; and *Coming to Terms*, which explores the evolving, dynamic relationship between young people and their FTs, shaped by time, psychological shifts, practical adaptations, new coping strategies, and resilience, amongst ongoing challenges.

Conclusion: This study highlights the need for greater awareness of the lived experiences of young people with FTs, including what helps and what hinders their well-being. The findings highlight the importance of compassionate, containing communication from professionals and the detriments of dismissive or invalidating responses. They also point to the complexity of online spaces, which offer both risks and benefits, and how young people navigate them. This study provides insight into a poorly understood condition and invites more attuned, context-sensitive approaches across both clinical and research contexts.

Chapter 1: Introduction

Functional tics, previously considered rare, saw a marked increase in presentations during the Covid-19 pandemic. This surge prompted heightened clinical and scientific interest, particularly in attempts to classify these tics and distinguish them from neurodevelopmental conditions such as Tourette Syndrome. While it is important to understand what functional tics are (or are not), what remains largely absent from the literature are the perspectives of the very young people who experience them. Little is known about the impacts of functional tics on day-to-day lives, wellbeing, identity, any support they have received, and/or their ability to cope. This thesis addresses this gap through a qualitative exploration of young people's lived experiences.

1.1 Chapter Overview

The chapter outlines the personal motivation and theoretical framework behind this research and provides a contextual overview of functional neurological disorder and neurodevelopmental tics to demonstrate how functional tics are situated amongst these two diagnoses. It also outlines the recent surge of functional tic presentations, the resulting research, and the theories proposed to better understand this phenomenon. Considering the above, the foundation of the empirical study that follows is set, and the chapter concludes with a rationale for the systematic literature review.

1.2 Theoretical Perspective

On Terminology

The terminology used to describe functional symptoms, including functional tics, has varied considerably, reflecting the cultural norms, beliefs, and theoretical positions of the era or author. For contextual accuracy, the terminology of the original sources or time periods is preserved. However, the term 'functional tics' (FTs) is used when referencing these symptoms more broadly or in the context of this study, per the preference of its participants.

Motivation and Researcher Position

My first encounter with functional symptoms took place in a paediatric liaison service, where, without knowing very much about Functional Neurological Disorder (FND), I witnessed a young person spontaneously collapse during an initial assessment. I felt panic and urgency to act, followed by immense confusion when the consultant calmly told me and their parent to "just wait." When they could eventually sit up, the consultant explained that they had experienced a functional seizure; not epileptic, but nonetheless very real. He explained what this meant clearly and compassionately, emphasising that the

distress this brought into their life was entirely understandable and justified, and outlined what was known about the mechanisms of FND and what helps to relieve it.

This moment left a lasting impression on me, highlighting visceral reality of functional symptoms, and the worry, confusion, and misunderstanding that permeate them, for individuals, families, and professionals alike. Since then, my understanding has evolved beyond my initial emotions, which I know represent a fraction of what those with functional symptoms themselves experience. This is my motivation: to contribute to the amelioration of this distress, not least as it continues to be compounded by stereotypes that functional symptoms are "made up" or "all in your head"; stereotypes that have been, in part, upheld by a medical establishment that I am both a part of and seeking to critically examine.

I believe that functional symptoms and their effects are indisputably real, and value lived experience as a legitimate form of knowledge that enables a robust and meaningful understanding of the condition and the people experiencing it. My clinical experiences and values, including compassion, self-awareness, and social justice, have undoubtedly shaped this research. Although I am an "outsider researcher" (Braun & Clarke, 2013) with no personal experience of functional symptoms, I cannot be considered neutral either. Therefore, I recognise the opportunities and limitations of this position (Dwyer & Buckle, 2009), and have critically examined how my own experiences, beliefs, and values inform the questions, interpretations, and meanings which form this research; this is detailed in Chapter 3.

I am bound by an ethical imperative to respond to distress with empathy, and to challenge systems and narratives that perpetuate it (BPS, 2021; HCPC, 2024). As a researcher, I hope to do this by contributing to the body of knowledge on how functional symptoms, particularly functional tics, are experienced, seeking to offer this population the same kindness and validation I witnessed from that consultant many years ago.

Ontology & Epistemology

To meet this objective meaningfully, it is necessary to articulate the ontological and epistemological stance underpinning this research. Crotty (2003) defines ontology as "the study of being". Engaging in ontological inquiry involves exploring "'what is there that can be known'" or "'what is the nature of reality"' (Guba & Lincoln, 1989). Epistemology, on the other hand, is an instrument of ontology, asking instead, "how, and what, can we know" (Willig, 2008). Both are essential for a researcher to consider, as different philosophical approaches will inevitably come to affect how they undertake their investigations.

Critical Realism

This research was undertaken from a critical realist (CR) theoretical perspective (Bhaskar, 1978), which combines realist ontology with relativist epistemology (Stutchbury, 2022). Ontologically, CR assumes the existence of true, objective realities which can be studied. Its epistemological stance, however, recognises that these realities are nonetheless mediated by the environments and contexts they exist within, meaning that the ways individuals make sense of these realities are shaped by their social, cultural, and psychological experiences.

This is particularly important when it comes to FTs, precisely because the nature and legitimacy of functional symptoms has been scrutinised throughout history. Although their specific, structural cause has yet to be identified, their impact is tangible and evident in people's lives. A CR lens acknowledges the reality of their experiences without needing 'biological proof' to consider FTs real. It also enables an exploration of how people understand and interpret this reality, given their unique personal and social contexts. In this way, CR facilitates a more nuanced understanding of what it means to live with FTs and offers a framework that pivots away from binaries such as real/imagined, or physical/mental, that have permeated perceptions of functional symptoms.

1.3 Functional Neurological Disorder

Historical Overview

FND refers to a spectrum of neurological symptoms, including seizures, sensory changes, limb weakness, gait disturbance, speech disturbance, and tremor, which are experienced as genuine and involuntary, but are inconsistent with known neurological disease (Hallett et al., 2022). Despite being the third most common presentation in neurology clinics (Ahmad & Ahmad, 2016), FND remains misunderstood and stigmatised. Throughout history, it has been known by many names: 'hysteria', 'conversion', 'medically unexplained', 'psychogenic', 'pseudo', reflecting both evolving aetiological theories and attitudes (Madva et al., 2019; Raynor & Baslet, 2021).

Early descriptions can be traced back to ancient Egypt and Greece, where a woman's 'wandering womb' was implicated in inexplicable maladies, or, 'hysteria' (from the Greek *hystera,* meaning uterus) (Madva et al., 2019). In the Middle Ages, such unexplained symptoms were attributed to demonic possession. Enlightenment-era physicians pivoted towards physiological explanations, reframing hysteria as a dysfunction of the nervous system, rather than a supernatural affliction. By the late 19th century, hysteria became a focal point of budding neurological science, thanks to Jean-Martin Charcot. A significant part of

his three-decade tenure at the Salpêtrière Hospital were his weekly lectures, where Charcot 'exhibited' his patients: predominantly young, otherwise healthy, women and their array of unexplained symptoms, which included displays of uncontrolled emotions, sexual assertiveness, physical contortion, and seizures, amongst others (Hustvedt, 2011). Despite Charcot's enduring determination to identify a lesion that could prove that hysteria was a condition of an 'organic' nature, he began to entertain its possible psychological causes towards the end of his life (Gelfand, 2025).

Charcot was likely influenced by his protégé, Pierre Janet. Janet believed that hysteria resulted from dissociation, or a 'split', between the conscious and unconscious due to trauma or psychological vulnerability, leading to symptoms beyond one's usual sense of control (O'Sullivan, 2016). Another keen attendee of Charcot's lectures, Sigmund Freud (1937), elaborated Janet's theory by proposing that it was repressed emotional experiences, particularly ones related to sexual trauma, which underwent 'conversion' into physical symptoms as a psychological defence.

Contemporary Conceptualisations

Freud's (1937) theory and its ensuing iterations lay the foundations of psychodynamic thinking around 'conversion disorder', which persisted throughout most of the 20th century (Raynor & Baslet, 2021). Whilst providing a feasible explanatory model, it also reinforced beliefs around patients' psychological weaknesses, inviting disparaging assumptions about their mental wellness, and worse yet, inauthenticity. As medical technology advanced, electroencephalography and structural imaging were frequently used to demonstrate that 'nothing was physically wrong' with people experiencing functional symptoms. A lack of clear cause was believed to indicate an absence of illness, reinforcing a divide between 'real' and 'imagined' symptoms (Raynor & Baslet, 2021).

Cotemporary theories have shifted from this binary position towards more integrative, neurocognitive conceptualisations. For example, predictive processing theories suggest that irregular 'top-down' expectations, which are influenced by past experiences and increased self-monitoring, override sensory signals and generate involuntary sensations or movements (Drane et al., 2021). Amongst others, this theory sits within with the biopsychosocial model, which posits that functional symptoms result from the dynamic interplay of neurobiology, psychological functioning, and social context (Drane et al., 2021; Pick et al., 2019).

Gender remains an important contextual factor: women are disproportionately diagnosed with FND, comprising between 70-80% of cases (Goldstein et al., 2019; Lidstone et al., 2022). Whilst this disparity

has been attributed to higher rates of trauma, particularly sexual abuse, amongst women (Kletenik et al., 2020, 2022), not all individuals with FND report adverse experiences, suggesting that trauma alone cannot account for this gender difference (Ludwig et al., 2018). Given FND's historical association with the uterus and femininity, this disparity may reflect a diagnostic bias, shaped by enduring assumptions about emotionality and credibility, contributing towards identifying FND more readily in women whilst considering alternative explanations for similar symptoms in men (Edwards & Aybek, 2020).

The diagnosis of FND has also shifted to focusing on the identification of various 'positive signs' to indicate the presence of FND, rather than an exclusion of a presumed disorder (Aybek & Perez, 2022). In this way, instead of being told 'it *isn't* that', individuals should be assured that their nervous system *is* experiencing a type of functional, rather than structural, error. Despite these developments however, the current Diagnostic and Statistical Manual of Mental Disorders (DSM-5) lists 'Conversion Disorder' in parentheses alongside FND (American Psychiatric Association [APA], 2013), demonstrating the enduring legacy of its psychodynamic roots.

Terminology and Stigma

Terms which emerged from psychodynamic thinking, such as 'pseudo', 'psychogenic', or 'medically unexplained', are deeply embedded within the existing FND literature, representing enduring perceptions about the illegitimacy of functional symptoms. This terminology alienates the very people whose experiences it describes, who find it offensive and pessimistic with regard to prognosis (Loewenberger et al., 2020). Conversely, clinicians report a lack of confidence and uncertainty around diagnosing FND (Lidstone et al., 2020), which drives factors like negative attitudes, fear, and avoidance in their interactions with patients, ultimately leading to 'passing the buck' to other specialities, perpetuating a cycle of impersonal and fractured care (Barnett et al., 2022). Similarly, several studies have found that clinicians frequently perceive FND symptoms to be fake or voluntary (Sahaya et al., 2012; Whitehead & Reuber, 2012; Worsely et al., 2011).

Although generalisation of healthcare providers' assumptions should be made cautiously, these results nonetheless highlight existing stigma amongst the very people one would turn to for support. Stigmatising experiences within FND encompass dismissal, prejudice, harm and negative attitudes from professionals, resulting not only in a lower quality of life, but persistent shame, low self-esteem, and social exclusion (McLoughlin et al., 2024). A recent international survey highlighted that over 80% of people with FND report experiencing FND-related stigma, and that this generates concern about both current and future care (Butler et al., 2021), with meta-ethnographic evidence indicating that many withdraw

from social or healthcare interactions in anticipation of FND-related stigma (Foley et al., 2024). Unsurprisingly, when people with FND experience clear diagnosis, validation, and access to relevant multidisciplinary treatment, clinical outcomes can improve significantly (Demartini et al., 2014; LaFaver et al., 2021; Nielsen et al., 2015).

Functional Movement Disorder

Functional Movement Disorder (FMD) is a subtype of FND, characterised by unwanted and involuntary movements such as tremor, dystonia, gait disturbance, and parkinsonism (Hallett, 2016). Like FND, FMD is diagnosed through positive signs, such as inconsistencies with known neurological factors or mechanisms, and symptom distractibility and suggestibility (Jankovic et al., 2006; Thenganatt & Jankovic, 2014), sharing many of the same underlying mechanisms as FND (Park, 2024). Another possible symptom within FMD are FTs. Before 2020, research on FTs was limited, reflecting their clinical rarity; they were estimated to comprise only 4-5% of presentations in specialist movement disorder clinics (Baizabal-Carvallo & Fekete, 2015; Ertan et al., 2009). Despite this, there was an established understanding that FTs were distinct from their neurodevelopmental counterparts (Ganos et al., 2019).

1.4 Neurodevelopmental Tics

Neurodevelopmental tics (NTs) are defined as 'sudden, rapid, recurrent, and nonrhythmic motor movements or vocalisations' (APA, 2013). They typically do not follow predictable patterns and can vary in frequency, timing, and intervals between occurrences (Ueda & Black, 2021). NTs are classified as either 'simple' or 'complex', based on their phenomenology (Table 1):

Table 1: Types of Neurodevelopmental Tics

Type	Simple	Complex
Motor	Brief, repetitive, abrupt and seemingly non-purposeful movements *Examples: blinking, grimacing, jerking head, shrugging shoulders*	Coordinated, seemingly purposeful patterns of movement, involving multiple muscle groups *Examples: tapping, hopping, touching objects, echopraxia[1], copropraxia[2]*
Vocal	Brief, involuntary sounds typically resulting from muscular contractions *Examples: whistling, throat clearing, inhalations and exhalations, coughing, tongue clicking*	Words, phrases, or sentences *Examples: shouting, yelling, echolalia[3], coprolalia [4]*

[1] *Involuntary imitation of movements*
[2] *Involuntary inappropriate or obscene gestures*
[3] *Involuntary imitation of speech*
[4] *Involuntary utterance of inappropriate or obscene speech*

Simple motor tics typically involve movement of the head and upper body, whilst complex tics incorporate broader muscle groups and more coordinated behaviours. Black et al. (2016) describe the sensation of a tic as an "inevitable capitulation to an almost irresistible urge." This 'premonitory urge' is a sensory phenomenon often reported prior to the tic itself and is temporarily relieved by the act of 'ticcing' (Bliss, 1980; Woods et al., 2005).

Tics are a common paediatric phenomenon, although accurately estimating their prevalence is challenging due to their often-transient nature. Some studies estimate that as many as 20% of children may experience tics at some point in their childhood (Scahill et al., 2014). Typically, they first appear in early childhood (between 3-8 years old), tending to wax and wane until peaking in severity in early adolescence (10-12 years old), before gradually diminishing (Ueda & Black, 2021). Whilst early presentations often manifest as simple movements, enduring tics evolve into complex behaviours, following a rostro-caudal progression[5] (Bloch & Leckman, 2009).

Tic Disorders

Persistence, severity, or increasing complexity of tics may be indicative of an underlying tic disorder. The DSM-5 classifies tic disorders into five categories, differentiated by age of onset, duration, and types of tics (APA, 2013). Within the three neurodevelopmental tic diagnoses, 'provisional tic disorder' refers to the presence of motor and/or vocal tics for less than a year. If the tics persist beyond 12 months but remain limited to either motor or vocal tics (not both), the diagnosis becomes 'persistent (chronic) motor or vocal tic disorder' (APA, 2013).

Tourette Syndrome (TS), perhaps the condition most associated with tics, is diagnosed when one has experienced multiple motor tics and at least one vocal tic for over one year. Across these three diagnoses, the onset of tics must occur before the age of 18, where symptoms cannot be attributed to another medical condition. Compared to other tic disorders, TS is often associated with more complex tics and a greater likelihood of comorbid psychiatric conditions (Müller-Vahl et al., 2019), as discussed below.

'Other specified tic disorder' and 'Unspecified tic disorder' are used when a person experiences significant impairment and distress from tics but does not meet the criteria of the three main tic disorders. The 'other specified' category is applied when a clinician specifies which diagnostic criteria is not met, whilst the 'unspecified' category is utilised in the absence of requisite information to make a diagnosis.

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[5] *Progressing from the head downward*

Prevalence and Clinical Features

Whilst transient tics are relatively common, neurodevelopmental tic disorders are less prevalent. For example, TS is estimated to affect between 0.4-3% of children, with a known male preponderance at a reported rate between 1.5:1 to 4:1 (Ueda & Black, 2021). Adult onset is incongruous with diagnostic criteria (Black et al., 2021), and is often either attributed to a secondary cause (Ueda & Black, 2021), or a recurrence of childhood tics, rather than de novo onset (Black et al., 2021).

Neurodevelopmental tics frequently co-occur with other psychiatric conditions. A large proportion of individuals with TS present with at least 1 (85.7%) or 2+ (57.7%) psychiatric conditions; attention-deficit/hyperactivity disorder (ADHD) and obsessive-compulsive disorder (OCD) are particularly common, alongside anxiety and depression which are seen across child and adult populations (Hirschtritt et al., 2015). There is also increasing recognition of the overlap between tic disorders and autism spectrum disorder (ASD). Research suggests that up to 11% of children with ASD meet criteria for TS, and that as many as 22% experience chronic motor tics (Canitano & Vivanti, 2007).

Such comorbidities have significant implications for diagnosis and treatment: clinicians must carefully distinguish tics from related behaviours, such as compulsions (as in OCD) or motor stereotypies (as in ASD), as misidentification can lead to inappropriate, and at times, contraindicated, approaches to treatment (Manbeck et al., 2023). Despite evidence that tic disorders cause psychosocial impairment from childhood into adulthood (Eapen et al., 2016), there are no NICE guidelines for the treatment of tics. A multidisciplinary approach encompassing pharmacological interventions and comprehensive behavioural therapies can improve the wellbeing of children and families affected by tic disorders (Pringsheim, Holler-Managan, et al., 2019).

Functional Tic-Like Movements

Given the structured diagnostic criteria of TDs, presentations outside of these parameters prompt consideration of alternative explanations, including a functional overlay. The clinical features of 'Functional Tic Like Movements' (FTLMs; Ganos, 2019), are a later age of onset (including in adulthood), a marked female preponderance, movements more commonly involving the limbs or trunk, without rostro-caudal progression and difficulties with symptom suppression (Müller-Vahl et al., 2023). Perhaps most informative, however, is the individual's broader context, as FTLMs commonly appear within a constellation of other functional symptoms (Ganos et al., 2019), usually in the aftermath of physical or psychological stress (Dreissen et al., 2016; Stone et al., 2009). To ensure accurate diagnosis, experts emphasised the importance of comprehensive and discerning clinical assessment, inviting particular

attention to phenomenology, context, and history (Ganos et al., 2019). At the time, Ganos et al. (2019) called for further research to move FTLMs from "unknown unknowns" to "known unknowns"; this call was soon answered.

1.5 The Pandemic Surge

A Sudden Spike

In the United Kingdom, March 2020 marked the beginning of multiple national lockdowns in response to the COVID-19 pandemic[6]. For young people (YPs) in particular, the restrictions intensified known mental health risk factors such as social isolation (Breaux et al., 2023), and suddenly prevented access to various protective supports, including school, peers, and recreational activities. Emerging data suggest the pandemic was a precipitant and exacerbator of mental health difficulties: the proportion of YPs with a probable mental health disorder increased from 10.8% in 2017 to 16% in 2020 (Vizard et al., 2020), rising again to 20-23% in 2023 (Newlove-Delgado et al., 2023). Similarly, longitudinal studies reported increasing severity of depression, anxiety, and stress amongst YPs during lockdown periods (Orban et al., 2024; Wolf & Schmitz, 2024).

Concurrently, clinicians in movement disorder clinics began to observe a rise in referrals of YPs with no prior tic histories presenting with symptoms akin to FMD. One US-based clinic reported a near doubling of paediatric-age FMD diagnoses within the first eight months of the pandemic compared to the previous year (Hull et al., 2021). A particularly notable trend was the increase in 'severe tic-like attacks', particularly amongst adolescent girls (Heyman et al., 2021). These presentations were thought to reflect a partial functional component, resembling the tic-like attacks described in pre-pandemic literature (Demartini et al., 2015; Robinson & Hedderly, 2016).

Despite their pre-pandemic rarity, clinics across North America, Europe, and Australia noted 15-30 fold increases in referrals for "functional tic-like behaviours" (FTLBs; Pringsheim et al., 2021), with some describing the emerging phenomenon as a "pandemic within a pandemic" (Olvera et al., 2021). In the UK, the rise was particularly pronounced. In 2019-2020, London's two specialist tic and neurodevelopmental movement clinics reported receiving 4-6 functional tic referrals per year, whilst the period between November 2020 and January 2021 saw this rise to 3-4 per *week* (Heyman et al., 2021).

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[6] *Henceforth referred to as 'the pandemic'*

The Rush to Classify and Differentiate

Although the prevailing hypothesis was that these presentations were functional rather than neurodevelopmental, some uncertainty remained around their underlying drivers. What was striking about these early cases was not just the incidence of new referrals, but also the rapid proliferation of similar symptoms seen across regions. This enabled researchers to aggregate and compare cases across international clinics, growing the literature to better understand FTLBs as an emerging phenomenon.

A Clearer Classification

Cavanna et al. (2024) conducted a comprehensive review of such studies, finding that most fell into two categories: descriptive case series, or comparative cohort studies. The former documented the symptom profiles of those with FTLBs, whilst the latter examined how these differed from cohorts with confirmed TDs. This research lent credence to earlier observations: FTLBs were seen predominantly in adolescent (12+) and young women as opposed to childhood onset of neurodevelopmental tics; likewise, their onset was consistently found to be acute, with symptoms escalating across a matter of hours or days, usually with a specific situation or trigger linked to their start (Cavanna et al., 2024).

In contrast to neurodevelopmental tics, FTLBs appeared as complex from onset. This included 'sprawling' limb movements, falling or freezing in place, throwing objects, or self-injurious acts; vocal tics manifested in unusually long and idiosyncratic phrases, sometimes direct references of those expressed by prominent tic-content-creators (Cavanna et al., 2024). Some German studies reported individuals demonstrating both motor and verbal tics seen specifically in videos by a popular German male YouTuber with TS (Fremer et al., 2022; Paulus et al., 2021). However, the authors emphasised that the behaviours observed in his videos were an atypical portrayal of TS and were likely to be functional in nature (Müller-Vahl et al., 2022), casting doubt on the neurodevelopmental origins of these behaviours. This observation led the authors to propose a new model of 'mass functional illness' (MFI), shaped by online exposure (discussed below).

To better understand the symptoms proliferating from online tic-content, two studies conducted analyses of TikTok videos tagged with tic-related hashtags. Olvera et al. (2021) found that coprolalia and self-injurious behaviours were present in the majority of TikTok videos they examined, despite being relatively rare in TS. Similarly, Zea Vera et al. (2022) found that over half the videos they assessed featured coprophenomena, long, complex vocalisations, environmentally triggered responses, and aggression; these results indicated that most online tic content was inconsistent with the known phenomenology of TDs.

Likewise, those with FTLBs had a distinct psychiatric profile. Although anxiety and depression are known comorbidities in TDs, these symptoms appeared more prevalent in FTLB cohorts (Cavanna et al., 2024), with anxiety present in nearly 70% of some samples (Cavanna et al., 2023; Ducroizet et al., 2025; Martino et al., 2023). Many also reported symptom onset following some form of psychosocial trigger (Cavanna et al., 2024), and presented with additional functional symptoms (Cavanna et al., 2023; Ducroizet et al., 2025). Compared with TS and TD cohorts, FTLBs had lower rates of ADHD and OCD (Cavanna et al., 2023; Fremer et al., 2023). Likewise, some studies reported that around a quarter of those with FTLBs had pre-existing ASD diagnoses (Cavanna et al., 2023; Martino et al., 2023); around double the rate usually associated with TDs (Kalyva et al., 2016).

An Accurate Diagnosis?

As a clearer clinical picture of FTLBs came into relief, efforts turned towards formalising a diagnosis. In 2022, the European Society for the Study of Tourette Syndrome (ESTSS) amalgamated a set of diagnostic criteria, organised by major and minor criteria, having synthesised case data, clinician experience, and comparative analyses, to enable clinicians to accurately identify FTLBs and distinguish them from TDs (Table 2; Pringsheim et al., 2023):

Table 2: ESTSS Criteria for Diagnosing Functional Tic-Like Behaviours

Criteria Type	Criterion	Specification
Major	1. Age at symptom onset	Onset at 12 years or older
	2. Rapid onset and evolution of symptoms	Symptoms escalate over hours or days, with a linear increase over time, peaking over weeks to months. Patient / family can often identify date and particular context around symptom onset
	3. Tic Phenomenology	At least 4 of 9 features: (a) More complex than simple tics (b) Variability in tic reproduction (c) Complex movements (e.g., hitting, throwing) (d) No rostro-caudal progression (e) Vocal tics include words/statements (f) Mimicry of social/cultural influences (g) Large within-day symptom variability (h) Frequent new tics (i) Exacerbation during clinical exam
Minor	1. Comorbid psychiatric symptoms and diagnoses	History of anxiety, depression, self-harm, trauma, or social difficulties
	2. Other functional symptoms	History or concurrent functional neurological symptoms, such as functional seizures, paralysis, or abdominal pain, etc.

Clinically definite FTLBs*: confirmed by all three major criteria*
Clinically probable FTLBs: *confirmed by two major criteria and one minor criterion*

Although the ESTSS framework has helped to clarify the distinct qualities of FTLBs, challenges in accurate diagnosis remain. Such frameworks offer a useful starting point but also risk 'pigeonholing' FTLBs into categorical parameters that may not be conceptually consistent. Whilst FTLBs are commonly positioned under the umbrella of FND, the diagnostic literature described above lacks a 'positive sign', without which a diagnosis relies more on interpretation, increasing the risk of misclassification (Andersen et al., 2024). NTs themselves can appear in ways that are inconsistent with typical presentations, putting their aetiology into question even when they are 'true' NTs (Jankovic & Stone, 1991). This ambiguity makes it difficult to clearly distinguish FTLBs from NTs in some cases (Andersen et al., 2024).

Further blurring the boundaries between the two is the fact that they are not mutually exclusive. Several studies have described cohorts with confirmed TDs who develop a secondary overlay of FTLBs. Accurately distinguishing the two remains a highly fallible endeavour, particularly when focusing on phenomenology. Rigas et al. (2023) found that even tic-experts struggled to accurately distinguish FTLBs from TDs based on observations alone, with confidence only increasing when additional contextual information, such as age of onset, symptom course, or premonitory urges became known. Distinguishing the two was even more difficult when FTLBs appeared in those with existing TDs, with agreement improving only from 'slight' to 'fair', even with additional clinical information (Rigas et al., 2023).

Despite the concerted effort to classify and differentiate FTLBs, Andersen and colleagues (2024) caution that the current literature may oversimplify a vastly complex and overlapping clinical picture. There is a need, therefore, for further research into the mechanisms underlying TDs, which could help to identify which feature may serve as the positive sign needed to confidently situate FTLBs with the FND framework. Whilst such research may be on the horizon, theories about the emergence and drivers of FTLBs have nonetheless been proposed.

1.6 Explanatory Models and Theories

Pandemic Social Media

Considering pandemic school closures and quarantine measures, it is not surprising that social media played a prominent role in the daily lives of YPs, particularly for maintaining their connection with the 'outside' word. In that time, social media served various functions beyond keeping in touch, including staying informed about current events, seeking advice, and sharing personal, existential, or emotional

concerns (Lygnegård et al., 2023). Social media also became a vehicle for disseminating health related information, from personal accounts and from health organisations and public figures (Wong et al., 2020), highlighting its role in 'public sense-making' during a time of global crisis (Shahbazi et al., 2023). Hudimova et al. (2021) found that during the pandemic, YPs primarily engaged with social media passively, i.e., scrolling through content forgoing interactions, which, while enabling access to a lot of information, also amplified negative emotions and the fear of the unknown experience by many at the time.

Tic-related content surged during the pandemic, particularly on TikTok, where videos tagged with *#tourette* and *#tic* had 4.9 billion and 3.1 billion views by late 2021 (Martindale & Mink, 2022). TikTok's algorithm amplified such content by promoting videos like those users interacted with. As short-form video gained popularity [TikTok's monthly users jumped from 54 million in January 2018 to 1 billion in September 2021 (Martindale & Mink, 2022)], Instagram and YouTube soon responded with 'Reels' and 'Shorts', cementing short-form video content as a primary means for disseminating both information and entertainment.

'TikTok Tics'

TikTok was implicated in the emergence of FTLBs that occurred early in the pandemic. For example, in one of the first case series, Hull et al. (2021) reported on a young girl who had developed 'functional tics' after watching a prominent content-creator with Tourette's Syndrome, cautioning that there may be further instances of what they termed "*TikTok Tics"* to come. They later published a follow-up case series of six adolescent girls, all of whom had viewed the same content-creator prior to the onset of their own symptoms (Hull & Parnes, 2021).

Social media exposure as a potential precipitant to FTLBs has since been echoed within multiple studies around the world (Cavanna et al., 2024). One of the largest, an international registry of people with FTLBs, found that nearly 60% reported to have engaged with tic-related content on social media (Martino et al., 2023). Clinicians' attention was drawn to the sudden and severe nature of these presentations, and the way some appeared to mimic very specific and complex movements, phrases, and vocalisations observed across videos online (Olvera et al., 2021; Zea Vera et al., 2022), like in the German sample (Paulus et al., 2021). Such presentations were deemed to evidence a new "*mass social media-induced illness"* (MSMI; Müller-Vahl et al., 2022); a digital-age variant of mass functional illnesses (MFIs) that have been recorded throughout history.

Mass ~~Functional~~ *Social Media Induced* Illness

MFIs refer to a collective manifestation of physical symptoms within a socially connected group, typically triggered by underlying psychological distress. Wessely (1987) distinguished between two types: 'mass anxiety hysteria', which is typically short-lived and triggered by a perceived, but false, threat (such as a mysterious, bad smell), and 'mass motor hysteria', which gradually develops across a (typically) local group in response to psychosocial stress. The latter features motor symptoms like twitching, shaking, or contractures (Bartholomew & Wessely, 2002), usually originating from a particular 'index case'; an individual, usually with high social standing (Wessely, 1987), whose symptoms became the 'template' for wider group manifestations. Whilst the group's symptoms lack an 'organic' basis, the initial symptoms exhibited by the index case may, or may not, have an 'organic aetiology' (Bartholomew & Wessely, 2002). In their later works, Bartholomew et al. (2012) wondered:

> *"MPI[7] is typically spread through sight and sound. Telecommunications are an extension of our eyes and ears. Are telecommunications and social media replacing the necessity of being in direct visual or verbal contact with other victims?"*

Building upon this idea, Müller-Vahl et al. (2022) have argued that the pandemic surge of FTLBs constitute a modern version of MFI; except, in MSMI, social media effectively dissolves the geographical boundaries around the index case. Instead, content creators act as '*virtual* indices', whose unique tic manifestations are broadcast to millions (Hull & Parnes, 2021; Müller-Vahl et al., 2022), within an algorithm that amplifies similar content, creating not only additional *virtual indices,* but a digital feedback loop of symptom modelling. This then generates '*secondary* virtual index cases' (Müller-Vahl et al., 2022), proliferating unique manifestations of symptoms en masse.

Similarly, the psychosocial stress experienced by YPs during the pandemic mirrors the conditions stipulated by Bartholomew & Wessely (2002). The same international registry that saw that nearly 60% of their cohort had viewed tic content online also found that over 60% reported to have experienced a significant stressor prior to the onset of their FTs, including social stresses (34%), pandemic-related stress (28%), academic difficulties (25%) and family conflict (13%) (Martino et al., 2023). Social media may, therefore, not just amplify index cases but also intensify the psychosocial stressors and vulnerabilities that make young people more susceptible, creating an incubator for a mass functional phenomenon.

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[7] *Mass psychogenic illness*

Diathesis-Stress Model

Although exposure to tic-related content was frequently observed in YPs presenting with FTLBs, it was not ubiquitous, leading Pringsheim et al. (2021) to suggest that it "cannot be considered a prerequisite or necessary causative factor" amongst those with FTLBs. Instead, they proposed an explanatory framework whereby social media exposure was a component, rather than a cause, of FTLBs, offering an adaptation of the *diathesis-stress* model tailored to the context of FTLBs. This model suggests that psychopathology emerges from the interaction between one's underlying biological or genetic vulnerabilities (*diatheses*) and environmental stressors, whereby symptoms develop if the combined impact of these factors exceeds one's resilience threshold (Ingram & Luxton, 2005).

Pringsheim et al. (2021) suggest that the FLTBs manifest in a similar way, through the interaction of three factors (Figure 1): *predisposing traits*, such as biological, genetic, or epigenetic vulnerabilities from previous adverse life experiences; *predisposing states,* such as the psychological vulnerabilities previously discussed; and, *precipitating environmental stimuli*, including exposure to FTLBs (through tic-content or otherwise) that are in some way socially reinforced or widely shared. In the cases of FTLBs, YPs who may be inherently more vulnerable to their influence are drawn to the FTLBs they see, and, often without realising it, may begin to repeat them, reinforcing them over time.

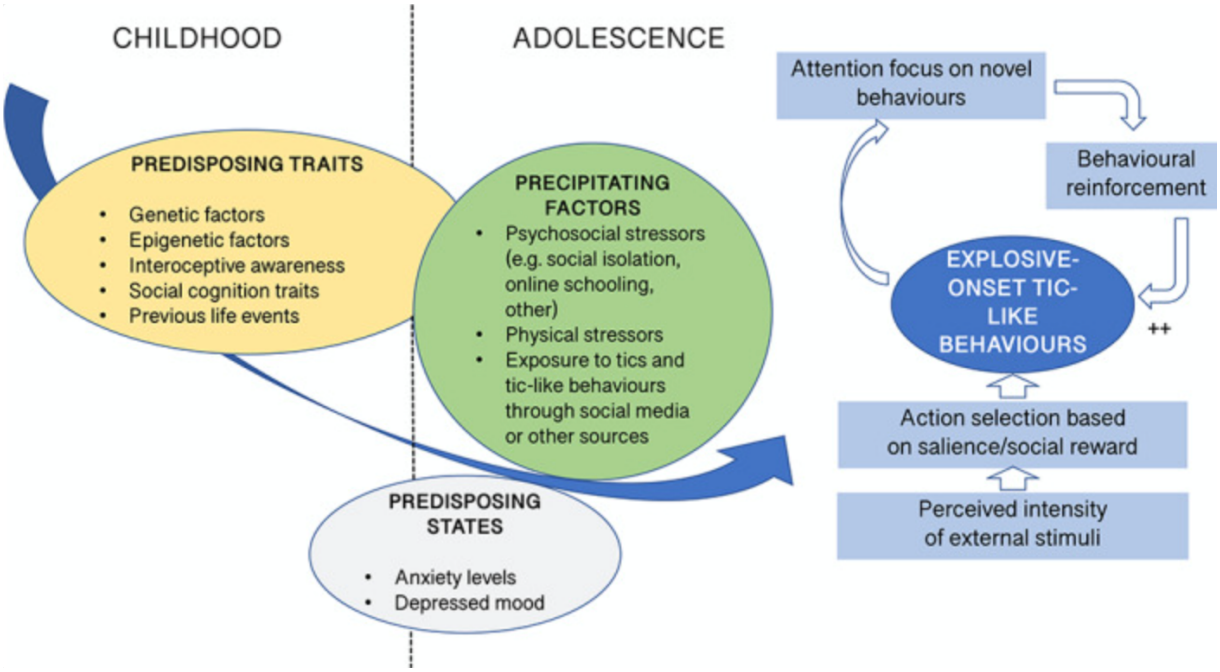

Figure 1: Model of Pathophysiological Mechanisms of FTLBs (Pringsheim et al., 2021)

Biopsychosocial Model

Berg et al. (2022) consolidated the aforementioned MSMI (Müller-Vahl et al., 2022) and diathesis-stress (Pringsheim et al., 2021) models by proposing an integrative *biopsychosocial* framework (Figure 2). Rooted in Engel's (1977) biopsychosocial model, which posits that health and illness are influenced by the 24interplay between biological, psychological, and social factors, rather than biology alone, Berg et al. (2022) suggest that FTLBs similarly emerge from a dynamic interaction of factors across these domains, leading to both the onset and perpetuation of FTLBs.

To support the biological dimension of this model, Berg and colleagues (2022) synthesised a range of neurophysiological and neuroimaging studies of FMDs, suggesting possible parallels, and positive signs, with FTLBs. For example, research has demonstrated that Bereitschaftspotential (BP), a brain signal seen on EEG before voluntary movement (Shibasaki & Hallett, 2006), is absent in over half of the time (59%) in individuals with FMD, suggesting that their functional movements are neither feigned nor voluntary (van der Salm et al., 2012). Further behavioural research summarised by Berg et al. (2022) indicate that those with FMD experience greater stress reactivity, increased limbic system activation, and impaired sensory processing, converging with previous findings of elevated cortisol and reduced vagal tone (implicated in activating the parasympathetic nervous system) within the population. They also highlight neuroimaging studies revealing abnormalities in brain regions linked to motor control, emotion regulation, interoception, and social cognition, which may explain the exacerbation of FMD symptoms during periods of psychological stress (Berg et al., 2022).

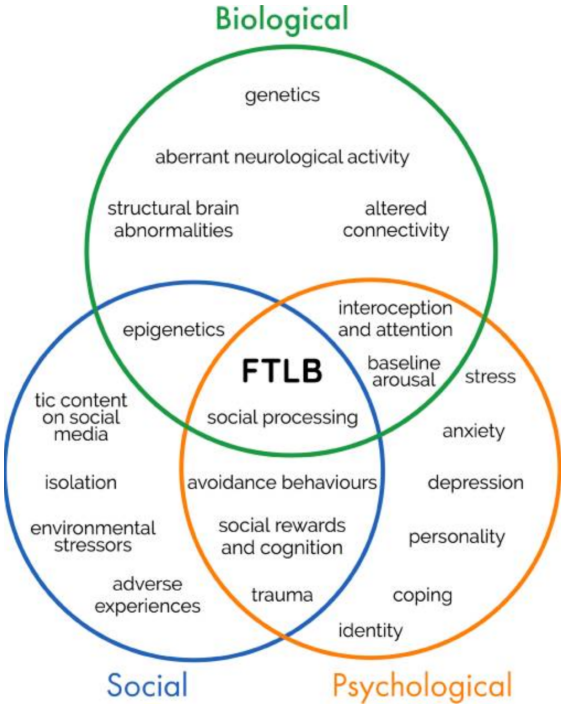

Figure 2: Biopsychosocial Model of FTLBs (Berg et al., 2022)

Although these findings relay promising biological insights, Berg et al. (2022) invite further, population specific research, cautioning against assumptions that these same processes underlie FTLBs, given the demographic and clinical differences between their samples and pandemic FTLB cohorts. Whilst such studies have yet to be conducted, these hypotheses add a valuable biological dimension to the conceptual framework. By integrating potential biological predispositions, psychological vulnerabilities, and social influences, a biopsychosocial model acknowledges the complex and likely multifactorial nature of FTLBs. As Berg et al. (2022) conclude, it not only supports the dynamic synthesis of these factors, but also provides a possible roadmap for interventions, offering multiple focal points for therapeutic support.

1.7 Outcomes and Next Steps

Recent research on the outcomes of FTLBs reveal a generally positive, albeit nuanced, prognostic picture. Cavanna et al. (2024) synthesised the results of numerous follow-up studies, demonstrating that in many cohorts, over half of those presenting with FTLBs experienced partial-to-significant symptom reduction within 6-18 months of onset. It is crucial, however, to recognise that this data reflects the experiences of those known to specialist clinical or research groups, where the possibility of receiving treatment, or at least accurate information and guidance around FTLBs, is far more likely than for those without such access. Specialist clinics across the world reported 'unprecedented' increases in FTLB referrals during the pandemic, but as Ludlow and colleagues (2024) point out, these figures only represent those who managed to *obtain* a referral, and do not account for those who remain unsupported, or are still undertaking the long, complex, and challenging task of acquiring support.

Rationale For Systematic Literature Review

Despite extensive quantitative research into the effectiveness of interventions for TDs (McGuire et al., 2014; Pringsheim, Holler-Managan, et al., 2019; Pringsheim, Okun, et al., 2019), there remains a gap in understanding how individuals with neurodevelopmental or functional tics actually experience obtaining support. Given the recent surge of FTLBs, the long-standing complexities of TDs, and the blurred boundaries between them, understanding how individuals and their families navigate available support, and where they turn to when it is lacking, is important to improving both access and quality of care for these populations. As healthcare systems continue to recover from pandemic disruptions, many continue to be pushed toward family, peers, and online platforms for information, connection, and support (Suresh et al., 2021) yet the relevance of online spaces to the tic community as a whole remains underexplored.

The systematic literature review presented in the following chapter seeks to understand both of these aspects through a thematic synthesis of qualitative research, capturing the perspectives of individuals

with tics and their families. It explores how professional and informal support is sought and experienced, with a focus on how this population experiences support from family, peers, and online communities.

Chapter 2: Systematic Literature Review

2.1 Chapter Overview

This chapter presents a systematic review exploring how individuals with tic conditions and their carers seek support across formal and informal contexts. It outlines the scoping exercises which informed the topic development, followed by various methodological aspects, including the search strategy, inclusion criteria, study selection, and quality appraisal. Thematic synthesis, the chosen analytic approach, is then described. The findings are presented through three themes, and the review's implications, strengths, and limitations are discussed. The chapter concludes by highlighting research gaps that inform the subsequent empirical study.

2.2 Methodology

Scoping and Topic Development

Initial scoping revealed several reviews and syntheses around tic disorders (TDs), on stigma (Malli et al., 2016; Pring et al., 2023), psychosocial experiences (Lee et al., 2024; Smith et al., 2015), and coping (Maxwell-Scott et al., 2024). A recent review examined barriers to care provision from the perspective of healthcare providers (HCPs), informed by service-user and carer experiences (Parker et al., 2024). Although these reviews explored a range of lived experiences, there remains a gap around how individuals and carers experience support-seeking across formal and informal contexts. 'Support' is often understood in terms of formal healthcare pathways yet scoping revealed that people frequently engage with a wider system of support, including educational establishments, workplaces, peer networks, and online spaces. This review aims to capture that system, and asks:

How do individuals with tics and/or their caregivers experience seeking and engaging with both formal and informal support, and what role do peer and online spaces play in this process?

The PROSPERO database was checked to ensure that there were no completed or in-progress reviews investigating the same question. Once confirmed, a PROSPERO protocol was published: CRD42024621530.

Searching

Scoping exercises showed that few studies focused on support-seeking as a standalone topic, and that this was often embedded in broader explorations of tic-related lived experience. The search strategy was designed to be specific enough to reflect the review's aims whilst not inadvertently excluding studies that

didn't explicitly investigate support-seeking (Table 3). Search terms focused on three key concepts: tics, lived experience, and qualitative or mixed-method research. Key concepts were listed first, then a thesaurus was used to identify synonyms. Boolean operators, phrase searching, MeSH terms, and truncation were utilised[8] to optimise search results.

Table 3: SLR Search Strategy

Search Concept	Search Terms
Population: Tic Conditions	tourette* OR "tic disorder*" OR "chronic tic*" OR "functional tic*" OR "motor tic*" OR "vocal tic*" OR "functional movement*" OR "psychogenic tic*"
	AND
Topic Focus: Experience & Meaning	experience* OR perspective* OR perception* OR view* OR belie* OR attitude* OR narrative*
	AND
Methodology Types: Qualitative & Mixed-Method	qualit* OR "mixed method*" OR "mixed-method*" OR "Qualitative Research" OR interview* OR "focus group" OR "focus-group" OR survey* OR narrative* OR case stud* OR case-stud*

The searches were conducted in December 2024 through SCOPUS, PubMed, Medline, CINAHL, and PSYCInfo, which were selected for their breadth in covering health, psychology, and social science literature. No date limits were applied, but searches were filtered to include only English-language, peer-reviewed studies. Alerts were set up to notify of any newly published research that may pertain to the review. Both snowballing and reverse-snowballing techniques were used to ensure any key papers which were not identified through the searches were considered during screening.

Inclusion / Exclusion Criteria

The following inclusion/exclusion criteria were applied to the searches and used to guide the screening process:

Table 4: SLR Inclusion / Exclusion Criteria

Criteria	Inclusion	Exclusion
Population	• Individuals (all ages) with tic conditions, including Tourette Syndrome, tic disorders, and functional tics • Parents / caregivers supporting an individual with a tic condition • May include those diagnosed with tics under broader categories (FND, FMD) where tics are core feature and focus of study	• Studies focused on broader neurological or functional conditions without a clear focus on tics, or clearly identified participants who experience tics • Populations without personal lived experience of tic conditions or caring for someone with one in a personal capacity (i.e. professionals, teachers, friends)

[8] *With guidance from a University of Hertfordshire librarian*

Outcome Focus	• Lived experiences of seeking, accessing, or engaging with support including professional services, informal networks, and online spaces • Exploration of barriers or facilitators in navigating support-seeking • Perspectives or experiences of building connection or community around tic-related experiences	• Studies which only focus on evaluations of intervention or service satisfaction without reference to the journey of support-seeking or broader support context • Research which describes therapeutic or intervention outcomes without providing service user or caregiver accounts / perspectives
Study Design	• Qualitative research which captures and conveys the experiences and perspectives of participants through "their own words" (i.e. quotations, direct feedback) • Mixed-methods research with substantial qualitative components aimed to understand and capture participants' experiences	• Purely quantitative studies using participant data to generate metrics or quantifiable results and outcomes • Qualitative studies which explore opinions or feedback of treatments without addressing the process of seeking or receiving support • Reviews or syntheses
Other	• Published and peer-reviewed articles • English language	• Grey literature, due to variability in methodological rigour and risk of bias

Screening

The resulting searches were uploaded into Covidence, a literature review management platform. Following duplication removal, 626 studies were systematically screened for inclusion through two stages: title and abstract screening, then full-text review, as outlined in the PRISMA flowchart (Figure 3). Both stages were independently completed, then discussed with a second reviewer[9]. Involving a second reviewer brings various benefits to the literature review process, including mitigating random errors and enhancing the consistency and reliability of inclusion decisions, thereby ensuring that all relevant studies are accurately identified (Stoll et al., 2019; Waffenschmidt et al., 2019).

Screening conflicts were discussed collaboratively until reaching an agreed decision on inclusion. The title and abstract screening resulted in 91.2% agreement, with a Cohen's Kappa[10] of 0.68, indicating 'substantial' agreement. These conflicts related to methodological queries, population criteria, and some human error. Following consensus, 96 studies proceeded to full-text review. In this phase, all studies were assessed in greater detail against the inclusion criteria, paying particular attention to the relevance of feedback around support-seeking and the attribution of participant feedback, i.e., ensuring that quotes could be clearly attributed to individuals with tics or their caregivers, particularly in studies with mixed populations. The full-text phase resulted in 9 conflicts, equating to 90.6% agreement, with a Cohen's Kappa of 0.79, indicating 'substantial' agreement. These discrepancies focused on the extent to which support-seeking was discussed and whether it constituted sufficient focus to warrant inclusion. After

[9] A student affiliated with the specialist movement clinic of the project's secondary supervisor
[10] A measure of inter-rater reliability

these were resolved, 17 studies were deemed eligible for inclusion in the review, pending quality appraisal.

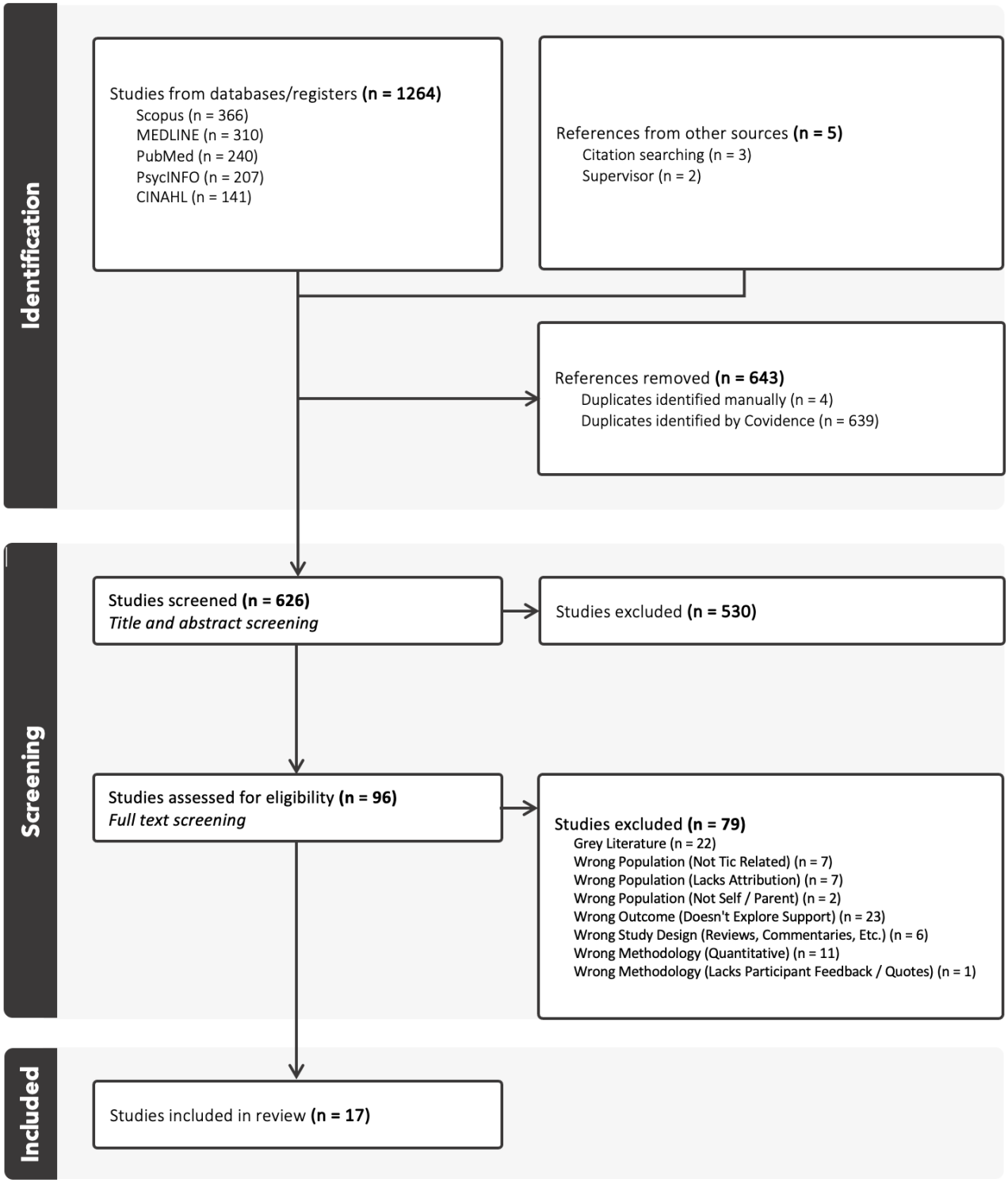

Figure 3: PRISMA Flow Diagram

Study Characteristics & Data Extraction

Of the seventeen include studies, seven focused solely on parent/caregiver perspectives, five on individual perspectives, and five on both. Eleven focused on adult participants, two on only children and young people (CYP), and four on both CYP and adults. Collectively, the studies represent the views of at least 980 participants (approximately 60 CYP and 920 adults), with personal experience of tic conditions or care for someone who does[11]. Of the known participants, 614 identified as female, 197 as male, 27 as non-binary, and 9 as other. In studies focused on parents/caregivers, there was a clear preponderance of participating mothers.

Ten studies recruited participants specifically with a diagnosis of TS, five recruited participants with any TD, and two focused specifically on FTLBs. Geographically, twelve studies were conducted and published in the UK, whilst others represented research from Spain, Norway, China, New Zealand, Australia, and the United States. Three of the studies contained samples without geographical restrictions.

Methodologically, fourteen studies were purely qualitative, whilst three were mixed-method with a substantial qualitative component; only qualitative data were extracted. Data were collected through interviews, open-ended survey responses, user posts, or focus groups, with Thematic Analysis being the most common analytic method. As previously discussed, most studies did not focus exclusively on support-seeking but explored a range of topics regarding the lived experience of tic conditions. For the purposes of this review, only data pertaining to the experiences of support-seeking were extracted. A summary of outcomes as they pertain to support-seeking, alongside the context around the support-seeking, study information, strengths, and limitations are presented in Table 5.

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[11] It is challenging to determine a precise total, as one study analysed posts from an online forum without providing demographic data, and others did not separate figures for CYP and adult participants

Table 5: Study Characteristics

Author, Title, Country	Research Aims	Sample & Recruitment	Study Methodology	Support Context	Findings Re: Support Seeking	Strengths & Limitations
Burn et al., (2025) *The journey to a functional tics diagnosis and experiences of post diagnostic support: perspectives from adolescents and their parents* **United Kingdom**	To understand how "How adolescents with FTs and their parents experience receiving a diagnosis of FTs, including their experiences of pursuing the diagnosis and the impact of the diagnosis" and "how adolescents and their parents experience post-diagnostic support for FTs and/or other co-occurring needs"	Purposive sampling; 9 families, including 8 parents (1M, 7F) and 7 female adolescents; Recruited via Tourette's Action website and social media channels	Interview data analysed through Reflexive Thematic Analysis	Seeking diagnosis and navigating medical system in search of care; Seeking community, social, and emotional support	• Families described undertaking a long, arduous journey to acquire a diagnosis, with many experiencing dismissal, disbelief, or minimisation by professionals. Becoming an advocate (whether a parent or oneself) was essential to get the distress caused by functional tics recognised, and to get onward referrals or further support. • Support post diagnosis was sparse, often leaving participants wanting, and unsure of how what to do to in periods of acute distress; some found CAMHS helpful, whilst some were left to contend with developing coping strategies on their own • Community support was cited to be more informative and helpful than professional care, particularly as it provided guidance, validation, and connection with people going through similar experiences	**Strengths:** • One of very few studies focusing on lived experience of people with functional tics; inclusion of both parental and young person perspectives offers a well-balanced picture of the functional tic diagnostic experience • Good outlining and use of reflexivity, with the author making clear their personal positioning and how this may have influenced their interpretation of the data • Thorough and comprehensive thematic analysis, offering a sufficiently broad but thorough exploration of the experience of an under-researched and underserved population **Limitations:** • Self-selected sample, recruited from one TS support organisation may not represent views of those who are not connected to this support stream; likewise, homogeneity of sample limits generalisability to more diverse populations • Although reflexivity was considered, the authors' backgrounds in psychological treatment of tic disorders may have introduced interpretive bias
Coleman & Melia (2023) *Me, My Tics and I: An Exploration of Self-Identity and its Implications for Psychological Wellbeing in Young Women with Tourette's Syndrome* **United Kingdom**	"…to explore self-identity in young women with TS and the implications of this for psychological wellbeing"	Purposive sampling; 11 adult women with a diagnosis of TS; Recruited via Tourette's Action website and social media channels	Interview data analysed through Reflexive Thematic Analysis	Seeking community, social, and emotional support	• Participants highlighted the importance of finding and connecting with others with lived Experience of TS; doing so gave them validation, facilitated self-acceptance, reduced isolation, and improved optimism about life and their future • Participants described self-stigmatising beliefs that prevented them from accessing support (having to 'prove' their TS) • Adult participants reflected that they felt abandoned by mental health services upon turning 18, reporting feeling 'not cared about'	**Strengths:** • Focused uniquely on women and their experiences in a research field underpinned by male participants and good attention to intersectionality, regarding gendered perspectives • Good use of reflexivity, with the authors reflecting on how their own experiences and perceptions have influenced this research • Thoughtful thematic analysis grounded in participants' quotes, with a nuanced exploration of lived experiences **Limitations:** • By way of recruitment, participants were educated young women who were already connected with a TS support organisation, and thus findings may not represent experiences of more isolated and disadvantaged people. • Some participants had trouble separating TS from co-morbid conditions, making it challenging to attribute their experiences to TS or broader mental health experiences
Cuenca et al. (2015) *Perceptions of treatment for tics among young people with Tourette syndrome and their parents: a mixed methods study* **United Kingdom**	"…to explore how young people with TS and parents of young people with TS perceive different treatment strategies for tics, and to explore similarities and differences between the views of parents and young people."	Purposive sampling; 42 young people (<18yo; 32M, 10F), and 295 parent / carers of a child with a TD (237F, 18M, 2O), Recruited via Tourette's Action website and social media channels	Mixed-method, combining survey responses from parents alongside young peoples' phone / F2F interview data analysed through inductive Thematic Analysis	Seeking diagnosis and navigating medical system in search of care	• Both YP and their parents described a lack of knowledge of TS amongst medical professionals, particularly GPs, resulting in delays to obtaining diagnosis and requisite support • Barriers to accessing care included long wait times and being bounced between doctors in the search to find a specialist practitioner • Despite being valued by those who took part in them, parents noted that behavioural interventions were very	**Strengths:** • Good triangulation between quantitative and qualitative data of a large and varied sample leads to stronger validity of findings • Addressed aspects of both seeking and receiving support, offering a longitudinal perspective of obtaining care for TS

					difficult to access or unavailable to them due to difficulty in finding knowledgeable and specialist practitioners	• Focused on experiences of young people, supported by data from their parents provide a comprehensive perspective of the support seeking experience **Limitations:** • Participants were recruited through a TS support organisation, meaning that results may not be representative of those who are not engaging with such support streams and are disconnected from other avenues of support • Authors highlight the possibility of recall bias amongst participants who had sought or received support years prior to taking part in the study
Hermansen & Miller (2008) *The lived experience of mothers of ADHD children undergoing chiropractic care: A qualitative study* **Norway**	"…to investigate the lived experience of mothers with ADHD children undergoing or having undergone chiropractic care and the IM course, and to get detailed information about their everyday life with a child who suffers from ADHD and the struggles this may bring."	Opportunistic sampling; mothers of children being treated at Norwegian clinic for ADHD ± Tourette's, in receipt of chiropractic treatment. Mothers of children with TS, *n = 2*	F2F interview data analysed through Thematic Analysis	Navigating medical system in search of care	• Mothers described their experience of navigating public healthcare and seeking a diagnosis for their child as "fighting the system", encountering dismissal, misunderstanding and blame for not handling their child's TS symptoms • Negative experiences with mainstream services led the parents towards alternative treatments, where they felt their concerns were validated and treated with care • For one participant, shame and non-disclosure prevented the child from getting the support they needed in school, whilst for the other, school did not carry out the promised accommodations, despite having an official diagnosis, highlighting both the emotional and systemic barriers in seeking support	**Strengths:** • The study lends a novel perspective of how experiences of help seeking within mainstream healthcare lead parents to seek support from alternative interventions • Despite the small sample size, the inclusion of participants with TS offer insights into experiences of support seeking within families where TS overlaps with ADHD **Limitations:** • Participants were recruited from a single clinic, limiting generalisability • The study's primary purpose Is to report positive experiences of a particular chiropractic intervention delivered at the clinic where participants were receiving treatment, which may bias the results reported • The lack of critical analysis of less favourable views on the intervention, limit the balance and nuance of the study
Hu et al. (2024) *A qualitative study of Chinese parental perspectives on the causes of Tourette syndrome in children* **China**	"…to examine and identify the Chinese parents' perspectives on the causes of TS in their children to discover the influence on their treatment-seeking behaviours."	Purposive sampling; 13 parents / caregivers (4M, 9F) of children with a diagnosis of TS; recruited via hospital	F2F semi-structured interview data analysed through Thematic Analysis	Seeking diagnosis and navigating medical system in search of care	• The authors reflected that a lack of knowledge and understanding of TS both amongst parents and professionals led to seeking help from multiple specialisms, thus delaying timely diagnosis and efficient treatment, and prolonging distress • Cultural misconceptions and misattributions of the cause of TS prevented or delayed help-seeking, or led parents astray towards ineffective treatments • Parents' feelings of guilt over improper parenting or stress drove them to seek a 'remedy' for their child, also leading them to bounce between multiple specialisms	**Strengths:** • One of only a few studies that highlights experiences of TS outside of a Western context • Provides good insights into ways in which language and cultural beliefs shape and influence parental perceptions and understanding of TS, and how these guide help seeking behaviours **Limitations:** • The study was conducted in a single, regional hospital and findings may therefore not represent broader regional or national perspectives • The stigma and guilt experienced by parents outlined in the paper may have prevented participants from openly expressing their perspectives and experiences • Limitations in language clarity may have obscured the results, affecting the possible insights and interpretations of the findings
Ludlow et al. (2018) *A qualitative exploration of the daily experiences and challenges faced by parents and caregivers of children with Tourette's syndrome* **United Kingdom**	"…to further explore the daily experiences of parents raising a child with TS with a view to describing and assessing the impact of the disorder on family life, identifying particular challenges the parents might	Purposive sampling; 15 parents / caregivers (4M, 11F) of children with a diagnosis of TS, recruited via Tourette's Action website	F2F semi-structured interview data analysed through Thematic Analysis	Seeking diagnosis and navigating medical system in search of care; Seeking community, social, and emotional support; Education support	• Nearly all carers considered professional support to be difficult to access. Many described needing to 'battle' the system and 'shout from the rooftops' to get access to any support, particularly from CAMHS. • Dismissal and minimisation of symptoms was a prevalent experience amongst the group, with many told by professionals (doctors, teachers) that their child	**Strengths:** • The study provides rich reflections on carer lived experience of support seeking across various domains, including professional, academic and peer support • The study attends to both practical and emotional experiences to support-seeking, offering a more holistic analysis on the impact of unmet needs, including carer strain, isolation, guilt, and blame

	face and to also evaluate their experiences with support services."				was 'fine', implying that a lack of discipline was driving TS symptoms • Once in services, many parents found the quality of support inadequate, citing a lack of specialist knowledge and approach. • Academic support was mixed, with some parents describing good allyship with their child's school, while others encountered an unwillingness to both make and upkeep promised accommodations for the child • Carers described peer support as essential, and found missing validation, camaraderie, and understanding from other parents. Not all support groups were found to be useful though, particularly mixed-age ones for people with TS.	**Limitations:** • Although methodological rigour is evidenced and reflected in a well-structured analysis grounded in participants quotes, there is no description of author's reflexivity and how researchers' perspectives or position may have influenced the research • Although reflecting the views of both male and female respondents, the study did not explore potential differences in maternal and paternal experiences, which could have added a valuable intersection perspective to the research • Participants were recruited through a TS support organisation, meaning that findings may not be generalisable to TS caregivers who are more isolated or disconnected from such support streams; similarly, it may under-represent perspectives of those who may have had more positive experiences of healthcare provision
Ludlow et al. (2024) *An investigation into mothers' experiences of their children's functional tic-like behaviour and tic attacks* **United Kingdom**	"…to explore the child/family history and parent's experiences of living with sudden onset functional tic disorders from initial onset, diagnosis, their impact and support."	Purposive sampling; 21 mothers of children who had developed functional tic-like behaviours during the C-19 pandemic; Recruited via Tourette's Action and social media channels	Video semi-structured interview data analysed through inductive Thematic Analysis	Seeking diagnosis and navigating medical system in search of care	• Participants described experiencing a lack of knowledge and dismissal from professionals, with doctors assuming that it was simply a reaction to stress, or worse, deliberate attention seeking; several reported that this led to delays in care and an increase in distress • Due to negative experiences with professionals, mothers described the push to become unabashed advocates for their children, as one of the only ways to achieve any sort of result with professionals • The paper highlighted a clear call for multi-disciplinary support, particularly around managing symptoms like anxiety alongside co-occurring conditions. Several mothers called for better awareness of functional tics amongst professionals, clear signposting and referral pathways, and access to peer support.	**Strengths:** • One of the only studies to look at a population whose tics are specifically functional in nature, filling a vital gap in research • The study provides rich participant accounts, providing insights into the emotional, psychological, and practical impacts of caring for a child experiencing functional tics **Limitations:** • Given the study's focus on the experiences of mothers, the study could be made stronger by considering the views of the young people themselves, and/or clinicians to add balance to the findings • Given the sample was self-selected, the findings may not be representative of the views of people who are not connected with a support organisation like TS; likewise, the sample is quite homogenous and may not reflect experiences of fathers or people from underrepresented groups
Malli et al., (2019) *"Tourette's Is a Lonely Place": an Interpretative Phenomenological Analysis of the Personal Experience and Identity of Adults with Tourette's Syndrome* **United Kingdom**	"…(a) to examine the lived experiences of adults with TS and explore how the condition is managed in the context of their lives; (b) to investigate the personal meaning adults bestow to their condition and how they conceptualise and express their social and self-identity due to TS; and (c) to understand the impact TS has had on their social and personal relationships."	Self-selected sample; 16 adults (12M, 4F) with a diagnosis of TS; Invited to interview following participation in survey as part of a larger research study; Recruited via Tourette's Action, Tourette Focus-UK/Europe and ADHD Wise UK, alongside social media channels	Telephone, F2F, and written interview data analysed through IPA	Seeking community, social, and emotional support; Navigating medical system in search of care	• Participants described experiencing significant loneliness and isolation due to a lack of adult support services for TS. Many felt the continuity of support was cut-off once reaching adulthood, leaving them to 'figure things out' on their own • Good, supportive interpersonal relationships appeared rare, but meaningful when found, particularly from partners or close friends, which contrasted with judgmental or dismissive experiences encountered from the general public • Participants noted that support groups seemed catered to either children/young people or parents of children with TS, and reflected that access to adult-specific TS support groups could decrease their sense of isolation and provide them with a sense of safety and acceptance	**Strengths** • The study focuses on experiences of adults with TS, a population that is typically excluded from research (which tends to be child or parent focused), adding a valuable perspective of TS across the lifespan • Rich and comprehensive data offers good, nuanced insights into internal experiences such as stigma, sense of identity, and other emotional and psychological effects of interactions with informal support networks **Limitations** • Despite the depth of reflections, authors do not explore how intersectional factors such as age, gender, class, or disability might moderate participants' experiences • The demography of the participants (predominantly white British) an recruitment through TS organisation may not reflect the experiences of individuals with TS who are more isolated and disconnected from such

						support streams, or who received support through more mainstream services
Malli & Forrester-Jones (2022) *Stigma and Adults with Tourette's Syndrome: "Never Laugh at Other People's Disabilities, Unless they have Tourette's—Because How Can You Not?"* **United Kingdom**	"1. To assess the extent and nature of stigma as experienced by adults with TS and to understand the influence of stigma on the participants' quality of life; 2. to evaluate whether sociodemographic and clinical variables, such as age and the existence of co-occurring conditions, influence stigma; 3. to explore the everyday difficulties experienced by adults with TS as a result of stigma, as well as, what they perceived to be the drivers and core beliefs that perpetuate TS stigma; 4. to map the coping strategies adopted by individuals with TS to help manage stigma."	Purposive and snowball sampling; 20 adults (14M, 6F) with a diagnosis of TS, recruited via Tourette's Action, YouTube, and other social media channels	Mixed-method, combining survey alongside video, semi-structured interview data analysed through Thematic Analysis	Seeking community, social, and emotional support; Navigating medical system in search of care	• Participants described experiences of structural stigma that impacted support-seeking. Many encountered professionals lacking knowledge of TS, placing the onus on them to educate them or request referrals to specialists. • Participants also described how education and employment establishments often denied reasonable adjustments; some relayed that they were excluded from school illegally, with school refusing to put any support in place • Given the lack of support in the medical system, participants reported feeling a sense of duty to take on the role of TS educator and advocate in online spaces, to reduce stigma and misinformation, despite this being draining and taking an emotional toll	**Strengths** • The mixed-method design of the study offers a comprehensive and nuanced exploration of the impact on stigma, and how it factors into support-seeking experiences • Very strong PPI component, as authors worked alongside a large advisory group of individuals with lived experience of TS • The focus on adult experiences fills a gap in research where parent or young person views tend to be the matter of examination **Limitations** • Participants accounts are retrospective in nature, and thus may be prone to recall bias • Many participants had high levels of psychiatric comorbidities, making attributing experiences solely to TS more difficult
Marino et al., 2023 *Patients' experience of accessing support for tics from primary care in the UK: an online mixed-methods survey* **United Kingdom**	"…to understand the experiences of people with tics and their families in UK primary care and the referral process to secondary care for support, and how they perceive the support provided."	Purposive sampling; 33 adults with a diagnosis of TD (10M, 20F, 3NB) and 94 parents / carers of a child with a diagnosis of TD recruited via Tourette's Action and their associated social channels, Neurodiverse.org, and Tourette Syndrome Support Group	Mixed method, combining questionnaire alongside open ended survey responses analysed through inductive Thematic Analysis	Seeking diagnosis and navigating medical system in search of care	• Participants reported that GPs were misinformed about tics, minimised their severity and distress, and left patients with little to no information about how to cope or move forward in seeking support. Some gave overly reassuring advice, insisting that the tics would go away; all of the above left patients feeling misled and frustrated • Many participants described needing to push GPs to make referrals into secondary care, and that many GPs lacked knowledge of available support services or referral pathways. This was particularly prevalent for the adults in the sample. • Once in secondary care, treatment and support was often fragmented and led to 'bouncing' around services, with many resorting to expensive private care for support. • Care by GPs who appreciated the distress of the tics, were able to recognise the limitations of their knowledge, and made onward referrals resistance was considered a lifeline	**Strengths** • The study includes perspectives of both adults with tics and parents / carers of children with tics, providing insight into a range of experiences amongst NHS service users • Mixed method design allows for more broad quantitative data to be backed up by more nuanced, in-depth qualitative perspectives • Author takes care to highlight their positionality and reflect upon how that may have influenced or impacted their interpretation and reporting of the data **Limitations** • Participants were asked to reflect upon past experiences of primary care, and recollections may be prone to recall bias • Although both adult and parent/carer perspectives are included, there are times where the analysis lacks clarity on which service is being commented on (adult or child's pathway), making it difficult to understand where the experience is situated
O'Hare et al., (2017) *Youth with Tourette syndrome: Parental perceptions and experiences in the Australian context* **Australia**	"…to address a current gap in the TS literature by exploring and identifying the stressors that the primary caregivers of youth with TS perceive as contributing to parental stress."	Purposive sampling; 22 biological mothers of children with a diagnosis of TS; recruited as part of a larger study evaluating attachment relationships of Australian youths; via Tourette Syndrome	Telephone semi-structured interview data analysed through eclectic content analysis	Seeking diagnosis and navigating medical system in search of care; Seeking community, social, and emotional support	• Mothers found the diagnostic journey to be a particular stressor, having to take on the role of advocate and educator in the face of professional dismissal, blame, lack of knowledge and wrong advice regarding TS • For some, having a diagnosis invited judgment and exclusion from family and existing social support. Peer support groups filled a vital role in remedying loneliness and isolation, provided validation, and connection with people who 'get it'	**Strengths** • The study provides a holistic analysis of parental stress in relation to their child's TS, looking at both emotional and structural dimensions around support seeking within healthcare, health services, and peer networks **Limitations** • Participants recruited mainly from TS support networks, meaning that findings may not be representative of those who are not connected to such organisations

		Associations of Australia and Victoria			• In the absence of external support, mothers highlighted the importance of creating a nurturing and supportive home and family environment	• Some themes and findings are backed up by single, illustrative quotes, with limited interpretation and analysis of meaning behind the experience
Perkins et al., (2020) *Using Online Support Communities for Tourette Syndrome and Tic Disorders: Online Survey of Users' Experiences* **United Kingdom**	"…to explore users' perceptions and experiences of using online support communities for TDs, in order to gain insight into their participation in online support communities, benefits and drawbacks of being using online support communities, and the impact of using online support communities upon their offline management of TDs."	Purposive sampling; individuals with a diagnosis of TD (n=68), carers of someone with a diagnosis of TD (n=14) or both (n=8) (25M, 56F, 6NB, 2O) recruited internationally via posts in OSCs, via Tourette's Action and the NIHR MindTech MedTech Co-operative	Open ended survey responses analysed through inductive Thematic Analysis	Support in online communities	• Participants' motivation to access online support was influenced by their disappointment in medical professionals who were felt to lack knowledge and understanding of TDs. • Online communities offered both practical and emotional support, including guidance on diagnosis and symptoms, sharing and finding strategies for managing and coping with TDs, building acceptance and resilience, and enabling users to build confidence to function with tics in the offline world. • Users also identified less helpful aspects of online support, including some communities developing narrow viewpoints or preferences for certain approaches, instances of cyber bullying, and carers of TD overtaking spaces from people with TDs themselves	**Strengths** • Perspectives from the study's large and international sample provides insights into cross-cultural perspectives of both people with TDs and their caregivers • Authors provide thorough discussion and implication, particularly around harnessing online support as a tool to improve the delivery of care and wellbeing • Good use of PPI consultation to inform study questions **Limitations** • Despite the large and international sample, the study being conducted in English meant that truly in-depth cultural perspectives may be limited due to language barriers • Given the study's recruitment strategy, the findings may not represent the views and perspectives of users who disengaged from online communities due to negative experiences
Pine et al., (2024) *Perceptions of Parents and Caregivers in New Zealand: Educational Experiences of their Children with Tourette Syndrome* **New Zealand**	"…to explore parents' and caregivers' attitudes around their experiences of education for their child with TS."	Purposive sampling; 75 parents / caregivers (61F, 9M, 5N/A) of a child with a diagnosis of TS recruited via Tourette New Zealand Patient Association	Open ended survey responses analysed through Thematic Analysis	Education support within mainstream schooling	• The study highlights varied experiences across parents seeking support from their children's schools. For some, getting necessary accommodations was positive and straightforward, while other parents had to 'fight', advocate or faced unwillingness • Collaborative planning between parents, children, and the school was a valued component of positive support-seeking experiences. • Parents raised that a lack of knowledge and training amongst teachers and peers led to stigma, misinterpretation of symptoms as misbehaviour, and inadequate support offered. • Parents raised many suggestions for how to improve support provision in schools, including teacher training, raising awareness of TS amongst both adults and peers, and clearer national guidelines for implementing support	**Strengths:** • Large sample of parents across the entirety of New Zealand provides a broader and more generalised view than most studies • Provides actionable recommendations as per the views gathered from parents, not just researcher impressions **Limitations:** • Analysis provides a description of what parents said, but at times lacks depth and specificity about the underlying factors of that experience (i.e., *why* school was unwilling to make accommodations or adjustments) • Study could have been made stronger through inclusion of young peoples' voices and perspectives
Rivera-Navarro et al. (2009) *The diagnosis of Tourette's syndrome: Communication and Impact* **Spain**	"…to explore personal experiences regarding the communication and impact of the TS diagnosis (in the Spanish context) in three groups: 1) those with TS, 2) their caregivers, and 3) health professionals."	Purposive sampling; 6 teenagers (4M, 2F) and 6 adults (4M, 2F) with a diagnosis of TS, and 12 relatives of someone with TS (2M, 10F), recruited through TS support groups in Madrid. Data from FG with 5 professionals not included in this review.	Focus groups responses analysed through Grounded Theory	Seeking and receiving a diagnosis of Tourette's Syndrome	• Participants described seeing multiple professionals on the path towards diagnosis, encountering dismissal, invalidation, and misinformation along the way, leading to damaged trust in professionals • Even after getting a diagnosis, many were left without further information or understanding of what to do and how to manage their symptoms, which led to worries about the future and impact on life moving forward • For some participants, the psychiatric implications of a TS diagnosis led to stigma, shame, and feelings of blame, which delayed both seeking the diagnosis and pursuing further support	**Strengths:** • The inclusion of both people with TS, cares, and professionals enabled the researchers to triangulate perspectives across three interconnected groups, offering a holistic perspective on the process and outcomes of receiving a TS diagnosis • The researchers do well to add a novel perspective to TS research by highlighting how language and delivery affects emotional reactions and meaning making **Limitations:** • Authors highlight that the retrospective nature of the interview may introduce bias into the results

						• Grounded theory is cited as the methodology used in the study, however, there is limited discussion of the analytic process including theme development and coding
Soós et al., (2022) *Exploring Social Support in an Online Support Community for Tourette Syndrome and Tic Disorders: Analysis of Postings* **United Kingdom**	"…to inductively analyze the content of messages posted in order to identify and describe the provision of social support within an online community for Tourette syndrome and tics."	Naturalistic sampling; 510 threads (3802 comments) uploaded by users of a public TS online support community	Posts and comments analysed through inductive Thematic Analysis	Support in online communities	• Online TS communities offer multi-faceted support to users, ranging from emotional support, peers validating one another, and information sharing on a variety of topics, including navigating the diagnostic and treatment process, lived experience, resources, and coping strategies. • Emotional validation and finding others sharing similar experiences was a key factor in participating in online communities, reducing feelings of aloneness. Users felt safe and able to 'unload' their feelings online and connect with others without judgment. • For many, online communities filled a need left by a lack of access to good quality professional care; despite this, users appeared cognisant that they are not medical professionals, and the communities were also used as a means of support and encouragement to persevere and persist in getting medical care for TS	**Strengths:** • The study's use of a large, naturalistic data set of user messages offers a unique and ecologically valid perspective on the views of online users, with themes emerging directly from user discourse • Good exploration of both practical and psychological functions of engagement with online communities for TS related support **Limitations:** • Sampling methods and naturalistic design mean that authors could not distinguish the author of the posts, limiting understanding of who benefits from specific functions of the online groups • Only one online support community was examined, and findings may not generalise to other platforms • Text-only analysis may influence reading and interpretation of quotes to due absence of emotional tone and nuance
Taylor et al., (2022) *"I'm in pain and I want help": An online survey investigating the experiences of tic-related pain and use of pain management techniques in people with tics and tic disorders* **United Kingdom**	"…to explore people's lived experiences of tic-related pain, the methods people have used to manage tic-related pain, and exploring whether they have sought and received any support and/or treatment from healthcare professionals for tic related pain."	Purposive sampling; 181 adults (>16 y.o., 58M, 105F, 18NB) with a suspected or confirmed tic disorder diagnosis, recruited internationally through charities, an online support community, and through NIHR MindTech MedTech Co-operative	Open ended responses to survey questions analysed through inductive Thematic Analysis	Navigating medical systems in search of care; Seeking community, social, and emotional support	• Whilst many sought support for tic-related pain, participants reported either inadequate support, or being refused treatment • A variety of systemic barriers, including long wait times, costs, and lack of specialist services prevented help-seeking • Many participants reported emotional barriers to helps-seeking, resulting from dismissal by professionals, encounters with professionals who lacked knowledge of TS and pain management; this led to frustration, hopelessness, and a disbelief that services are actually able to help them in their time of need • Support from loved ones can be a double-edged sword; some can be catalysts for seeking help or even take the role of HCPs (massaging away pain), whilst for others, the shame and stigma arising from others' judgment prevented help-seeking	**Strengths:** • Novel research addressing a prevalent aspect of the tic experience that has not been well studied, thus adding additional nuance and dimension to the literature • Meaningfully explores the emotional aspects and tolls of help-seeking alongside the logistical aspects • Robust PPI involvement supports the research to be considerate of the lived experience of participants **Limitations:** • Nature of online recruitment and written responses mean that results may not represent views of more disadvantaged individuals • Length of online survey may have led individuals who struggle to maintain focus or complete tasks (as ADHD is often comorbid alongside tic conditions), or those with limited time resources, to successfully take part in the study • Although the study was open to an international audience, the survey was conducted in English, thus excluding non-English speakers and limiting the cultural generalisability of the findings
Travis et al., (2020) *Experiences of Tourette Syndrome Caregivers with Supportive Communication* **United States**	To explore how caregivers of children with TS experience and perceive supportive communication from their social network	Purposive sampling; 11 mothers of children with a diagnosis of TS recruited via a Facebook support group for TS caregivers	Semi-structured interview data analysed through Grounded Theory	Seeking community, social, and emotional support	• TS caregivers sought support from various avenues (friend, family, professional), but encountered communication that was more often than not invalidating, dismissive and stress-inducing • Although positive communication experiences were outnumbered by negative ones, validation from professionals was highly regarded as 'transformative', resulting in caregivers feeling listened to, understood, and having their difficulties acknowledged.	**Strengths:** • The study offers a unique perspective on how caregivers experience supportive and unsupportive communication across various domains (friends and family, professional, online), offering a rich analysis of the emotional experiences resulting from these interactions. • Authors provide a nuanced analysis of experiences, demonstrating a good balance of both positive and

- In contrast, recipients of negative communication felt dismissed and unsupported, reinforcing the burden of advocating and educating, and erosion of trust in professionals.
- Peer networks and online support offered highly valued relief, normalisation, relatability, and practical guidance. Feeling seen and understood by peers helped caregivers feel less isolated and improved their coping capacity.

negative aspects of communication between TS caregivers and their support networks.

- Authors take care to make practical recommendations in terms of how the findings may be applied to improve support experiences of caregivers, including highlighting the importance of validating both the struggles of TS, and the struggles of caregiving for someone with TS.

Limitations:

- As the sample was recruited from an online support group, the results may not fully represent the views of TS caregivers that are not connected with such support streams
- The authors acknowledge the homogeneity of the sample, and thus the findings may not reflect how various intersectional factors (race, gender, geography), may affect experiences of supportive communication

Quality Appraisal

The Critical Appraisal Skills Programme (CASP) checklist for qualitative research[12] (CASP, 2023) was used to assess methodological rigour of included studies. A range of study criteria are assessed and receive a rating of: 1 'Yes', 0 'No', or 0 'Can't Tell', a rubric taken from Hanks et al. (2020). A total score is tallied, and an overall rating is assigned, with a score of 0-3 indicating poor, 4-6 indicating medium, and 7-10 indicating high quality.

The appraisal was undertaken independently with the second reviewer and resulted in 27 discrepancies, equating to 83.0% agreement and Cohen's Kappa of 0.59 ('moderate' agreement). Discrepancies were primarily around the threshold for differentiating a 'can't tell' rating from a definitive 'no', particularly where methodological details were implied but not explicitly stated. All disagreements were resolved prior to assigning a final score. A concise rubric can be seen in Table 6 and the full version in Appendix A, alongside an example assessment (Appendix B). Of the 17 studies, 16 were appraised as high quality and one as medium quality. As per the CASP criteria, Hermansen and Miller's (2008) study was appraised as lower quality in comparison to the other included studies due to its small, clinic-based sample and limited detail on analytic rigour. However, it was retained because it added a valuable perspective to the review, particularly as it illustrated how negative experiences within conventional healthcare could lead people to seek alternative forms of support, thereby enriching the synthesis of help-seeking experiences. All studies were thus included in the synthesis of findings.

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[12] This 10-item checklist is endorsed as a thorough tool for assessing the relevance, quality, and transparency of qualitative research (Long et al., 2020; Noyes et al., 2018)

Study	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research?	Rating
Burn et al., 2025	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	10/10 Good
Coleman & Melia, 2024	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	10/10 Good
Cuenca et al., 2015	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓	9/10 Good
Hermansen & Miller, 2008	✓	✓	✓	?	✓	✗	✓	?	✓	?	6/10 Medium
Hu et al., 2024	✓	✓	✓	✓	✓	✗	?	✓	✓	✓	8/10 Good
Ludlow et al., 2018	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓	9/10 Good
Ludlow, et al., 2024	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓	9/10 Good
Malli et al., 2019	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	10/10 Good
Malli et al., 2022	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	10/10 Good
Marino et al., 2023	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	9/10 Good
O'Hare et al., 2017	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓	9/10 Good
Perkins et al., 2020	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓	9/10 Good
Pine et al., 2024	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓	9/10 Good
Rivera-Navarro et al., 2009	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓	9/10 Good
Soós et al., 2022	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓	9/10 Good
Taylor et al., 2022	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓	9/10 Good
Travis & Juarez-Paz, 2020	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓	9/10 Good

✓ = Yes ✗ = No ? = Can't Tell

Table 6: CASP Results

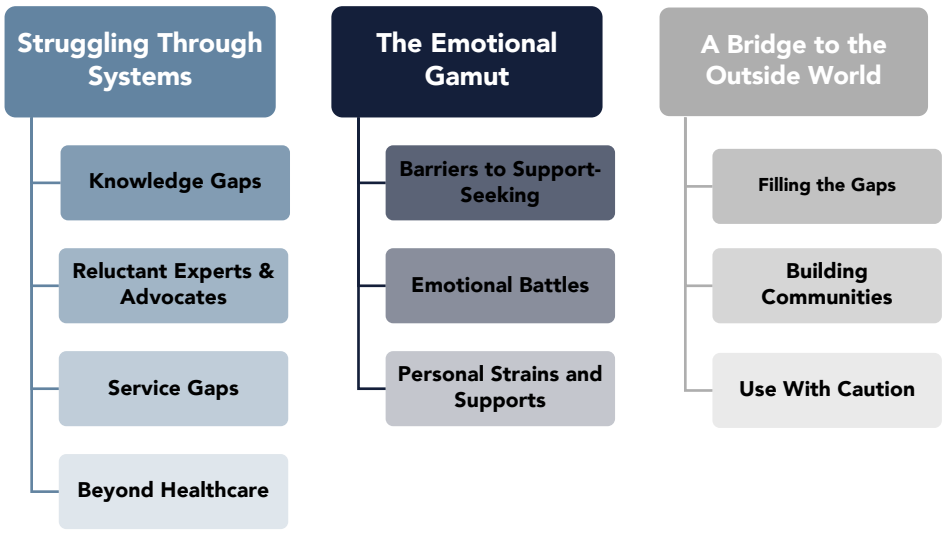
Synthesis Method

Thematic synthesis (Thomas & Harden, 2008) was chosen as the method to analyse the included studies, as it is well suited to reviews seeking to understand lived experiences, aligning with the review's aim to understand how individuals with tic conditions and their carers describe their experiences of seeking formal and informal support. Thematic synthesis supports a structured but interpretative approach, enabling the identification of patterns across datasets alongside the development of novel insights when considering the data holistically and reflecting on its implications. In line with Thomas & Harden's (2008) guidance, only the results section of each study was coded.

Per the 3-step process (Thomas & Harden, 2008), all included studies were coded line-by-line within NVivo 14 software. The resulting codes were then grouped into descriptive themes before generating the final analytical themes. Whilst descriptive themes reflect concepts or ideas recurring across studies, analytic themes require the researcher to "go beyond" the literal findings by considering how these ideas intersect, contrast, or build upon one another, thereby enabling interpretations about the patterns, meanings, and implications held within the data. This process was approached iteratively, involving ongoing and repeated engagement with the studies, the generated codes, and descriptive themes, which enabled deeper reflection on what analytic themes might best address the review question.

2.3 Findings

The thematic synthesis led to the emergence of three themes and accompanying subthemes. A tabulation of the studies and the themes they touch upon can be found in Appendix C.



Theme: Struggling Through Systems

This theme explores participants' experiences of navigating systems ill-equipped to recognise and support tic conditions, where gaps in knowledge and fragmented, inaccessible services shoehorned both individuals and carers into educator and advocate positions just to access help.

Knowledge Gaps

Participants in all but one study (Travis & Juarez-Paz, 2020) reported encounters with professionals who lacked knowledge around tic conditions. Many clinicians, particularly GPs, the usual first point of contact, appeared to approach tic conditions with what Malli and Forrester-Jones (2022) describe as "inaccurate and outdated beliefs". For some, this led to ill-informed but benign interactions: *"When we said our son's got Tourette's, he went 'oh, swearing?' And that's a medical professional (laughs)"* (Ludlow et al., 2018). Similarly, an adult participant reflected: *"I've kind of just been told to deal with it, because I can't 'stay still'… a fully qualified GP… asked me what tourettes was, and said 'is that a form of exercise?"'* (Taylor et al., 2022)

In many cases, however, professionals' knowledge gaps had more serious consequences. Marino et al. (2023) reported that many felt their doctors couldn't distinguish tics from other conditions, which was echoed in Hu et al.'s (2025) study, where parents reported numerous referrals to incorrect specialisms, leading to misguided explanations and treatments. Participants within several studies described how diagnostic errors prevented effective treatment and increased distress (Burn et al., 2025; Hu et al., 2024; Malli & Forrester-Jones, 2022; Rivera-Navarro et al., 2009). Others reported receiving misinformed advice, such as false reassurance that complex tics would go away on their own (Cuenca et al., 2015; Marino et al., 2023), to ignore them (Ludlow et al., 2018) because they were a behavioural issue (Hermansen & Miller, 2008; Malli et al., 2019; O'Hare et al., 2017), or even to bribe their child to stop ticcing (O'Hare et al., 2017).

One of the most harmful consequences of clinicians' knowledge gaps was what Perkins et al. (2020) describe as a lack of "appreciation of the difficulties faced by their patients". Many described feeling unheard, disbelieved, and invalidated in their encounters (Burn et al., 2025; Ludlow et al., 2024; Malli et al., 2019; Marino et al., 2023; O'Hare et al., 2017; Taylor et al., 2022), leading to frustration alongside significant detriments to wellbeing: *"We felt that the GP had as little clue as to why my daughters previously quite innocuous tics could have turned so noticeable, life changing and violent overnight. Almost felt as if we weren't believed"* (Marino et al., 2023). Instances of dismissal and invalidation also exacerbated peoples' existing distress: *"Because I have a long history of mental health, that any*

problems […] it's put down to anxiety. […] When you get told it time after time you just think, what on Earth is wrong with me?" (Burn et al., 2025).

Reluctant Experts & Advocates

Contending with what O'Hare et al. (2017) described as "high levels of professional ignorance", participants found themselves pushed to become experts in tic conditions, just to be able to navigate the healthcare system. Participants expressed feeling more knowledgeable than professionals (Burn et al., 2025; Cuenca et al., 2015; Ludlow et al., 2018, 2024; Marino et al., 2023; O'Hare et al., 2017; Perkins et al., 2020): *"…most of the places we have been to about my Tourettes like it seems like no one actually knows about it… when we go there they usually ask us about it more than we ask them"* (Cuenca et al., 2015). Indeed, becoming knowledgeable appeared to be a necessary response to counter professionals' dismissal and invalidation. As one parent cautioned: "*Try and look at sensible websites about it. I would speak to your GP but not be fobbed off, because that is what they do"* (Ludlow et al., 2024).

What came hand-in-hand with self-educating was advocating, for oneself or one's child, as simply knowing about tics was insufficient to get support, with Marino et al. (2023) reporting that some participants required over five GP appointments to secure a referral to secondary care: *"I had to go back and say 'No, I want to see a specialist' … I had to tell the GP exactly who to refer me to, I had to say that quite a few times. He kept saying he couldn't make the referral…"* (Cuenca et al., 2015). Participants reported different strategies and approaches towards advocacy. Some adopted an assertive stance: "*I shouted it from the rooftops, kicked and screamed, wrote snotty emails, sent them a handwritten letter"* (Ludlow et al., 2018), whilst others were more cognizant of the possibility of alienating professionals: *"If we go up there screaming and shouting to the odds, that gives them a reason. So we need to do it in a very sensible and calm manner"* (Burn et al., 2025).

Gaps in Services

Whilst advocacy could result in fruitful outcomes with professionals who listened, valued individuals' expertise, and supported alternative treatments or made onward referrals (Hermansen & Miller, 2008; Marino et al., 2023; Travis & Juarez-Paz, 2020), this was often just the first step in a long and arduous journey of support-seeking. Even after being referred into secondary care, it was described as fragmented, inaccessible, or unavailable. Multiple participants reported being on waiting lists for months, if not years (Burn et al., 2025; Cuenca et al., 2015; Ludlow et al., 2024; Marino et al., 2023; Taylor et al., 2022) before they could receive a diagnosis or access specialist treatment: *"…Unfortunately, we were then kind of left in limbo waiting for the pediatrician appointment with took* [sic] *8 months… to*

be honest we felt very alone and scared. Our daughter went from a happy little girl to a very withdrawn sad girl" (Marino et al., 2023).

Even securing a diagnosis did not necessarily improve peoples' circumstances or expedite treatment. While some found relief and validation (Burn et al., 2025; O'Hare et al., 2017), others experienced "more confusion than clarity" (Rivera-Navarro et al., 2009) and faced a lack of clear treatment pathways and limited access to adequate, evidence-based interventions (Burn et al., 2025; Cuenca et al., 2015; Hu et al., 2024, Ludlow et al., 2018; 2024; Malli et al., 2022; Marino et al., 2023; Perkins et al., 2020; Rivera-Navarro et al., 2009), with one participant being told: "*there was no help on offe*r"(Marino et al., 2023).

Cuenca et al. (2015) reported that many participants sought to access behavioural interventions, but found them unavailable, whilst Malli et al. (2022) found others were not offered the option despite it being the first-line treatment "recommended by European clinical guidelines". For some, the wait for support was so long that it rendered it obsolete: *"The psychoeducation sessions on functional tics that were offered were pointless, as having lived with it for a year, it was kind of pitched at someone who had just had it in the first month"* (Ludlow et al., 2024). As a result, some opted for expensive private treatment (Burn et al., 2025; Ludlow et al., 2024; Marino et al., 2023). Others, having lost faith in mainstream medicine, looked to alternative interventions such as chiropractic care (Hermansen & Miller, 2008), physiotherapy, massage, and osteopathy to alleviate accompanying pain (Taylor et al., 2022).

Adulthood also presented additional challenges in support-seeking. Several studies described how existing services and resources were catered mainly towards CYP, leaving people feeling abandoned once they became adults (Coleman et al., 2024; Malli et al., 2019; Marino et al., 2023; Perkins et al., 2020). One participant articulated their sense of neglect: "*Once you hit 18, you feel a bit like 'oh, we're not gonna care now… you're not a child, you're not interesting anymore"* (Coleman et al., 2024), whilst another showed their frustration at the lack of available support: *"I was told because of my age the NHS doesn't really have any support network in place [for tics] so everything is going to be really slow in getting to see anyone or diagnosed. I don't think this is fair at all just because of my age. I'm 30 years old"* (Marino et al., 2023).

Beyond Healthcare

Schools and workplaces mirrored much of the same challenges. Some participants described schools as collaborative and invaluable in ensuring peoples' academic and social wellbeing (Burn et al., 2025;

Ludlow et al., 2018; Ludlow et al., 2024; O'Hare et al., 2017; Pine et al., 2024), but it appeared that such experiences were highly variable and contingent upon both academic staffs' attitudes and families' persistent advocating: *"I feel sorry for the child that doesn't have a parent that wouldn't have a voice to be able to speak up…you don't always come out (after talking to school) with brownie points but I think, well I have to do it!"* (O'Hare et al., 2017).

Some studies touched on the necessity of diagnosis to guarantee that requisite adjustments were put in place (Burn et al., 2025; Marino et al, 2023). However, despite having obtained it, some schools and workplaces were either unable, or worse, unwilling, to implement accommodations to support individuals within those environments (Burn et al., 2025; Hermansen & Miller, 2008; Ludlow et al., 2018; Malli et al., 2022; O'Hare et al., 2017; Pine et al., 2024). Even seemingly minor adjustments were delivered inconsistently or refused: "*We wanted extra time for her when she comes to do some exams and studying, she found it difficult to read … we asked if they could make notes for Emma, you know just minor adjustments like that, which they didn't really carry through"* (Ludlow et al., 2018). For some families, the consequences of this were severe, resulting in children being removed from lessons, not being permitted to offer psychoeducation to peers, experiencing ongoing bullying, or even being asked to leave school altogether (Burn et al., 2025; Ludlow et al., 2018; Malli et al., 2022; O'Hare et al. 2017; Pine et al., 2024). One participant's workplace experience followed a similar pattern, where a lack of amenability compromised both professional and personal prosperity: *"They basically said to me you can't be on this medication and do this job. It's another way of them saying you can't do this job with Tourette's. They said you have to stop taking it, without saying it… I did that and got really ill and basically they didn't renew my contract cause of the sick days I had trying to get off the bloody stuff."* (Malli et al., 2022).

Theme: The Emotional Gamut

Alongside systemic obstacles, support-seeking was also characterised by powerful emotional experiences which shaped whether individuals sought support and how it felt to do so. This theme explores the gamut of emotions when seeking support.

Barriers to Support-Seeking

Some participants described emotional barriers to seeking support in the first place. Shame emerged as a pervasive barrier, rooted in embarrassment around the tics and worries that they would not be taken seriously (Hermansen & Miller, 2008; Malli et al., 2019; Perkins et al., 2020; Taylor et al., 2022): *"[a] doctor diagnosed me with tics but I was too ashamed and embarrassed to tell my parents about*

every tic I experienced" (Taylor et al., 2022). Worry often came alongside shame as a powerful deterrent, and participants spoke of worrying about having to 'prove' oneself to access disability schemes (Coleman et al., 2024) and being believed about their tics (Soós et al., 2022). This was often rooted in previous negative encounters where symptoms were dismissed or trivialised. Some participants actively chose not to seek help because of previous negative encounters and the resulting doubt that support was attainable: *"I have never sought help because I didn't believe there was anything anyone could do to help with my particular problems"* (Taylor et al., 2022).

Emotional Battles

For those who sought support, navigating support systems was often characterised by participants as a 'fight' or a 'battle' in order to secure the appropriate or desired outcome (Burn et al., 2025; Ludlow et al., 2018, 2024; Marino et al., 2023; Pine et al., 2024). Their experience of support-seeking fostered evident frustration: *"The doctor suggested his behaviour was 'Tourettish' but it was behaviourally based and recommended parenting lessons! I was in stunned silence and I just felt so angry"* (O'Hare et al., 2017). For some, anger turned to desperation, particularly when their search for support was fruitless and left them bereft of any help or direction: *"Something's terrible going on, and nobody wants to help, no one even knows. Even throwing money at it, we can't get any help"* (Ludlow et al., 2024).

For parents in particular, blame was a catalyst for feelings such as shame, guilt, and anger. Across various studies, there appeared to be a widespread perception that parents were responsible for causing or exacerbating their child's tics (Burn et al., 2025; Hermansen & Miller, 2008; Hu et al., 2024; Ludlow et al., 2018; O'Hare et al., 2017; Rivera-Navarro et al., 2009; Travis & Juarez-Paz, 2020), with their behaviours, disciplining, and emotional responses placed under scrutiny: *''He said that we just had to be firmer and fight the battles with her more until she gave in. [The psychologist] said that he could not understand me because [my daughter] hit me a lot and he said to me: 'I don't know why you let yourself get hit?'''* (Hermansen & Miller, 2008). Such comments became internalised, fostering guilt among parents and shaping subsequent support-seeking. As outlined in Hu et al.'s (2024) study, in an attempt to mitigate the guilt and shame they felt for 'causing' their child's tics, parents either withdrew from trying to manage their child's tics for fear of making them worse, or engaged in desperate and excessive help-seeking from misinformed professionals who could not provide them with answers.

Personal Strains and Supports

Many described the emotional toll of their personal networks not believing, dismissing or outright rejecting their experiences of tics. Although some loved ones attempted to be helpful by questioning

the diagnosis, such reactions were unwelcome and ultimately increased a sense of alienation (Travis & Juarez-Paz, 2020). Similarly, it fostered a sense that others would be as dismissive or invalidating, leading towards peoples' withdrawal from peers and social networks: *"…the tics really made me less likely to reach out socially. Well, to socialise at all or to seek out friends, cause I was worried about being the joke"* (Malli et al., 2019).

Some encountered overt humiliation and hostility from family members (Ludlow et al., 2018; Malli et al., 2019; O'Hare et al., 2017; Rivera-Navarro et al., 2009; Travis & Juarez-Paz, 2020), with one participant describing a particularly harrowing experience with their family, who not only did not believe in their symptoms, but punished them for having tics: *"My parents …they were horrible to me. They thought by telling me off or slapping me or whatever, punishment, you know, name calling […] And they would humiliate me in public, you know, they would say stop being a monkey and then my sisters [...] they saw my parents having a go at me and bullying me for that they would do exactly the same"* (Malli et al., 2019). Whilst not as extreme, others described feeling more subtle, but equally painful, forms of dismissal, simply because their loved ones could not relate: *"friends and family never supported my tics, probably because they don't have them"* (Taylor et al., 2022).

Alongside these negative experiences, others described equally powerful feelings of relief, hope, and safety when family and friends offered empathic and thoughtful support. Within several studies, family, partners, and friends were noted as essential in helping those with tics feel understood and accepted (Malli et al., 2019; 2022; O'Hare et al., 2017; Soós et al., 2022; Taylor et al., 2022). Importantly, these studies demonstrate just how pivotal parents are in ensuring the comfort and wellbeing of their child, even if not explicitly acknowledged. Some parents took great care to create an environment where their child could be comfortable and free of judgment: *"We said honey you just tic as much as you want and as often as you want and as loud as you want because we don't care"* (O'Hare et al., 2017). Some loved ones offered more practical forms of support, to help alleviate feelings of embarrassment in public, provide stability and reduce financial pressure (Malli et al., 2019), or offer pain relief (Taylor et al., 2022). Importantly, loved ones encouraged individuals to seek help, particularly in times of crisis: "*My wife forced me to seeking [sic] help. It was a time when the pain was insanely painful and I had thoughts of ending my life"* (Taylor et al., 2022).

Theme: "A Bridge to the Outside World"

Whilst contending with these emotional experiences, many found comfort and support outside formal systems. Peer-led spaces, in-person and online, became invaluable sources of information,

understanding, and validation. This theme explores how such spaces became what O'Hare et al. (2017) call "a bridge to the outside world".

Filling the Gaps

Both individuals with tics and their carers spoke to how peer support, including online communities, act to fill the gaps that were encountered when support-seeking (Burn et al., 2025; Coleman & Melia, 2023; Ludlow et al., 2024; Malli et al., 2019; Marino et al., 2023; O'Hare et al., 2017; Perkins et al., 2020; Soós et al., 2022; Travis & Juarez-Paz, 2020). When formal support systems such as healthcare or education lacked necessary knowledge or resources, these spaces became invaluable alternatives: *"Medical professionals need to realise that people go to these forums more than their doctors because your standard GP etc has no idea what TS is really like, we provide our own support because no one else will. We are like a forgotten element of the medical society"* (Perkins et al., 2020).

Peer-led communities, whether online spaces, charities, or support groups, became essential repositories of practical information about living with tics, including seeking clarity around diagnosis, advice on managing symptoms and comorbid conditions, experiences of medication and treatment options, helpful research, reading, and media, and navigating conversations with loved ones and professionals (Burn et al., 2025; Ludlow et al., 2024; O'Hare et al., 2017; Perkins et al., 2020; Soós et al., 2022; Travis & Juarez-Paz, 2020). As Soós et al. (2022) commented, online communities enabled participants to pose individualised and specific queries and receive tailored advice from others with similar experiences, offering a degree of personalised guidance that, as per *Struggling Through Systems*, was not guaranteed when consulting health professionals: *"I've found out a lot more information through social media groups than through our community paediatrics"* (Burn et al., 2025).

It is precisely the opportunity to exchange personal experience and advice that participants most valued. Whether it was carers or individuals themselves, peer support was characterised as an antidote to the loneliness and isolation that many felt: *"Seeing other people having to grow up and deal with the same I went through is amazing. I knew no one else, so I could never talk about the issues I was dealing with at school etc."* (Soós et al., 2022). This sentiment was evident in several studies (Coleman & Melia, 2023; Ludlow et al., 2024; Malli et al., 2019; Marino et al., 2023; O'Hare et al., 2017; Travis & Juarez-Paz, 2020), with some expressing that even the most supportive loved ones could not fully understand the realities of living with tics, whilst peers allowed people to be open without worrying about misunderstanding or acceptance: *"You can tell [people without TS] all the time what a tic feels like…but*

they won't understand it fully, whereas someone who's got Tourette's understands it fully" (Coleman & Melia, 2023).

Building Communities

Feeling alone and isolated, many turned to online and in-person peer support to find communities built around shared experiences, empathising with one another, and offering encouragement (Burn et al., 2025; Coleman & Melia, 2023; Ludlow et al., 2024; Malli et al., 2019; O'Hare et al., 2017; Perkins et al., 2020; Soós et al., 2022; Travis & Juarez-Paz, 2020): *"..although, well it's nice to be unique, I would always like… a group of people, or someone I can talk to about… and I feel I'm like...I'm part of something…"* (Malli et al., 2019). Some took opportunities to foster acceptance: *"You also don't have to hide your tics! ...You're unique in your own way and you shouldn't have to hide yourself!"* (Soós et al., 2022). Participants also spoke to how connecting to other's lived experience increased their self-confidence and enabled them to cope better in the 'offline' world: *"I've learned that I shouldn't be so self-conscious when I tic, that if people ask, just explain and move on."* (Perkins et al., 2020).

Such communities also instilled hope and optimism, as seeing others with tics living fulfilling lives allowed participants to envisage more positive futures (Coleman & Melia, 2023; Perkins et al., 2020): *"When I went to a support group…I met four or five women…who were married and had kids and jobs and doctorates…and I never thought that I could. I'd never seen a girl grow up with Tourette's and get married… I'd never seen women with Tourette's with a job"* (Coleman & Melia, 2023). Connecting with others also encouraged seeing beyond the limitations imposed by their tics: *"Seeing other people with TS who are happy, successful and empowered helped me to embrace my TS as it showed me that my condition should give me strength and not hinder me"* (Perkins et al., 2020).

In addition to discovering shared and hopeful experiences, a key function of these spaces was being a safe outlet to vent emotions and both seek and offer validation. Peers provided reassurance and solidarity, helping others feel less alone: "*I feel your pain!"* (Soós et al., 2022) and: *"Please let me know I'm not the only weird one in having this tic?"* (Soós et al., 2022). Participants also described online spaces as ones where they could express the frustrations, worries, and challenges they felt they had no other outlet for: *"The struggle is real… It's a nightmare and I needed to vent"* (Soós et al., 2022). Importantly, the positivity exchanged in these communities was reciprocal, and many found purpose in offering support or advice to others going through similar experiences: "*If people are going through the same struggles I did when I was younger I want to offer advice"* (Perkins et al., 2020).

Use With Caution

Not everyone's experiences with peer spaces, particularly online ones, were positive. Some groups were described as holding rigid, narrow viewpoints which limited discussion: *"This one strongly supports CBD, that one strongly rejects it. This one loves CBIT, that one is sceptical. (...) either way one isn't getting a healthy, integrated community or understanding of TS*" (Perkins et al., 2020). This rigidity could cause conflicts and feelings of exclusion, particularly when carers shared opinions in ways that felt invalidating to individuals with tics (Perkins et al., 2020).

Some also reported instances of hostility and judgment, including competition over *"whose Tourette's is the worst"* (Perkins et al., 2020), undermining the supportive atmosphere of the spaces. As Burn et al. (2025) noted: "Some families moderated their exposure to online groups as they found content could be negative and disheartening". There were also concerns about online advice, which some worried could be misleading or even harmful (Perkins et al., 2020). As one participant cautioned: "*we are not neurologists"* (Soós et al., 2022), highlighting the risks of relying solely on online peers in lieu of professional advice.

2.4 Conclusion

This review aimed to synthesise how individuals with tic conditions and their carers experience seeking support across formal and informal settings. The resultant thematic synthesis identified three overarching themes: Struggling Through Systems; The Emotional Gamut; and "A Bridge to the Outside World". Collectively, the results of the themes demonstrate that support-seeking is often characterised by multiple barriers, including gaps in professionals' knowledge, dismissal of symptoms and their effects on daily life and wellbeing, pervasive stigma, unclear referral pathways and fragmented services. These factors leave individuals and their carers feeling judged, invalidated, blamed, and unsupported, contributing to significant emotional strain, which is further compounded in those without compassionate understanding from their personal networks. To remedy this, many turn to peer-led spaces, particularly online ones, which, despite some shortcomings, fill gaps left by other support systems and offer communities built upon information exchange, shared experience, and validation.

These findings are consistent with other reviews and syntheses which highlight the systemic shortcomings, psychosocial experiences, and emotional burdens associated with tic conditions (Lee et al., 2024; Malli et al., 2016; Maxwell-Scott et al., 2024; Parker et al., 2024; Pring et al., 2023; Smith et al., 2015). Whilst the existing research has focused on healthcare as the primary locus of support, this review broadens the lens to encompass the wider system of support, and aggregates participants'

feedback on how experiences within healthcare, education, workplaces, personal relationships, peer-spaces, and online communities shape and influence the active pursuit of both practical and emotional support. In so doing, this review hopes to offer a holistic understanding of the support-seeking journey, and how individuals with tics and their carers navigate it.

Further Implications

A consistent perception amongst participants was the significant gap in professional knowledge and understanding about tic conditions, contributing to misdiagnosis, dismissal, and distress. This reflects recent research showing clinicians lack confidence in identifying and treating tics (Parker et al., 2024), highlighting the necessity of increased education and training. In the UK in particular, these issues are exacerbated by the absence of NICE guidelines for tic conditions, leaving professionals without clear frameworks for assessment, referral, or treatment, resulting in fragmented care pathways that incur significant costs to the NHS (Hall et al., 2024) and undue burdens onto individuals and carers.

Beyond healthcare, this review highlights instances of discrimination within education and workplace settings, where some individuals encounter not only prejudice but a denial of reasonable adjustments. In the UK, this is particularly concerning, given that these adjustments are protected under the Equality Act (2010). This not only points to an urgent need for further awareness and training, as above, but the development of clearer frameworks to systematically ensure inclusive environments across settings, rather than leaving individuals' experiences to a 'luck of the draw' whether they encounter supportive clinicians, educators, or employers.

Finally, this review highlights the value and utility of peer-led and online spaces in remedying the practical and emotional tolls of support-seeking. People with mental health difficulties increasingly turn to online communities for emotional support and information, which can positively impact their wellbeing (Merchant et al., 2022). However involvement in online communities subsequently shapes the way individuals interact with healthcare professionals and evaluate their advice (Kjærulff et al., 2023). Therefore, clinicians should recognise the value of peer and online spaces as support mechanisms, guiding individuals and carers toward reputable, well-moderated platforms, whilst also providing them with clear, evidence-based information and cautioning against possible pitfalls of online engagement.

Strengths and Limitations

A strength of this review lies in its thematic synthesis approach, which enabled the aggregation of diverse studies, even though few focused specifically on support-seeking as their primary research

question. Synthesising data through this lens demonstrates how individuals and carers navigate different support contexts, homing in on the interplay between systemic barriers, one's agency, and the emotional experience of support-seeking. The analysis of these factors stems from the feedback and responses of participants, centring their voice and perspectives.

However, this also introduces a limitation: because few studies specifically sought to explore support-seeking, some studies lacked depth or detail around this particular topic. As a result, the analysis is constrained by the extent to which participant feedback addressed this question directly, thereby possibly missing important factors or considerations. Similarly, most included studies were small in scale, and often recruited participants through advocacy or support groups, which may introduce sampling bias, as those with more negative experiences may be more inclined to participate than those who have had more positive experiences. Likewise, although this review captured diverse contexts around support-seeking, further research is needed into how factors such as cultural perspectives and aspects of personal identity, including additional health conditions, might factor into support-seeking. The absence of these considerations reflects not only a limitation within this review, but an area warranting further research generally.

Rationale for Empirical Study

This review examined the spectrum of tic conditions, including both neurodevelopmental and functional. Despite its scope, it revealed a notable lack of qualitative research focused on functional tics (FTs). Whilst two included studies offer valuable insights (Burn et al., 2025; Ludlow et al., 2024), they largely capture parental perspectives, leaving much about young peoples' (YPs) personal experiences of FTs to be explored. Existing research around FTs has focused on distinguishing them from neurodevelopmental tics, rather than understanding how those directly affected navigate the practical, social, and psychological realities of living with FTs. Without such knowledge, there is a risk of ongoing failures to provide informed and compassionate support, and of perpetuating stigmatising and misinformed attitudes around FTs, as evidenced in the review above. As such, the study presented in the following chapters aims to explore the lived experience of YPs with FTs, by asking:

1. *How do YPs navigate daily life, and what coping mechanisms have they developed in response to the challenges posed by the FTs?*
2. *How do YPs experience the social and psychological impacts of FTs, and how have they affected their identity and psychological wellbeing?*
3. *In what ways have YPs sought support for their FTs, and what role does social media play within this?*
4. *What has been helpful, and what gives YPs hope for the future?*

Chapter 3: Methodology

3.1 Chapter Overview

This research seeks to better understand the lived experience of young people (YP) with functional tics (FTs). By exploring how they navigate the practical, psychological, and social dimensions of life with FTs, this study aims to highlight perspectives which have largely been overlooked in existing literature. This chapter first addresses the theoretical and epistemological underpinnings of the study, followed by a description of the research design. Reflexive Thematic Analysis (RTA), the chosen method, is described and justified. Ethical considerations, recruitment procedures, data collection, and analysis are elaborated upon, and the chapter concludes with a brief statement on member reflections.

3.2 Design

Ontology / Epistemology

This study is rooted in a Critical Realist (CR) paradigm, which provides both its ontological and epistemological lens. In this study's context, a CR ontology posits that FTs are real phenomena with real physical and psychological effects on YPs' lives. It also recognises that each YP's experience of FTs is shaped by their personal histories, perceptions, and beliefs, and mediated by broader cultural and societal contexts. This stance, therefore, acknowledges that whilst FTs are experienced *subjectively,* they are real and can, therefore, be studied. In so doing, it supports the study's aim to understand YPs' experiences holistically, considering both personal narratives and the contexts that shape their understanding and meaning of such experiences.

Qualitative Research Design

Qualitative methods are particularly helpful in investigating subjective experiences and participants' own interpretations of these realities. Such methods can elucidate complex facets of the human experience, including beliefs, attitudes and reflections, by exploring how participants make sense of "how" and "why" (Cleland, 2017; Tenny et al., 2025), particularly where empirical theory and evidence around a phenomena are still emerging (Cassell & Symon, 2011). Hence, a qualitative approach can help capture the context, meaning, and nuance necessary to develop a holistic understanding of complex phenomena such as FTs.

Despite the initial surge of research aiming to classify and differentiate FTs from NTs, few studies have explored the experience and impacts of FTs. As demonstrated in the SLR, individuals with tics frequently encounter stigma and dismissal within clinical settings. For those with FTs, these experiences may be

compounded by widespread negative attitudes around functional symptoms (Foley et al., 2024), making it both an empirical and ethical priority to make their experiences known. In utilising a qualitative design, this study upholds a social justice commitment which seeks to humanise care by highlighting beliefs, experiences, and systemic conditions in order to shape clinical practice (Cypress, 2015; Morse, 2012). Such research can become a powerful tool for demarginalising underrepresented groups by challenging dominant assumptions, identifying gaps in care, and developing a greater understanding of health experiences (Denzin, 2018).

Reflexive Thematic Analysis

Rationale for RTA

To enable a meaningful exploration, as outlined above, it was important to utilise a method that recognises that participant's experiences are necessarily interpreted through the researcher's lens. From a CR perspective, this is an inevitable reality of the research process, as the mediation of context, language, and the researcher's own positioning is an "indisputable" mechanism of the participant-researcher relationship through which data is shaped (Maxwell, 2012). As such, choosing a method that actively foregrounds this form of reflexivity felt particularly important. RTA was therefore chosen as the method, both because it acknowledges the subjectivity of the researcher, treating it as a resource rather than a bias to be controlled (Gough & Madill, 2012), and offers a flexible yet rigorous method for identifying and analysing meaningful themes and patterns within data (Braun & Clarke, 2006, 2013; 2021b).

A strength of RTA is its analytic flexibility, enabling the researcher to move along the continuum between inductive and deductive analysis, and latent and semantic coding, thus generating a representation of lived experience and the mechanisms shaping it (Braun & Clarke, 2021b). When adopting these approaches flexibly, analysis can oscillate between an inductive approach, which captures participants' own meanings, and a deductive one, which ensures that interpretations remain anchored to the study's aims and questions (Byrne, 2022). This may be further complemented by flexibility within the coding techniques used. Semantic coding preserves the explicit content of participants' accounts, whilst latent coding fosters interpretation of underlying perspectives, beliefs, and contextual influences (Byrne, 2022). By utilising these approaches in a thoughtful and complementary manner, the ensuing analysis reflects both what participants say outright and imply, upholding the interpretive and reflexive strengths of RTA, and the CR stance of this research.

Self-Reflexivity

True to RTA's interpretative framework, I engaged in active and ongoing reflexivity throughout this research. Reflecting on my positionality, and how it is shaped by the values, beliefs and assumptions I brought into this research enabled my awareness of its evolution throughout the research. Being an outsider researcher (Braun & Clarke, 2013) presents both opportunities and challenges. On the one hand, I can approach the research with fresh eyes and question assumptions that might be taken for granted by insiders (Fay, 1996). On the other, participants may find it difficult to be fully open with someone who cannot claim to truly understand what they're going through (Dwyer & Buckle, 2009).

To navigate this position, I utilised several reflexive strategies to support my interactions with participants and data. Keeping a reflexive diary (Appendix D) helped me track the evolution of my interpretations and note potential influence of any preconceptions or emotional reactions. This was particularly true during coding, where I needed to stay attuned to both what was said, and how I was making sense of it. I also drew on my supervisors as critical friends, which encouraged reflection on possible alternative explanations or interpretations of the data, particularly during write-up (Smith & McGannon, 2018). Finally, I invited member reflections, giving participants the opportunity to engage with and respond to the findings, ensuring they are comprehendible and meaningful to the participants (Tracy, 2010).

Alternative Considerations

Whilst RTA was chosen as the most suitable method to meet the study's aims, other qualitative methods were considered. Table 7 outlines these options, and the rationale for why RTA was utilised:

Table 7: Alterative Analytic Methods Considered

Possible Alternative Method	Rationale for RTA
Interpretative Phenomenological Analysis (IPA) (Smith et al., 2009, 2022) • Rooted in phenomenology and hermeneutic inquiry, thus producing detailed analyses of individuals' lived experiences and how they make sense of them • Typically utilises small, selectively homogenous samples	• IPA prioritises individual, in-depth sense making, whereas this study hopes to understand people's experiences and shared patterns shaped by wider socio-cultural contexts (Braun & Clarke, 2021a) • IPA may be less suited to initial exploration of under-researched topics like FTs, where a broader understanding of shared experiences is warranted
Coding Reliability Approaches (Boyatzis, 1998; Guest et al., 2012)	• These approaches view researcher subjectivity as a bias to be avoided (Braun & Clarke, 2021a), sidelining

• Involves early theme development based on identifying pre-existing patterns in the data; Themes are treated as topic summaries rather than interpretive constructs • Typically requires multiple coders applying a shared codebook, with inter-rater reliability being a paramount feature of quality analysis	reflexivity in favour of objectivity and consensus, which could limit the depth of interpretations • The focus on descriptive summaries of data could inhibit latent analysis of experiences, their nuances, and influences, which are a key focus of exploration in this study

3.3 Ethical Considerations

The University of Hertfordshire Research Ethics Committee provided ethical approval for this study, under protocol number LMS/PGR/UH/05773 (Appendix E). Additional amendments to the protocol were requested and approved (Appendix F).

Informed Consent, Assent and Right to Withdraw

Three age-appropriate information sheets were developed for YPs (Appendix H, I) and for parents/carers for those under 16 (Appendix J). These clearly outlined the study's aims, procedures, policies on confidentiality, data storage, and usage. Informed consent was obtained through signed consent forms from all participants (Appendix K-M). In line with frameworks for ethical research, consent was obtained from YPs older than 16 and parents/carers of YPs under 16, whilst informed assent was sought from younger YPs themselves (BPS, 2019; HRA, n.d.). Assent is the child's informed, affirmative agreement to participate in research (Modi et al., 2014), such that it is them, and not their parent, that decides whether they wish to participate in a study. Consistent with Sibley's (2016) ethical guidance, young YPs received developmentally appropriate versions of the study materials, and were provided opportunities throughout recruitment, screening, and participation stages to confirm their willingness to take part. They were reminded that their participation was entirely voluntary, regardless of parental consent or desire for their participation.

The same approach was extended to older YPs, ensuring they were meaningfully involved with the consent process and maintained a clear understanding of their rights as participants. YPs of all ages and their careers were assured that they could withdraw at any point, and all were regularly invited to ask questions or seek clarification on the study.

Anonymity, Data Storage, and Confidentiality

Information pertaining to data storage and use was articulated to participants at various points, including before signing up (via the information sheet), during screening, and during the interview. Once

expressing interest, prospective participants were assigned a numerical ID and a password-protected folder was created to store their identifiable information on the University of Hertfordshire's encrypted OneDrive server, which is compliant with European GPDR (2018) standards for safe data storage. Participants were asked to confirm the suitability of their assigned pseudonym. Completed interview transcripts were saved in a pseudonymised file with identifying information removed. Interview recordings were deleted once fully transcribed and error free.

To maintain their sense of autonomy, privacy, and dignity within the research (BPS, 2021), participants were assured that they need not disclose any information that they felt uncomfortable sharing. The option to 'pass' on a question was available to all participants, and every conversation with the researcher (screening, interview) was premised on their right to choose whether, and how, they answered. Participants were also made aware of the parameters around confidentiality, including instances in which it may need be broken, as per the BPS Code of Conduct (2021).

Mitigating Distress

Participant Distress

Mitigating participant distress was a focus of supervisory discussions in the planning phases. As discussing the experience of tics posed the risk of intensifying them and exacerbating distress, safeguards were put in place. For younger YPs, a parent/carer must have been present in the same location during the screening call and interview, should they be required to offer immediate support. Older YPs were asked to provide an emergency contact that could be reached if necessary. Additionally, a distress management protocol was developed, encouraging check-ins, offering breaks, utilising grounding or distraction techniques if necessary, and giving reminders about their right to withdraw. Following the completion of the interview, each participant was sent a debrief sheet (Appendix N).

Researcher Distress

In recognition of the possible emotional impacts of conducting an interview on sensitive topics including complex symptoms and experiences, supervisory support was embedded into the study's risk assessment. The supervisory team indicated that they would be available to answer questions, offer debriefing and provide support throughout the data collection phase, as required.

Consultation

To ensure that this research was meaningfully informed by lived experience, Expert by Experience (EbE) consultation was sought. Despite concerted outreach and advertising across multiple channels, attracting consultants proved challenging; however, thanks to an introduction by a colleague, an EbE

with Tourette's Syndrome kindly agreed to consult on the project, particularly its participant-facing aspects. Their feedback informed several reflections and refinements, which are discussed throughout this chapter.

3.4 Recruitment & Participants

Recruitment Strategy

Purposive sampling was used to recruit YPs with lived experience of FTs. This enabled gathering data from individuals with specific knowledge or experience related to the phenomena-in-question (Palinkas et al., 2015). Alongside personal expertise, YP's willingness to engage, availability, and their capacity to reflectively articulate their experience are benefits inherent to purposive sampling (Bernard, 2017).

Based on the supervisory team's past success recruiting parents of YPs with FTs, Tourette's Action was chosen as an initial recruitment avenue. Given that YPs with FTs may also seek support for functional symptoms more broadly, FND Hope was also approached. Both are well-established charities in their respective fields and have an active research arm. Once requisite permissions were granted, both organisations shared the study advert on their website and social media channels. However, uptake from these sources was limited. Recognising the importance of online spaces for this group, recruitment was extended towards online communities where YPs with FTs may be seeking support or sharing experiences. Reddit was particularly effective; following moderator approval, the study advert was posted on various subreddits, including, r/Tourettes and r/FND amongst others pertaining to mental health. Additionally, two mental health practitioners, one specialising in functional tic treatment, agreed to share the study advert on their Instagram pages.

As per Braun and Clarke (2021b, p. 28), high-quality RTA prioritises discovering diverse perspectives and insights over data saturation. As such, recruitment remained open until 'information power' (Malterud et al., 2016) was achieved. In this study, information power was evaluated based on the depth, relevance, and richness of participants' responses in relation to the research aims. The successful collection of reflective, nuanced accounts indicated that adequate information power was achieved with 12 participants.

Inclusion Criteria

Participation criteria for the study were developed with the support of the supervisory team. The final criteria, following the amendments described in Appendix F are outlined in Table 8:

Table 8: Study Inclusion and Exclusion Criteria

Criteria	Inclusion	Exclusion
Location	Residents of the UK, to ensure consistency in healthcare context and service availability	Individuals residing outside of the UK, due to the study's focus on the UK context
Age	Young people aged 12-25 years, reflecting the NHS definition of 'young person' representative of the population typically presenting with FTs	YPs outside the age range of 12-25 years
Tic Type and Onset	Young people experiencing sudden-onset functional tics, with at least 3 months of duration or within 6 months of symptom cessation	Symptom duration less than 3 months or cessation more than 6 months prior
Gender	Inclusive of all genders and identities	No exclusions, to foster gender-inclusive research
Mental Health	Open to young people with co-occurring mental health conditions as these are commonly associated with functional tics	Individuals with mental health conditions which significantly impair communication, functioning, or participation

Participants

YPs with FTs, or their carers, who were interested in taking part were invited to get in touch via the e-mail provided on the study advert (Appendix G). A total of twenty people expressed interest; of these, four were politely declined due to not meeting the age or geographic criteria of the study. Most respondents noted their age and location in their introductory e-mails and were subsequently sent the relevant information sheets and consent form (Appendix K-M). In the two instances where parents expressed an interest on behalf of their child, both parent and child forms were sent. YPs and parents were asked to carefully read what participation entailed, consider the inclusion criteria, and return their signed consent form if willing to take part. Of the sixteen individuals who were sent the above forms, one indicated that they were not eligible and three did not return their consent form. A follow-up e-mail offering an opportunity to ask questions was sent several weeks after the expression of interest but received no response.

Screening

After providing signed consent, a screening call was arranged to gather relevant background information, including demographics, co-occurring mental health conditions, tic presentation and any associated support. Recognising that requiring a formal diagnosis might exclude those who have struggled to access a professional knowledgeable in functional tics, particular attention was paid to phenomenology to ensure alignment with functional tic presentations. YP's descriptions were compared against current ESTSS consensus criteria (Pringsheim et al., 2023) to ensure that at least clinically probable criteria were met, as outlined in Chapter 1. All prospective participants met inclusion criteria. Following their screening call, the twelve YPs were invited to proceed with their interview. Pseudonymised participant information is presented in Table 9:

Pseudonym	Gender	Ethnicity	Age	Location (UK)	Age at Onset (Date)	Tic Phenomenology	Diagnosis Given; By Whom	Professionals Involved	Mental Health Profile
Brooke	Female	N/A	14	Northeast	13 (July 2023)	Eye blinking, neck and hand jerks, flapping, facial grimacing, high-leg kicks, finger cramps, clicking noises	Functional Tics Paediatrician Diagnosed w/ FND	Neurologist, CAMHS, paediatrician, physiotherapist	Low mood; anxiety; autism
Simon	Male	Mixed- White / Caribbean	20	Northwest	~16/17 (Nov 2021)	Sudden neck and limb movements, striking motions towards self and others, choking; screeching and patterned breathing (inhaling/exhaling); tics frequently combine movements and sounds	Functional Tics Neurologist Diagnosed w/ NEAD	Neurologist	No mental health experiences
Riley	Male	White British	17	East of England	~13/14 (2022)	Backward limb movements, neck jerks, aggressive blinking, sweeping arm/leg kicks, punching; beeping, context-specific phrases	Functional Tics GP + Neurologist Suspects FND	Psychiatrist, clinical psychologist	Anxiety, low mood, depression, Tourette's Syndrome
Paige	Female	White British	21	Wales	19 (July 2023)	Repetitive chest hitting, head turning, bilateral arm raises, high-leg kicks; loud vocal tics (squeaking, screaming)	Functional Tics Neurologist Diagnosed w/ FND	Neurologist On waitlist for CMHT	Anxiety, depression, PTSD
Tessa	Female	White British	24	Northeast	~15 (2016)	Head jerking, body shaking, facial grimacing, chest hitting, leg kicks; context-specific phrases	Functional Tics Psychiatrist Diagnosed w/ FND	Psychiatrist, neuroCBT therapist	Low mood, anxiety
Cleo	Female	White British	19	Wales	~16 (2021)	Throat and coughing noises, facial grimacing, rapid blinking, eye rolling, sudden head jerks, limb swinging; humming, context-specific phrases	Functional Tics Psychiatrist	None	Tourette's Syndrome
Kit	Male	White- Other	23	Northwest	23 (May 2024)	Sniffing, head jerks, progressing to variable movements (bicep contraction, full-body turns), head snapping, blinking, finger twitching; inhalations	Functional Tics A&E Doctor Suspects FND	Private therapist, on waitlist for neurology	Anxiety, low mood, ADHD, autism
Norah	Female	White British	21	West Midlands	21 (Dec 2024)	Forceful self-directed movements and repetitive actions involving the head (wearing or knocking off objects); context-dependent phrases and exclamations	Functional Tics Neurologist Diagnosed w/ FND	Neurologist, occupational therapy, CBT therapist	Anxiety, low mood, querying autism
Isla	Female	White British	19	East of England	~14 (2020)	Sharp neck jerks, facial twitches, grimacing, blinking, and large limb movements, hitting out; whistling and repetition of context-specific phrases	Functional Tics Neurologist	Counsellor	Anxiety, autism
Juliette	Female	White British	13	Southeast	12 (Dec 2024)	Head jerks, clapping, waving, hitting out, knocking on surfaces, tongue clicking; echolalia and context specific phrases	Functional Tics Private therapist	Private Therapist, on waitlist for neurology	Anxiety
Avery	Male	Mixed- Other	21	Southwest	~13/14 (2018)	Head jerks, large hand and arm movements, head hitting, slamming or hitting objects; context-specific phrases and exclamations	Functional Tics Neurologist Diagnosed w/ FND	Awaiting mental health support	Anxiety, depression, OCD, ADHD, autism
Sasha	Female	White British	22	Wales	21 (Oct 2024)	Head jerks, limb extensions, lip pumping, head hitting; clicking, short phrases, inappropriate words or phrases dependant on context, short phrases	Functional Tics GP	On waitlist for neurology	Low mood, insomnia

Table 9: Participant Information

3.5 Data Collection

Semi-Structured Interview Schedule

Semi-structured interviews were chosen for data collection as they offer a flexible framework that enables participants to articulate their lived experience in their own terms, whilst maintaining consistency across interviews. This method also complements this study's CR epistemology, as it scaffolds participants to speak to their reality of FTs and enables exploration of how individual attitudes, experiences, and contexts influence these realities (Moore & Kelly, 2024). Similarly, semi-structured interviews support reflexivity by allowing the researcher to follow on what feels meaningful, even if it deviates from the script, making it possible to gain a deeper, more nuanced understanding of both individual stories and patterns across the group (Smith et al., 1995).

The interview schedule (Appendix O) was developed from existing literature alongside discussions with the supervisory team around which aspects of life are likely to be affected by the FTs. As such, it was designed to explore impacts to the practical, psychological, and social dimensions of YP's experiences. Questions were written to be delivered flexibly, with possible prompts listed to facilitate more in-depth discussion. The schedule was also reviewed by the EbE consultant, who offered valuable input around clarity and wording, emotional sensitivity, and how to best prompt reflections on overlapping experiences. This included suggestions to be explicit when asking about support related to tics specifically, acknowledgment that it may be difficult for participants to recall or reflect on challenging emotions at onset, and questioning the usefulness of future-oriented questions within a condition that may persist or even worsen. These suggestions were embedded into the final version of the interview schedule to ensure it was both sensitive to the needs of participants and aligned with the study aims.

Conducting the Interview

Interviews were conducted through either Microsoft Teams or Zoom, and began with introductions, the confirmation of consent, understanding of study aims and interview process, agreement with the recording policy, and reiterating the right to withdraw. YPs were also invited to ask questions or seek clarification about the study or the interview.

Although the study did not intend to cause strain or distress, participants were made aware that reflecting on personal hardships may become upsetting. Signals indicative of discomfort were discussed, but most YPs stated they felt able to say if they felt uncomfortable. Permission was sought to check in throughout the interview. Both YPs under 16 chose to have their parent/carer in the room. Carers were reminded that only YP's contributions would be captured in the findings. Older YPs confirmed their emergency contacts

and reiterated consent to contact them if necessary. Nobody reported feeling distressed during the interviews.

An insight arising from the EbE consultation was that tics represent one aspect of mental and physical health experiences, making it potentially challenging for participants to disentangle their impacts from other symptoms. A suggestion to mitigate this was to invite participants to orient their reflections to the FTs specifically. This was conveyed to YPs, and permission was sought to note if this was happening. All YPs agreed to this approach, and many helpfully signalled when they were speaking to broader symptoms, clarifying how FTs factored into these experiences.

The EbE consultation also highlighted that ways people refer to tics may vary, and that terminology like 'Functional Tic Like Behaviour' may feel too clinical and unrelatable. YPs were, therefore, offered an opportunity to specify their preferred terminology to use during the interview. Although some YPs mentioned occasionally using unique terms, including 'jitters', 'shakes' or 'violent tendencies', all preferred using 'tics' or 'functional tics' during the interview. This preference is reflected in the presentation of the study's findings, with the aim of enhancing resonance and authenticity of the data (Tracy, 2010).

Before ending the interview, YPs were invited to contribute any relevant information or experiences they felt weren't captured during the conversation. YPs were also asked if they wished to be kept up-to-date with the research process and the findings. Upon conclusion, participants were e-mailed a study debrief sheet (Appendix N), alongside the requisite participant form for their receipt of the £10 participation voucher.

3.6 Data Analysis

Interview data were analysed in accordance with Braun & Clarke's most recent guidance on the 6-phase framework for quality RTA (Braun & Clarke, 2021b). Table 11 describes how these phases were followed:

Table 10: Six-Step RTA Process (Braun & Clarke, 2006, 2013, 2022)

	Application of Braun & Clarke's RTA Phases to Current Study
Phase 1: Familiarisation	Given the relatively poor quality of the transcripts generated by the meeting software, these were manually corrected whilst listening to the respective interview multiple times, providing thorough familiarisation with both content and the way in which it was conveyed. This ensured that the emotional dimension of interviews was also captured and considered. During this phase, personal thoughts and analytic ideas were annotated in a reflexivity journal and considered both on an individual and dataset level.

Phase 2: Initial codes	Each anonymised transcript was coded within *NVivo* (Version 14; Lumivero, 2023). With the research questions in mind, I read each transcript line-by-line and generated initial codes that aimed to capture not just the semantic (explicit) meaning of the codes, but also more latent, interpretive (implicit) undertones (Appendix P). A selection of excerpts and their accompanying codes were shared with a fellow researcher to support reflexivity and identify how personal views, perceptions, or assumptions may be affecting the coding process. As new codes emerged in later transcripts, I returned to earlier transcripts to see if any passages resonated with newer, evolving codes to uphold the iterative nature of RTA.
Phase 3: Searching for themes	As the coding progressed, I began noticing patterns emerging across the interviews which resonated with the research questions and aims. These were noted as the beginnings of candidate themes which captured recurring and significant moments (similarities, contradictions, paradoxes, etc) within the data. Codes were grouped in ways that captured these significant moments, which were then mapped to conceptualise possible themes and subthemes (Appendix Q).
Phase 4: Reviewing themes	Tentative themes gradually emerged from these groupings. These were discussed with the supervisory team to catalyse further reflexive analysis. We focused on the possible 'story' of each theme, and how the codes might bolster its validity. During this process, both codes and (sub)themes were repeatedly rearranged, combined, or removed to fine tune the thematic structure.
Phase 5: Defining themes	Once themes and subthemes were broadly established, I shifted my focus to understanding the 'story' told by each theme and its respective subthemes. This included writing "theme definitions" (Braun & Clarke, 2022, p. 108) to better capture the gist of each central organising concept and how they related to the study's aims and questions (Appendix R). This also supported the naming of the themes, which aimed to capture participant perspectives within the recurrent significant moments of the dataset.
Phase 6: Producing the report	During the writeup, I was mindful of avoiding the pitfall of simply paraphrasing participants' accounts and providing what Braun & Clarke (2022, p. 104) refer to as "topic summaries". Throughout the write-up, I edited sections iteratively to ensure I was conveying interpretations, and not just descriptions of what was said. This involved mindfully engaging with participant quotes and considering how to convey the meaning they held within the overall analysis.

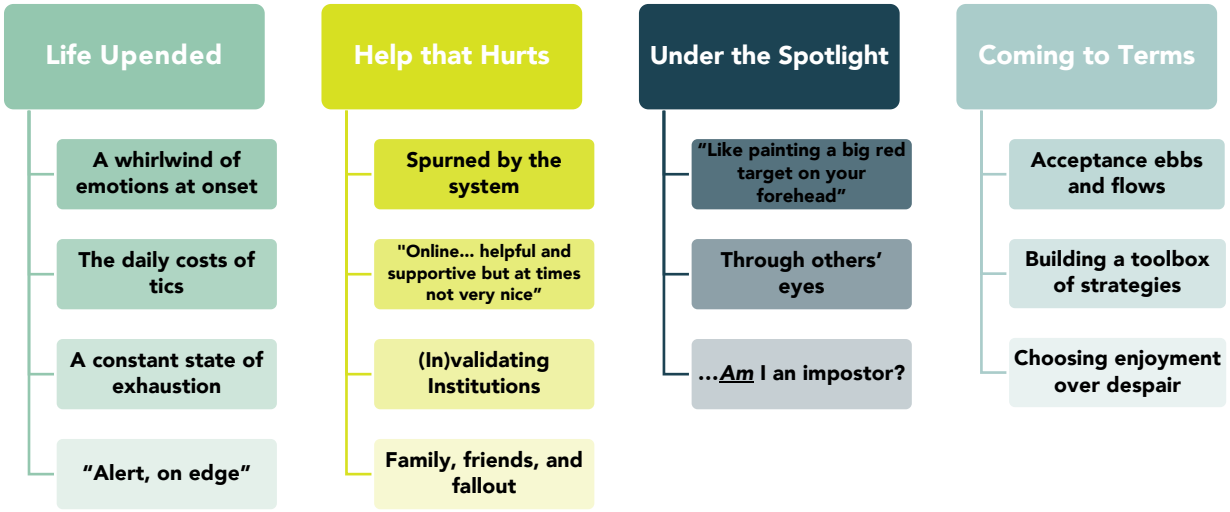
3.7 Member Reflections

Member reflections provide an opportunity for participants to engage with findings, offering impressions, questions, critique, or affirmation to enhance the relevance, resonance, and ethical grounding of qualitative research (Tracy, 2010). This process is distinct from 'member checking', which focuses on factual agreement; instead, member reflections support interpretive depth and participant involvement. Given the near-absence of YP-FTs perspectives within research, it was important that they were offered a chance to reflect on how their experiences had been represented. This aimed to ensure that the findings felt authentic, respectful, and grounded in their perspectives. All YPs were invited to take part (Appendix S-U) and those who wished to, returned a consent form (Appendix V-X) and were then sent the consolidated results (Appendix Y). Of the five who agreed, three returned responses which were affirming but warranted no adaptations (Appendix Z). The remaining two were followed up but did not reply.

Chapter 4: Findings

4.1 Overview

This chapter presents the findings pertaining to the research aims and questions outlined in Chapter 3, derived through a reflexive thematic analysis of 12 semi-structured interviews. The emergent data is represented through four main themes, each made up of sub-themes, illustrating young peoples' (YPs) experiences of life with functional tics (FTs). These themes reflect shared experiences amongst YPs, rather than retelling each YPs' unique story. The analysis of the data is supported using quotes from participants, with slight adaptations for context, clarity or brevity[13].



4.2 Theme: Life Upended

This theme gives readers their first insight into the actual *experience* of FTs. It captures various disruptions that were described, and the adjustments to daily life that the FTs required.

Subtheme: A whirlwind of emotions at onset

Across the board, the unexpected onset of FTs evoked a complex array of emotions. Whilst contending with a sudden emergence of unusual movements and speech, YPs also found themselves grappling with a spectrum of challenging feelings, ranging from confusion and fear to frustration and shame. These reactions were underpinned by an absence of a clear and meaningful explanation of what was happening to them, fuelling distress and emotional volatility.

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[13] *Ellipsis '…' denote where content has been removed for brevity; brackets '[ ]' denote the omission of identifiable information or the addition of words or phrases to improve clarity and/or provide context to the quotation. Underlined words or phrases denote participants' vocal emphasis.*

Many spoke about their emotions surrounding the sudden loss of bodily control. For Simon and Cleo, this confusion was defined both by the loss, and by questioning *who was* in control, if *they* weren't. Their reflections demonstrate how FTs destabilised their sense of bodily autonomy:

> *"I think it was just kind of, a bit of confusion, a bit of, not sure why I suddenly didn't have control over my body and a bit of just like… heavy doubting myself. Like why did I do that? Did I do that?"* (Simon, 20)

> *"I just started hitting myself in the face. And I couldn't stop. Like, why couldn't I make myself stop? So… scary, uncomfortable."* (Cleo, 19)

Juliette and Isla's confusion came with a desire for clarity about what was happening, and why. When no feasible explanation came, confusion turned to frustration, highlighting how ambiguity drives emotional distress:

> *"Mainly I was just kind of confused… I wanted answers about what was happening… because no one really knew."* (Juliette, 13)

> *"Yeah, it was sort of a thing of fear and anger because it was: 'is there actually something wrong with me?' And why? Just a lot of 'why'… Because nobody really seemed to have an answer as to why."* (Isla, 19)

Fear was a common experience, particularly in the absence of a clear cause. Some attempted to find answers online, only to compound their worries whilst piecing together information about their symptoms. This self-initiated research amplified concerns rather than abating them, demonstrating the harms brought by a dearth of accurate, easy-to-find information:

> *"There are lots of scary things that when you Google tics are like, oh, it could be this… I worried so much about so many different things. I thought I've got brain tumour... a neurodegenerative disorder... schizophrenia."* (Sasha, 22)

As discussed further in the theme *Help that Hurts,* a lack of clarity and containment by the medical system supercharged YP's anxiety. Beyond fearing that the tics may indicate other medical issues, YPs also

experienced more existential concerns around what the tics meant for their future and whether life would ever return to normal:

> *"[Tics] definitely have a big impact on your life and your confidence… at the time when I walked into that first doctor's appointment I was thinking, how am I ever going to do anything again? How am I going to… see my friends?"* (Sasha, 22)

> *"It was taking so long to go away, and I was like… am I just gonna have this forever? Like have I developed like a permanent tic? Because this is really annoying and hurting my neck."* (Kit, 23)

Shame was also prominent amongst the YPs, particularly in public spaces. Paige described her guilt after a tic caused her to knock someone's shopping basket:

> *"I got such a dirty look from [her] and I felt awful because I couldn't explain it... So embarrassment was a big one."* (Paige, 21)

The discomfort of an awkward interaction was compounded by being unable to provide context or explain the (lack of) intention behind the tic. In this sense, YPs face both the frustration of being unable to control their bodies, and their circumstances:

> *"I was quite angry because I was doing really well on my GCSEs. I'd had quite a stressful time and that was over and I was ready to live my life. And I was anxious... because it was literally: one day I woke up and [the tics] happened, and I became severely disabled."* (Tessa, 24)

As YPs described life beyond the onset of the FTs, it became clear that these experiences would shape their sense of self, social contexts, and behaviours. Rather than resolving, these emotional states evolved, re-emerging at time when the YPs faced dismissal, invalidation, or doubt from others.

Subtheme: The daily costs of tics

Whilst the emotions accompanying onset came just as suddenly and acutely as the FTs, adjusting and adapting was an effortful process. This reflects a shift from initial emotional crisis to problem solving, without necessarily ever reaching a resolution. Although YPs' management of the FTs was usually relayed in a pragmatic way, the calibre of their disruption was nonetheless evident, suggesting that the true level

of distress they caused was challenging to articulate. A key psychological effect was that the FTs had compromised their autonomy:

> *"I was eating my lunch… and I started ticcing and I tried to throw my cheese across the room… like, I just want to be able to feed myself. A lot of the time, I can't hold cutlery, and my parents have to feed me sometimes… I just want my independence."* (Norah, 21)

Similarly, Brooke and Riley described yearning to be self-sufficient after FTs impacted their ability to walk, and how devastating it was to feel unable to do so. Their experiences, and Norah's, capture the way in which the loss of autonomy intersected with striving for self-reliance, a crucial aspect of YPs' development:

> *"I think when my legs locked, that was probably one of the worst [tics]… because I just wanted independence… It was awkward because, if I wanted to go anywhere or like… move around the house… I needed some help again."* (Brooke, 14)

> *"I still can't walk. I've had to start physio and I'm getting crutches... I'm not able to do my job. I'm not able to walk around college much. I can't go out anywhere after college."* (Riley, 17)

For those whose tics posed a risk of harm, family often offered physical protection. For Simon (20), this meant being supervised, even in his own time. Norah's (21) family literally 'softened the blow' by placing a pillow between her fist and chest when she ticced. Although these were acknowledged as helpful interventions, they also symbolised YPs' loss of freedom.

YPs also described the subtler but nonetheless disruptive changes they made to accommodate FTs, particularly those which impacted mobility and fine motor skills. What may appear as minor adjustments were daily reminders that their bodies could not be trusted to cooperate with once-ordinary tasks:

> *"… you typically think of tics as like... movements from time to time. But it's so much more than that. It impacts so much of your life… like you're at risk when you're cooking. You're at risk if you're holding a knife. If you're holding something with just a bit of weight, it's going to hurt when you drop it… You've got the fact that you might accidentally hit someone if you're in a crowd. It just impacts so many more areas of your life than you think."* (Paige, 21)

YPs adopted a variety of practical strategies to minimise the impact of FTs, from using plastic plates and cutlery, drinking from bottles, to removing access to sharps. Both Riley (17) and Tessa (24) cheekily remarked that their tics "*got me out of doing the dishes",* but despite the housework hall pass, their responses reflected a sense of loss.

This was particularly true of the activities that brought joy and connection including sports, hobbies, or just feeling relaxed around friends. Sasha (22), a musician, had not yet returned to performing, and worried about coping with the 'spotlight' on her tics. Tessa (24) had enjoyed trampolining and PE but couldn't partake due to her physical exhaustion. Kit (23) cancelled plans with friends he hadn't fully disclosed his tics to, whose possible reactions and curiosity felt too much to manage. These losses marked significant changes in how the YPs interacted with the world around them.

Subtheme: A constant state of exhaustion

There was unanimous recognition of the physical and emotional toll of FTs. Most spoke about their impact and intensity, and how they would leave them in significant physical pain and emotionally deflated. Paige (21) described constantly giving herself "*bumps, bruises… and all sorts"* whilst Tessa (24) reflected her resentment of the physical exertion which left her too tired to do much else. Consistently, physical exhaustion ushered in emotional fatigue:

> *"I was in pain a lot of the time because after a while, muscles don't like to engage anymore… I was just exhausted… so I was just always very on edge and upset."* (Avery, 21)

> "*I think when you start doing stuff like smacking yourself around the face very hard, choking yourself out... you start to question [yourself]… I don't think I'm just doing this to be a bit quirky and silly."* (Simon, 20)

The ensuing stress was widely acknowledged to exacerbate FTs. This was particularly true of YPs who did their utmost to suppress or control them throughout the day, leading to such exhaustion that they could no longer hold them in once reaching their safe space:

> *"The minute I got home, or into the car… I'd just break down in tears or just start ticcing really bad."* (Brooke, 14)

> *"When I come home from school… the more tired I get, the worse they get….So after a busy day or a late night… or if I'm stressed about something, I'll be extra ticcy."* (Juliette, 13)

This fatigue appeared to be cumulative, resulting from the energy expended to suppress and exert the tics, manage people's responses, or simply go about daily activities. For many, attempting to maintain control over their FTs made them, paradoxically, even worse:

> *"Tics can be related to stress and anxiety… the more conscious you are of having them, the worse they're going to be… and that relates to a lot of situations… if you're anxious that you're going to have tics…you're going to tic."* (Avery, 21)

Those who had become attuned to this noted how being stuck in this loop meant that FTs would become all-encompassing, causing disruption to various aspects of their existence. Ultimately, the tics not only affected participants' emotional and physical states, but their ability to *simply be*:

> *"You just wish that it could stop. You just wish that you could relax and have some time to yourself… you know when you're just sitting and trying to enjoy your food or watch a show and you're just ticcing and shouting or hitting yourself in the head and it just… you just want to break from it all."* (Avery)

Subtheme: "Alert, on edge"

Regarding being out-and-about, YPs reflected that the FTs weren't so disruptive that they wholly prevented them from doing things in public. They did, however, alter, their experience of public spaces, such that they suddenly became the focus of unwanted attention and scrutiny from strangers. Being out in public became not so much about the discomfort of the YPs, but rather that of those around them. For many, this meant becoming increasingly self-conscious and hypervigilant about how their FTs affected others, leading to avoiding places or activities they previously enjoyed:

> *"If it's crowded, because there is more chance of me hitting someone or scaring them with a very loud noise, that makes me a lot more aware. More alert, on edge type of thing."* (Paige, 21)

> *"I started to avoid spaces where quietness was expected. You know, library, cinema… because I didn't want to mess up anybody else's experience of those spaces."* (Simon, 20)

Cleo reflected how the prospect of being in public came hand-in-hand with anxiety about how people would react if she weren't able to contain her tics. This underscores how tics become intertwined with moral judgments, particularly around self-control:

> *"I've definitely had the feeling of, 'oh God, I don't wanna go here', especially if it's a silent place where… everyone would just stare at me… And also sometimes, if the hitting ones are quite bad, I'm like, what if I go into a crowded place and then I smack someone and I have to explain, 'It's actually just a tic', but they think I've just hit them. It's worrying."* (Cleo, 19)

Other YPs similarly reflected that it was others' reactions, rather than the FTs, that made being in public difficult. This was particularly true of environments with 'nowhere to hide'. For Kit, the idea that his tics might invite not just attention but involvement from strangers was a particular challenge:

> *"If I'm like on the bus and I start ticcing really badly, I'm always concerned that they're going to come up and be like... 'are you okay, do you need anything?'… I don't want that... I don't want you to talk to me both about this, or in general. Strangers, don't approach me... I don't want to talk to you."* (Kit, 23)

Therefore, being out in public became an exercise in moderating the public's response. Some YPs found strategies to mitigate this pressure, including being with someone whose presence could take the edge off and provide a social cue:

> *"If I'm out on my own, it feels a lot more awkward when I tic than if I am with others. When you do something embarrassing in public, it's a lot easier to deal with if you're with someone than if you're alone."* (Paige, 21)

> *"If I'm by myself, I'll be a little bit self-conscious… whereas, when I'm with a friend, and that person is clearly not bothered by the fact that I'm ticcing, that signals to the rest of the public that everything is fine."* (Kit, 23)

In lieu of a companion, some found the Sunflower Lanyard to be a helpful shield. For Avery, it offered permission to tic because it evidenced his disability, rather than a wilful disruption of public order or an invitation to be gawked at:

> *"It makes me feel like I'm allowed to be disabled in public because I've definitely had people very rudely staring at me. And I guess knowing that I have almost like an armour… I've got something informing them that I'm disabled. And at that point, if they're continuing to make comments or stare, then they're the ones in the wrong."* (Avery, 21)

4.3 Theme: Help That Hurts

This theme unveils a paradox flowing throughout YPs' accounts of their experiences in help-seeking; systems meant to offer validating, compassionate, and informative support can instead perpetuate confusion, pain and suffering.

Subtheme: Spurned by the system

The NHS was not the source of containment and clarity YPs hoped it would be. Throughout their journey, they encountered dismissal, invalidation, and disempowerment, their search for help bringing harm instead. Most reflected that their experiences of care were marked both by a lack of knowledge about FTs and clinicians' unwillingness to offer support for something they didn't feel knowledgeable in:

> *"With the GP… trying to explain what I was going through… felt like an argument… She was like, 'No, we don't do that. No, we can't deal with that.' [So I thought], alright. Who's actually gonna deal with me then?"* (Brooke, 14)

At best, YPs were referred onward to appointments across different specialisms which may or may not have the relevant tools at their disposal, used with varying degrees of compassion and care:

> *"Just a lot of things at CAMHS… when I was talking about tics with one of the therapists, she was like… 'Oh, can you not just like, suppress them or something?'… yeah, that was really shocking, that was really shocking to hear."* (Brooke, 14)

Time and again YPs expressed frustration that they were not heard**.** Isla (19) reflected her sadness that none of her doctors took the time to understand her history, her context, or her medical background. She felt no effort was made to get to know her, and therefore, her tics. *How*, her reflections conveyed, *could there be a way forward, if they don't take the time to understand me*? Sasha also encapsulated the essence of many YPs' experiences; that the true gravity of their sudden distress was entirely underappreciated by doctors:

> *"At that initial appointment I felt really frustrated that like… it wasn't something that was serious to him, because it was incredibly serious to me and impacting my life very much and I just felt like, come on, there's some urgency here! … Come on, professionals… it's serious… it's not just jerking around and saying silly things. It'll have a big effect on people's lives…"* (Sasha, 22)

Many were made to feel that, lacking a biological underpinning, their FTs, and indeed other symptoms, were not valid or worthy of significant medical attention. Simon's experience of his medical encounters showed a devastating level of stigmatisation and indignity faced by those with functional symptoms:

> *"I mean, I literally had one neurologist step over my body as I was unconscious. That's what my mum said he did… He just stepped over me and looked at me in disgust… that's the sort of attitude we get from doctors. Either they take one look at us and go, 'maybe it's FND, bye' which is what happened with my first neurologist. Or, there's people who act really concerned until they go, 'Oh, somebody's diagnosed you with functional stuff,' and then they disgustedly step over us."* (Simon, 20)

YPs were often told that their FTs were due to stress or mental health issues, which mirrored a classic FND trope, captured by Kit (23): *"if you have like…unexplained [symptoms], they're just like 'You could be making it up. It could be all in your head.'"* Unsurprisingly, YPs received such suggestions as invalidations, not solutions:

> *"It's so frustrating… I've seen this doctor multiple times and then one day I'm [ticcing] uncontrollably, and I say, 'I'm pretty worried'. And he says, 'You're stressed and well, you have been depressed before, did you know?"* (Sasha, 22)

Those YP who were willing, and able, to pursue mental health treatment described experiences of being shoehorned into an intervention that didn't meet their needs or meaningfully address the distress caused by their tics. As Brooke's experience shows, many lacked knowledge, or worse yet, delivered interventions that exacerbated their struggles.

> *"In CAMHS… I had 3 or 4 therapists… all doing different things, just quite unclear and rather than asking me what I needed, they'd either ask my parents or ask their supervisor, and it was just like please just ask me, I'm your patient."* (Brooke, 14)

For Tessa this meant not only getting the wrong diagnosis, but also receiving treatment that specifically contradicted the approach she needed:

> *"I got diagnosed with Tourette's and… they were trying to do… habit reversal techniques, which didn't work and made it worse in the context of functional tics. I was [being taught to] replace a movement with a movement. But then I was, like, very conscious of my body. And the more attention I'd put on that, the worse the tic got."* (Tessa, 24)

Similarly, Riley highlighted that despite the detriment that FTs posed to his mental health, his therapist's apparent lack of confidence in formulating their role in his overall wellbeing compounded his suffering:

> *"She had no idea how to help me cope with having tics. I would like, bring up my tics and she'd just change the subject… I needed one thing… validation from my therapist… who never explicitly told me that I was faking them, but, she definitely went around the topic."* (Riley, 17)

After enduring significant wait times, some finally reached a specialist, only to find that this highly anticipated appointment did not deliver the outcomes they sought:

> *"I wasn't left confused, which was nice. But it was very much just, 'Right, based on your presentation, it's functional tics. This is why it's not Tourette's. No, there's no medication. If you go on this part of this website and read, it will tell you more. Have a nice life.'"* (Paige, 21)

Hearing YP describe their neurology appointments, it was clear how much their hopes hinged upon this meeting. Whilst many left the office with a diagnosis, they also left with what could, at best, be described as a consolation prize:

> *"I was reassured in knowing that my symptoms weren't life-threatening, but at the same time there was definitely a grieving process because there was nothing they could do. And that was really hard to come to terms with, because you go through this huge process and you're just begging for them to help you figure out what's going on and then you get to the end of it and they say, 'This is what we think you have. Here is a website. What else do you want us to do?'"* (Avery, 21)

Those who were lucky to have a clinician frame their explanation in a thoughtful and compassionate way found this to be a step forward, one which validated their worries and gave them a sense of direction. This enabled some of the YPs, particularly those who'd either had therapy or were accessing it, to apply their skills and reflections to reducing tic-related distress:

> *"The CBT I'm having… they used the phrase, 'it's a software rather than a hardware issue', which was helpful: realising that it <u>can</u> change made me believe that it <u>could</u> change."* (Tessa, 24)

Having recently found a more understanding therapist that didn't shy away from discussing his tics, Riley reflected on his resulting cognitive shift:

> *"It used to take me a long, long time to be OK with [feeling accused of faking tics]. If I'd had those looks four years ago, I would have had a little cry in a corner. Now it's kind of like, OK... that's something that comes along with having tics. I can't change their perspective any quicker. I can't control their perspectives of me."* (Riley, 17)

Subtheme: "Online… helpful and supportive, but at times not very nice"

Given the experiences highlighted above, it is not surprising that the encounters with the medical system left many YPs searching for support and information elsewhere. That place was online. YPs explained that specific online spaces served specific purposes. For example, Reddit was consulted when soliciting comprehensive information or advice. Facebook groups, on the other hand, were predominantly used as 'venting' spaces, to offload and commiserate with others. Discord was a place to connect and chat with one another about shared experiences. Content-based platforms, like TikTok and Instagram, served a particularly important function: a visual representation that there were people like them, living life, despite their tics:

> *"Just to see someone else that has the same thing as me, like the same symptoms and stuff… It makes me feel happy."* (Juliette, 13)

> *"… because I could see that she [tic content creator] was OK, I was able to be like, it's not the end of the world. It's gonna be all right… She's got tics, this, that and the other. But she leads a normal life and so do I. So it's just perspective."* (Norah, 21)

What underscores, and perhaps differentiates, the support YP get from social media compared to professional help, is the vital element of lived experience; the opposite of the 'generic' overlay within medical guidance. Each of these platforms enable the YP to experience the validation they are missing from services: to find relevant information, to be able to ask questions, to see oneself in others, to feel less alone, to confirm that if other people can do it, they can too.

> *"I mean, if I'd have just had the NHS websites and medical resources, I would have struggled to accept that what they're talking about is what I'm going through… but it's being able to see other people ticcing the way I do."* (Sasha, 22)

> *"You end up turning to online support… you know, support by people with these disorders for people with these disorders… and you can feel seen and you can feel heard. And people like to put those resources down by saying that you shouldn't be discussing these things with people who aren't professionals, but if professionals aren't willing to discuss it with you… Where else are you supposed to turn?"* (Avery, 21)

YPs were not purposefully replacing NHS support with social media, but rather using tools at their disposal to make up for the ways that the existing provision had failed them. Brooke highlighted how she would have been happy to attend a local support group, had an administrative error not precluded her doing so:

> *"In CAMHS, they'd advertise these things on the wall, but it never had a date or how to contact them or anything. And I just found a lot more on my own by being on the chat groups and researching rather than going to professionals, which is concerning."* (Brooke, 14)

Whilst reflecting on its positives, YPs also acknowledged the less pleasant aspects of the online world, which Cleo (19) summarised as *"helpful and supportive, but at times not very nice"*. Many spoke of their frustrations about the proliferation of videos by people known to fake their tics, due to the way it altered public perception of FTs, and in so doing, invalidated their pain and struggle whilst intensifying their self-doubt. Likewise, spaces typically fostering acceptance and community were prone to infiltration by online trolls; Cleo (19) recalled being called a "*liar*" on one of her posts, and Norah (21) reflected on the stigma that members of the chronic illness community face, labelled as "*benefits scroungers*".

Perhaps the most widely acknowledged downside of engaging with any tic-focused community or content was that it exacerbated their own. Whether it was written, visual, or in person, YPs were acutely aware

that exposure to others' ticcing had the potential to trigger them, and as a result, had decided to moderate their engagement with any form of tic-related material. This decision, however, had developed over time, as many YPs expressed that, especially at the beginning of their experience, the point most saturated with uncertainty, confusion, and loneliness, this was a price worth paying:

> *With the chat groups, even if I do tic when I talk about it, it's for a good reason: I'm getting information... Yeah, it makes them happen more when I'm talking about them. But as I said, when I was quite unconfident, I was looking on FND Hope and some of their ambassadors… are ticcing, and it's like, yes, that provoked my tics, but then it [also showed me that it's] OK to tic."* (Brooke, 14)

While much of the discourse, and research, around FTs questions whether TikTok did enflame a 'pandemic within a pandemic' (Olvera et al., 2021), what may be more meaningful is how YPs themselves make sense of this relationship. Kit reflects a nuanced perspective shared by many YPs: that social media may interact with existing vulnerabilities rather than act as a direct trigger. As above, the YPs' reflections on the matter disrupt simplistic binaries of cause and effect, good and bad, harmful and helpful, highlighting the importance of context, nuance, and balance around support-seeking in the online world:

> *"In terms of the like, is it caused by TikTok thing... I have noticed… as many professionals say is the case, giving attention to them can make them worse. But I don't think anything that I did in terms of the media that I consume now or before caused any of it... I just think there is a chance that it could be a contributor to my focus of attention, which then carries over into the rest of it."* (Kit, 23)

Subtheme: (In)validating Institutions

Given the age range and life circumstances of the study's participants, their daily activities varied: some were in secondary school, others in college or university, some working. For others, their condition made partaking in further education or employment impossible. This subtheme encapsulates YPs' experience of whichever context was most prominent in their daily life.

Much like the results of the SLR (Chapter 2), the willingness of academic or professional institutions to offer informed, thoughtful, and compassionate accommodations around FTs was highly variable and luck-of-the-draw. Most participants recounted at least some amenability in schools, receiving extra time for exams, access to a private room, or the ability to leave class if necessary. For older YPs, the confluence of the Covid-19 pandemic and online learning when entering sixth form or college, where students are

entrusted with greater autonomy and self-direction, meant that their FTs largely went unnoticed in these settings, mitigating the need to face questions or judgment from others during their most acute phase.

Whether within the pandemic, or outside of it, the experience of these environments hinged significantly on the people they were shared with, be they peers, teachers, or colleagues. What shone through YPs' reflections was the importance of having someone who could support them. Cleo (19), for example, reflected how impactful it was to have a teacher who "*instantly dealt with"* bullying in her class. Riley (17) recalled his appreciation for a teacher who gave him time, space, and safety during a tic attack, even though it meant keeping the next class waiting at the door. These small but mighty gestures contrasted starkly with experiences of those who were left to fend on their own:

> *"A lot of the time…the teacher who was meant to be in the [study room] with me wasn't there, so I was just… alone in a dark room, isolated from people. … We tried to approach the school, and they were just quite awkward saying they don't have the 'facilities'… we were trying to tell them what was happening and they just were either not understanding or just not willing to understand. I was… according to them, a health and safety risk."* (Brooke, 14)

Norah recalled how her previous employer was unwilling to make any sort of reasonable adjustments, despite their legal obligation to do so. Not only did this make her working day unbearable, but it had crushing consequences for her psychological wellbeing:

> *"It was very, very dark time for me and I was having a lot of thoughts about hurting myself and perhaps ending my life. And I had no intention to sort of act on the feelings, but the fact that they were there was unpleasant."* (Norah, 21)

Thankfully, through finding work in a more compassionate and understanding setting, Norah's experience transformed:

> *"They absolutely love [the tics], and they've been so supportive of my disabilities. To be honest, I couldn't ask for them to do anything more, which compared to my last job, is such a breath of fresh air."* (Norah, 21)

These reflections highlight how those around the YPs could make or break their experience. While some found support in personal acts of kindness, others were lucky to find themselves within systems that

understood their needs and ensured they were met. This was especially true for YPs in university who utilised on-campus disability services. What made these experiences so valuable was that they removed the burden of repeated disclosure, becoming a centralised point of advocacy and coordination to ensure YPs' needs were known and met:

> *"When I started there, I was like, very nervous about disappointment with the inclusion team… The [needs assessment] call was supposed to be a half hour, but it was an hour and a half because we just yapped… It just put me at ease about the whole thing… it felt very led by what I wanted and needed."* (Kit, 23)

> *"She was absolutely phenomenal… I could not ask for a better support system because [the disability support coordinator] made it very clear to my lecturers and tutors… what disabilities I have, what accessibility requirements I had. She made sure that the lecturers were informed, because at first, I was telling them personally… She made sure a sheet with the different needs that I had got read before I started my classes… which was a huge help because I no longer felt like I stood out. I didn't have to raise my hand in front of a whole class of people and go, 'I'm sorry, but here's my situation.'"* (Avery, 21).

Even with such arrangements in place, however, for some, like Avery, the cumulative toll of trying to manage chronic, functional symptoms without adequate professional support meant they had to leave their studies, a stark reminder of the limits of reasonable adjustments in the face of complex and enduring disability.

Subtheme: Family, friends, and fallout

Much like institutional support could aggravate or assuage the challenges experiences by YPs, so could responses from their nearest people. Support from loved ones was instrumental in filling the voids left by other support systems This was not always guaranteed, though either scenario left a significant impact on the YP.

Consistently, YPs reflected that one of the most important things their families did from the onset of the FTs was maintain a sense normality, despite the destabilisation to everyone's life. In so doing, loved ones helped abate YPs' emotional turmoil, maintaining a semblance of stability despite a very different internal experience:

> *"I don't know where I'd be without [parent + step-parent] … They don't make a big deal of it. One time, we were having dinner, and I have a handshake [tic] and just [spilled water] all over my food… they just cleaned up… they just moved on… Like it's inconvenient, yeah, but they never let me know that it's inconvenient."* (Riley, 17)

> *"There were a few friends who acted as though nothing had happened, and I very much appreciated that. Then there were a few even closer friends who were like 'what can we do'? And I was like, 'I don't know. I don't know what you can do. But it's very nice that you asked.'"* (Isla, 19)

Isla's reflection beautifully captures not just the value of maintaining the status quo, but also of loved ones expressing an earnest desire to understand what the YPs were going through and how they could help. Even when they lacked a clear answer, the willingness to figure it out together was deeply appreciated:

> *"My mum asks me all the time, 'Oh, is it OK if I laugh at that or would you rather I didn't? … Just asking how I would like them to respond… it's been important for both of us, figuring out what helps and what makes things worse."* (Sasha, 22)

Others valued gestures which echoed Riley's (17) experience; where their loved ones just 'got them', even without being briefed. This was particularly true for Juliette, whose friends not only carried on despite "*[me] not saying much"*, but also quashed any tic-related concerns on her behalf:

> *"They talk to teachers for me about it if I didn't want to and they'll stand up for me to other people… Well, my friends are very just to the point. They just normally say, 'oh, she has tics'. They don't say more than that."* (Juliette, 13)

Loved ones advocating on YPs' behalf was particularly important when navigating the challenges posed by the health system. Apart from achieving tangible outcomes like referrals, more importantly, this gave some YPs a fundamental understanding that they weren't in this alone:

> *"At least when I went back to the doctor last week, me and me and my mum, we went in there like, you know, guns blazing: 'We want a neurology referral!', and luckily he gave us one."* (Sasha, 22)

Whilst many described their families doing what they could to make their new reality more manageable, not everyone had safe and accepting circumstances where they could be open about their symptoms and rely on family for support. For Avery, this meant navigating the entirety of his functional symptom journey on his own, a daunting challenge for anyone, let alone an adolescent with a disabling condition. Although one can see the immense inner strength and resilience carrying him through, his description also conveys the scars obtained along the way:

> *"… I was the only person that I could really rely on. As time went on that only sort of became clearer to me… there was so much support that I missed out on. And I sort of, made myself strong. I had to be, you know, to survive in that sort of situation… And that's very much how my survival has been up until now: you've got to get through, you've got to fight for it… I sort of learned very early on that no one else was going to do it for me."* (Avery, 21)

The loneliness of Avery's experience echoed in other participants' descriptions of how the FTs illuminated their true friends, with many undergoing what Tessa (24) described as a *"culling process".* Some saw the silver lining of being shown which of their friendships were premised on acceptance and integrity:

> *"There were some [friends] that were like, 'this is completely embarrassing, I need to walk away'. And I was like, 'okay, so be it'. I sort of realised… rather than being upset about losing some friends, maybe this is actually a good thing because maybe they were not the right kind of people to be wasting my time on..."* (Isla, 19)

Others, on the other hand, were rocked when friends who were meant to have their back suddenly turned on them. To lose not just the support, but the confidence, of those around them was particularly destabilising:

> *"My closest friend of about six years at the time… she just so casually dropped in a sentence, 'when you first had them, I thought you were faking them'… And it was just completely crazy how she'd have known me all that time and yet she just didn't believe me… it was very… ouch, OK, I see how it is."* (Riley, 17)

Across the various systems of support explored in this theme, the difference between YPs being validated or dismissed, supported or ignored, believed or accused could be the difference between wilting or

thriving. Such experiences had significant effects on YPs' sense of self, initiating shifts towards a new understanding of their identity as a person with FTs.

4.4 Theme: Under the Spotlight

This theme captures the shift from invisibility to hypervisibility brought about by the FTs, and how this, alongside the scrutiny and judgment that came with this unwanted spotlight, thrust YPs into an internal struggle with self-doubt.

Subtheme: "Like painting a big red target on your forehead"

Something which consistently shone through the narratives of many YPs was their strong preference to blend into their environment and to exist under the radar of those around them:

> *"High school was pretty hard… because I was just terrified to be perceived at all… It's like, I just hate being known to people, which is weird because I have [distinguishing feature], so you know, how blended in can I get?"* (Riley, 17)

> *"I just have always preferred it: I'm not like that when I'm around people that I enjoy being around, but like if I'm out in public, like, don't look at me. I just... don't ever want to be perceived."* (Kit, 23)

Many identified this as innate to who they are, the way they've always lived their life, and in so doing, illuminated how the onset of FTs was not just an upheaval to their daily functioning, but how they understood themselves. Invisibility, which had once been an adaptive coping strategy was suddenly off the table, leaving them unsure of how to navigate this new, ultra-noticeable version of themselves:

> *"It was genuinely distressing to be going through at the time because, you know, it's like painting a big red target on your forehead and saying, 'look at me'. I definitely tried my hardest to blend in with everybody else. So to then suddenly not be able to… it was like, whoa, okay, this is even worse than before. [It's] scary… in a 'everybody knows me all of a sudden' kind of way. Which is weird for somebody who's sort of just slipped under the radar all the time."* (Isla, 19)

> *"I'd always be trying to give no one any reason to be mean to me, and give myself no reason to stand out... And so then to have that taken out of my control and now I'm visibly different and vulnerable in that way… it's tough because it goes against the way I've been trying to present myself my whole life."* (Sasha, 22)

These accounts further evidence hypervigilance in social environments. Taken in tandem with those outlined in *Alert and on Edge*, these reflections clarify that this existing tendency worsened with the FTs. For many, this meant having *even more* to be aware of when it came to minimising their effect on others:

> *"It was my problem... but it affected other people. I didn't have any kind of idea of how to make anything better, which then in turn affected me as well, because I was worried that I was making them worried."* (Isla, 19)

> *"I'm more worried about distracting them than anything else. I just don't want to impact other peoples' chances on learning and stuff."* (Juliette, 13)

Subtheme: Through others' eyes

Given this preoccupation, it is not surprising that YPs sought to pre-empt others' responses towards them. Doing so meant they exerted much effort in anticipating others' thoughts, both about them, and about their tics:

> *"I was just acutely aware of everyone around me having, you know, less-than-nice thoughts about me. So then it was, 'Hmm, I need to think about everyone, and I need to be acutely aware of everything that everyone thinks, because I need to be normal and non-annoying and I need to not make anybody's day worse.'"* (Isla, 19)

For many, these internal concerns manifested in their external realities, with some becoming acutely aware of how FTs affected peoples' attitudes and behaviours toward them. The confluence of sudden, highly noticeable symptoms and peoples' visible responses meant that the FTs 'outed' them as different in front of everyone:

> *"So I knew I was different to most people my age, but suddenly everyone knew I was different… and that was weird for me because I was like, 'Whoa… now I really don't feel like I fit in.'"* (Isla, 19)

> *"It's the assumption, based on the fact that I'm visibly ticcing… that I'm mental or slow... like that's what I interpreted. And because [of that], you think it's OK to be rude to me so blatantly."* (Sasha, 22)

> *"It's hard to not feel like a freak when talking to people about it… With tics, because people don't really understand them, when people don't really understand things, they tend to get very hostile about them."* (Avery, 21)

YPs encountered numerous situations whereby peoples' misunderstandings, assumptions, and curiosity about FTs left them with no option but to confront, and even challenge, them. This was not necessarily conveyed through a sense of empowerment; rather, it was more an act of requisite damage-control. From this position, YPs began to develop strategies which enabled them to reclaim the narratives constructed about them. Oftentimes, this entailed the burden of educating others, which although challenging, gave the YPs some control over the telling of *their* story:

> *"Whenever I went out to like social events, I would be very aware that it would come up and I'd have a little explanation in mind… I didn't want to make a big deal of it. It was just… something that I had, something that was part of me. I didn't want it to just <u>be</u> me."* (Paige, 21)

> *"I've always been the one who's said, 'oh, you might have noticed I do this'. Because there's a point where I like people knowing what it is. I like people knowing that <u>I know</u> I'm [ticcing]."* (Sasha, 22)

Subtheme: …<u>Am</u> I an impostor?

Yet despite their concerted efforts to enable others' understanding of the FTs, YPs frequently faced responses that could rock the core of their identity: the assumption, and too often, accusation, that they were faking their tics:

> *"There's a lot of people that look down on teenagers as a whole, especially if they're on TikTok and stuff like that, and it very much came across in the way of 'look at what these stupid teenagers are doing now' and it's like, no, hang on, this is a <u>real</u> thing, it has <u>real</u> effects!"* (Paige, 21)

This frequently came up as one of the most compromising aspects of FTs, particularly because it threw the YPs into a tailspin of hurt, confusion, and self-doubt. Whilst not only experiencing destabilisation and distress daily, YPs found themselves having to *prove it*; a behemoth, and virtually impossible task, as many felt that the prevailing discourse around FTs meant the public's mind was already made up. Tessa's reflection captures this impossible conundrum:

> *"And then some people… including teachers as well… assumed that I was faking it for attention. And it was difficult to explain like, 'No, I know that this is not fake', but I've never known: how do I explain something I don't understand?"* (Tessa, 24)

Apart from the unpleasantness of not being believed, arguably the most painful aspect of such accusations was the doubt cast upon one's integrity. In this way, it was not just a hurtful assumption, but a reckoning with their self-trust. Many found themselves questioning whether they were, in fact, doing this for some purpose, and feeling worse when their concerted efforts to suppress their tics exacerbated them:

> *"You know I'd be sitting in my room alone and it would still happen... there's nobody watching me, it's not like there's somebody to prove to that it's still happening. But I very much had this thing of, 'Oh god… maybe they're right, maybe I'm <u>not</u> telling the truth and this <u>isn't</u> actually happening… I think that was quite a dark time of not really knowing where I stood with myself as well as with other people."* (Isla, 19)

> *"When people accuse you of exaggerating… you end up doubting yourself… because even now I'm like, 'Surely, <u>surely</u>… it would become more prominent in certain situations like it does for other people because, <u>surely</u> I know some people who can't go more than an hour without ticcing, whereas I can go a few days at least'… It just makes you feel worse about your own disorder."* (Avery, 21)

What made this even more challenging was that much of the YPs' journey was marked by confusion around whether the FTs represented something that was a *part* of them, or something that was happening *to* them. Several externalised their FTs, portraying them as "*little goblins in my brain having a fight"* (Sasha, 22) or a little *"demon… friend… that you can't kick out [because] he has nowhere to go"* (Riley, 17). This illustrates their inherent dichotomy: familiar enough to be one with me, but uninvited and intrusive, leaving YPs unable to determine whether it was them or the tics that was the impostor. In some cases, the intrusion went so far as to subsume one's social identity:

> *"It was weird because I was quite unpopular at school as well, and then suddenly people would remember my name… So that was the hardest part, that people remembered me because of the functional tics and not because of me."* (Tessa, 24)

Although not becoming any less challenging, as time went on, some became more accustomed to these unwelcome companions. Doing so meant they were able to find a way to see through the fallacies of self-doubt, by attuning to the nonsensical nature of the underlying premise that they could just stop ticcing if they wanted to:

> *"I mean, I couldn't imagine… waking up and just suddenly deciding to have a problem that was basically making my life a hundred times harder. That just that felt insane to me… it came to a point where I was like, 'Okay, this is just stupid, like why, why would I be making this up? Who would make this up?"* (Isla, 19)

Avery's summary, not just of his experience but his learning from it, demonstrates the small but mighty steps taken towards accepting the reality of FTs:

> *"And that's something that I think a lot of people… need to come to terms with is: if you could control [the tics], you would. I cannot emphasise enough how important that is because every single person that I've interacted with anything similar to this, has needed… to be reaffirmed and reassured. I'll even do trials with the people and be like, 'Okay if it's within your control, control it right now'. And they won't be able to and I'll say, 'So why aren't you controlling it right now?' And they're like, 'Well, because I can't!' And I'll sort of give them the look like, you know… you know what I'm getting at here. And they'll sort of do a frustrated sigh and go, 'okay, maybe that does make sense. Maybe you are onto something here.'"* (Avery, 21)

Although their struggle with self-doubt led YPs to question themselves and their reality, some came to realise that their suffering was evidence enough. By doing so, they found a slight opening into a space of understanding of how they might coexist with their FTs.

4.5 Theme: Coming to Terms

Although it could not be said that the YPs had become welcoming and friendly with FTs, nearly all spoke to factors which have at least enabled some level of *coexistence*. The 'ingredients' of this are explored in the theme below.

Subtheme: Acceptance ebbs and flows

Throughout the interviews, 'acceptance' appeared in many ways: something to strive for, something that felt occasionally within reach, or frustratingly elusive. YPs varied in the duration of their FTs, reflecting

being at different points on their personal 'journey towards acceptance'. Regardless of where they were, many described the ebb and flow of this process:

> *"You sort of go through phases, like mini cycles, where one day you'll be very negative about it and the next day you'll be back to sort of normal, accepting. And it's just taught me that sometimes you just need to wait those feelings out."* (Avery, 21)

Various factors discussed in this chapter undoubtedly contributed to these phases. While experiences like physical exhaustion, an unkind look from a stranger, or yet another fruitless medical appointment triggered more distress, some factors facilitated a degree of acceptance, bringing a semblance of relief. Not all YPs could say they reached this point, but for those who touched upon it, it came through various inflection points. For some, receiving a viable explanation meant finally getting some clarity on what FTs were. For others, developing new perspectives loosened the grip of self-doubt, leading to the realisation that they simply couldn't sustain faking FTs for this long. Older YPs particularly found themselves becoming more able to tune out of others' brains, recognising that their opinions didn't matter as much as they initially thought:

> *"I knew I wasn't going crazy eventually. It… helped seeing an actual medical professional and them going 'this is what's going on'… and that this wasn't just something… in my head I've just made up."* (Isla, 19)

> *"Ironically, it's the moments of <u>least</u> control that make me feel most certain. The worse it is and the harder I'm fighting against myself, the more I'm like, 'oh, OK, that isn't me'. Because if it was me, I would just stop."* (Simon, 20)

> *"People don't think about it as much as you think they do, and if they do think that much about it, then they need a busier life, you know."* (Paige, 21)

These cognitive shifts are underscored by the recognition that no matter what YPs did, or how hard they tried to get rid of them, FTs were going to remain a part of their life to some degree. Getting to this point was transformative, easing both the physical and psychological toll of the FTs:

> *"I think part of the tics was that they were quite vocal... you know, the thing that you would <u>not</u> say in a situation... I would think 'I'm going to get quite a lot of backlash', but I didn't… so I was*

just [able to feel] lot more relaxed about stopping the tics... So then the tics lessened because I was freer." (Tessa, 24)

"I'd say is the sooner you accept that this might be the rest of your life… That's going to make it easier on you. The more time you spend trying to cure yourself and get back to your old body, the worse it's going to get." (Norah, 21)

Subtheme: Building a toolbox of strategies

Although not entirely in YPs' control, acceptance was an active process involving trial-and-error to discover practical strategies that could help. Be it hobbies, humour, or mindful mental shifts, the interventions comprising YPs 'toolboxes' were carefully curated to support coping with FTs.

While many initially lamented the changes the FTs demanded, they came to accept that these small changes made life easier to navigate. Having gradually embedded these adaptations into their routines, the YPs were enabled to live with increasing predictability, normality, and confidence:

"I think it's mostly just a bunch of little things added up. You know, little things you do throughout your day to make it a bit easier, a bit safer. There's no big singular coping mechanism that has a huge difference. It's just a bunch of little differences." (Paige, 21)

For many, humour was vital in the way that it removed some of the sting from the FTs. This played into how loved ones maintained a sense of normality whilst also de-catastrophising the effects of FTs. Similarly, YPs taking a more light-hearted stance toward themselves appeared to offer some relief:

"It was really great because the first time I ticced around [my partner]… they kind of made a segue off of it, and it was really funny… and it was really nice to be able to, like, be around someone that understood it to the point that they could… help me not feel disconnected from everyone else." (Riley, 17)

"I started to lean more into acceptance again… I might as well just have a laugh… just giggle when [the tics] happen and just try and stay confident." (Avery, 21)

Whilst the practical strategies were relatively straightforward to implement and become accustomed to, there seemed to be some reluctance to adopt those which had a more psychological underpinning. For some, taking on stress reduction or emotion regulation strategies meant confronting the possibility that at least some aspect of their FTs was psychological in nature, lending a level of credence to the invalidating assertions from medical professionals that FTs are 'all in their head'. Even if this delayed YPs reaching this understanding, nearly all came to acknowledge the connection between their stress levels and tic severity. One way of achieving this was through shifting their focus away from the FTs (an antidote to the paradox of attention outlined in *The daily cost of tics)*:

> *"I just kind of try and distract myself… I might put on a film or something and like, just do something I like to do… I'll just be kind to myself."* (Cleo, 19)

> *"Usually a distraction, something simple, something easier. It's like a little game on your phone or a scroll on social media… something that will occupy your brain but not in the way of 'it takes brain power.'"* (Paige, 21)

As these quotes highlight, the effectiveness of distraction lay not just in shifting attention away from the FTs but also relieving brain strain. Pushing oneself too much, whether it be through study or work, was a common experience amongst participants, and many noted that finally giving themselves permission to rest had a positive effect on the severity of FTs:

> *"Most of the things that I've learned about myself are just in regard to my self-care. I didn't realise how little I prioritised my own welfare until [the tics] started, and… that like, if I don't take care of myself, I will suffer real physical consequences."* (Kit, 23)

> *"I would work myself to the bone and I just wouldn't stop. So when [the tics] started to become a more prominent issue for me, I didn't know how to stop. And being reminded… to take care of myself, take breaks… that really helped me."* (Avery,21)

In circumstances where much felt outside YPs' control, making practical adaptations, choosing rest, and accepting humour were invaluable coping mechanisms and a means of regaining their agency. Most importantly, they enabled YPs to understand that life with FTs could contain joy and connectedness.

Subtheme: Choosing enjoyment over despair

YPs were unambiguous: if they could make FTs go away, they would. Despite their frustration, YPs also spoke of their resolve to not let FTs take away their enjoyment of life:

> *"It's hard, because if I could choose not to have them, I would… And I feel as though basically everyone who I know with tics would choose that. But at the same time, it is still possible to be able to laugh about it… if you're not laughing about it… what a miserable life, you know?"* (Avery, 21)

> *"I tic and it's that's OK… it makes for a good joke every now and then, you know? So, as much as it's not a good thing to have tics, you can make light of it."* (Paige, 21)

> *"Don't get me wrong, I would love to be able to go and do a two-mile run and then not have to lie in bed for three days, but at the same time, I have this newfound ability to share power and information with people that they wouldn't necessarily know."* (Norah, 21)

Norah's quote speaks to another powerful way in which YPs turned their challenges into something meaningful: finding ways of using their experience to support others. As previously highlighted, Avery (21) supported his friends by compassionately challenging their experiences of self-doubt. Simon (20) found purpose in connecting people with functional symptoms through Discord, alongside meaningfully engaging in long-form conversations on Reddit in the service of answering others' questions and sharing his experience. Norah (21) set up a local support group to create a community around the thing that she found most to be most helpful: understanding that life can be normal, even with FTs and FND in the picture.

Such acts mark neither a rejection of the reality of life with FTs, nor succumbing to their symptoms. They demonstrate resilience and dedication to continue to live, move, and find peace even while FTs persist:

> *"If you let the tics and anything else going on limit you and what you do, and you just sit around doubting yourself and doing nothing with your life, you will feel so much worse … Even if you just like go on a little walk; if you don't feel like it, you can sit in the sun for a bit … Actually do stuff. Don't <u>think</u> about doing stuff, just <u>do</u> it."* (Simon, 20)

The choices made by the YPs to find ways to co-exist with their tics and accept their ongoing presence ultimately meant choosing to live in ways that enabled them to hold meaning, connection and a view of the future:

> *"Most of the time we just laugh at them because you've got to haven't ya? 'Cause if I don't laugh again, I'm wallowing in that hole of my own self-pity. And you know… I don't want to spend the rest of my life in that hole."* (Norah, 21)

Chapter 5: Discussion

5.1 Overview

This chapter concludes the empirical study, summarising its key findings, presented through four themes and accompanying subthemes. These findings are situated within existing research, and their implications are considered, alongside invitations for future research. This chapter concludes the thesis with a discussion of the study's strengths and limitations, and a quality appraisal.

5.2 Results Summary

This study investigated YP's experiences of FTs, examining their effect on daily functioning and psychosocial wellbeing. It highlights the challenges faced by YPs in navigating social perceptions whilst receiving largely inadequate support from healthcare and other systems and explores the role of personal relationships and online communities in shaping their experiences. Beyond capturing their consequences, the study also offers insights into the ways that, over time, YPs found strategies to coexist alongside their FTs. This is one of few studies qualitatively exploring lived experiences of FTs, and the only known one focused exclusively on perspectives of YPs, contributing to the limited research around this topic.

5.3 Results Within Literature

Life Upended

The findings captured in this theme demonstrate the daily, lived reality for YPs with FTs. They are consistent with existing research, which speaks to the physical and emotional tolls that the sudden onset of FTs had on both parents and YPs (Burn et al., 2025; Ludlow et al., 2025), where confusion and fear permeated their attempts to understand what was happening, why, and what could be done about it. These results expand this by capturing how initial confusion morphed from concern into pervasive, almost existential, uncertainty, as YPs grapple not just with the loss of bodily control, but their autonomy and independence, and questions around whether, and when, they might return to 'normal'. Anxiety was a recurring theme in YP' accounts, with many describing themselves as 'anxious'. While not formally assessed, this aligns with cohort studies reporting elevated anxiety levels among those with FTs (Cavanna et al., 2024). This vulnerability may potentially both predispose and perpetuate the emotional challenges around FTs, leading to catastrophic interpretations of what's going on, in the absence of clear explanations or professional containment.

The phenomenology of FTs experienced by this study's participants is in line with the literature outlined in Chapter 1, and their accounts add further depth by describing how their manifestations affect their

daily functioning and psychological wellbeing. Participants spoke to how FTs erode their independence, causing them to become (re-)reliant on others during adolescence or young adulthood, developmental phases typically defined by an increase in autonomy as one shifts away from depending on caregivers and establishing a clearer sense of self (Arnett, 2004; Christie & Viner, 2005). For many YPs, this enforced dependence triggered a 'biographical disruption', whereby a sudden health condition upends narratives of one's anticipated future and identity, derailing routines, plans, and goals (Bury, 1982). For YPs, whose sense of self is rooted in activities and social roles which define *who they are*, this can pose significant obstacles to *who they are becoming*. FTs disrupted activities that were essential to their sense of self, from Sasha's musical performance to Kit's carefree socialising to Riley and Brooke's ability to mobilise freely, leaving YPs to grapple with both the physical and psychological impacts of FTs.

The cyclical relationship between the stress posed by FTs, and YP's concerted, but ultimately unsuccessful, attempts to suppress them, parallels the literature around FND, where individuals are shown to become hyper-focused on their bodily sensations (Drane et al., 2021; Kozlowska & Scher, 2024). In this study, YPs described becoming fixated upon their FTs all the while devoting immense mental effort to stopping them. Paradoxically, these efforts backfired, inadvertently heightening their awareness and making their symptoms harder to manage. Predictive processing may help to explain this, wherein the brain continuously generates expectations about physical states based on past experiences, beliefs, and emotional contexts (Edwards et al., 2012). In states of heightened anxiety or fatigue, much like those described by YPs, these predictions become overly sensitive and take over one's perception, reinforcing the symptom rather than relieving it. What emerges is an exhausting feedback loop: attempts to suppress FTs focus attention on them, increasing their intensity and exhausting YPs mentally and physically. This exhaustion and failure to 'make the tics go away' then increases stress, and stress amplifies the intensity and frequency of the tics, re-capturing YPs' attention and leaving them in a cyclical battle between mind and body.

This hyperawareness extended beyond YP's inner state into the outer world, as many described how navigating public spaces required constant self-monitoring to avoid causing others discomfort. Societal responses tics, and the reactions which YPs hoped to avoid, may be shaped in part by over sensationalised media portrayals, contributing to public misconceptions and driving stigma around the condition (Calder-Sprackman et al., 2014; Malli & Forrester-Jones, 2016; Pring et al., 2023). Several studies have shown that even people with a knowledge of tic conditions continue to judge those who tic negatively (Cox et al., 2019), demonstrating how deeply rooted negative perceptions of tics are.

Help That Hurts

For many YPs, the most challenging reactions didn't come from strangers, but from those they turned to for help. Their experiences of seeking support are consistent with previous qualitative findings (Burn et al., 2025; Ludlow et al., 2024), as well as the broader literature on tics (SLR, Chapter 2) and FND (Bailey et al., 2025; Szasz et al., 2025), where health professionals often left people feeling more distressed than reassured. Across accounts, YPs described clinical encounters characterised by uncertainty and invalidation. Even if a functional diagnosis was finally offered, it often came without adequate explanation or a plan forward. This reflects known clinician discomfort with FND populations (Stone, 2014), often tied with low diagnostic confidence and uncertainty around treatment (Barnett et al., 2022), and mirrors the experiences of those with tic conditions, described in Chapter 2. Similarly, rather than providing clarity, explanations that attributed FTs to 'just stress' or a 'mental health issue', reinforced the feeling of YPs not being taken seriously. As noted in Chapter 1, terminology associated with functional symptoms is widely experienced as stigmatising and delegitimising (Loewenberger et al., 2020; Stone et al., 2004), and in the context of the emotional upheaval that accompanied the onset of FTs, such explanations are likely to be interpreted as "the doctor thinks I'm crazy" or "it's all in my head" (Stone et al., 2016). As a result, such interactions planted seeds of self-doubt at a pivotal point when YPs were trying to make sense of their symptoms.

The experiences highlighted in both these findings and wider literature demonstrate the epistemic injustice (Fricker, 2007) experienced by those with FTs. At the heart of this is hermeneutical injustice, marked by a gap in sense-making. In the absence of legitimised frameworks around FTs, clinicians struggled to explain the symptoms, while YPs were unable to understand their experiences in ways that felt intelligible. As outlined in Chapter 1, the surge of otherwise rare FTs was as perplexing for the clinical community as it was for those experiencing them. YPs' confusion exemplifies what Fricker (2007) describes as a "gap in the shared tools of social interpretation", leading to "an inability to understand or articulate their experiences in ways that make sense to them, due to…being marginalised by the dominant narrative in a medicalised environment" (Hassall, 2024). Coliva (2025) helps account for this, arguing that hermeneutical injustice is maintained by the legacy of outdated or prejudiced concepts, such as that of 'hysteria', and its continuous shaping of clinical and societal perceptions of functional symptoms. In the case of FTs, this historical 'baggage' appears to undermine the perceived credibility of YPs' reports, which is a form of testimonial injustice. The disbelief and invalidation experienced by YPs may result from these inherited biases. Both forms of epistemic injustice were highly consequential, delaying diagnoses, prolonging uncertainty, and resulting in inappropriate interventions, catalysing YPs' disillusionment with medical support.

At the same time, several YPs encountered professionals who met them with thoughtfulness and compassion. Experiences where YPs felt understood, had their symptoms framed in a way that made sense, and were given some sense of direction or reassurance were highly valued. Although only one YP had mentioned accessing an FT-specific intervention, what appears to have been helpful and reparative is being given the opportunity to better explain, and in effect, understand, their symptoms and their impact on their life, highlighting the importance of clinicians remaining curious and collaborative.

Experiences within education and work settings reflected similar patterns. Although some institutions offered thoughtful and appropriate accommodations and support, others failed to follow through, denying reasonable adjustments and exacerbating distress. YPs' accounts of these settings reflect the literature on stigma towards both tics (Pring et al., 2023) and FND (McLoughlin et al., 2024), which demonstrates that negative attitudes towards these conditions exist across interpersonal and structural levels. YPs accounts similarly suggest that they faced cumulative stigma, compounded across multiple settings, reinforcing a sense of being misunderstood, judged, and the hopelessness that accompanied it.

The impact of this was softened when YPs encountered support and recognition. Far more reliably than in person, this was found online. In contrast to the prevailing discourse around 'TikTok tics', many YPs described online spaces as a resource they turned to *after* the onset of their FTs, in order to find the information and connection they could not otherwise access. Seeing peers successfully coping with FTs was particularly powerful, as was getting information or seeking advice from those with lived experience. Structured peer support is known to help in some aspects of mental health recovery, but this resource is typically sparse and only available to those accessing clinical services (Cooper et al., 2024). Online communities remove this barrier by making lived-experience accessible anytime, anywhere. Rayland and Andrews (2023) draw on Naslund et al.'s (2016) model to demonstrate how online peer support enables individuals to challenge existing stigma through connecting with others they can express themselves with, learning how to navigate and cope with their condition, and increasing access to additional resources, much like the YPs in this study did in relation to their FTs. Several YPs described being comforted by seeing others successfully managing their FTs, offering powerful reassurance through shared experience and demonstrating 'upward comparisons' in action, where one looks to others who are coping successfully (Festinger, 1954), instilling hope, motivation and alleviating their sense of aloneness.

Importantly, YPs were not naïve to the risks of online engagement, speaking candidly about the way that exposure to tic content could exacerbate FTs, expose them to hostility, or fuel self-doubt. However, they

also demonstrated their ability to moderate their engagement, seeking out what was helpful and stepping away when it wasn't. From the perspectives of these YPs, their main engagement with online tic content came as a response to their onset, particularly in the absence of help and containment within institutional support, summarised eloquently by Avery: "*If professionals aren't willing to discuss it with you… where are else are you supposed to turn?"*.

Relationships with family and friends also played a role in compounding or counteracting FT-related distress. Similarly to experiences captured in Chapter 2, loved ones stepped into advocate roles, particularly when supporting YPs in seeking help or sticking up for them in social settings. Perhaps the most valued gesture, however, was their effort to maintain the status quo despite the disruption brought by the FTs. Joachim and Acorn (2000) explain that striving towards normalisation is one of the most common coping strategies used by those with chronic conditions, citing Goffman's (1963) idea that a goal of stigmatised people is to avoid further alienation from "so called normals", by "fitting in" (Thorne, 1993). In this context, 'fitting in' reflected families' efforts to preserve a sense of normalcy, enabling YPs to maintain, to some degree, a part of their lives that was less impacted by the FTs. Many commented that they appreciated that their loved ones didn't make a big deal out of the tics, and that being met with humour, acceptance, or curiosity about preferred responses helped buffer against the judgment and alienation they felt elsewhere. In contrast, disbelief and judgment from those closest to them left YPs feeling lonely, betrayed, and pushed into self-reliance.

Across these systems, moments of compassion made a meaningful difference, where even small acts of understanding mitigated the pain of invalidation and dismissal. Although these moments did not resolve the difficulties around FTs, they provided a psychological buffer that enabled YPs to cope and persevere, particularly when navigating others' negative perceptions, and the way these influenced their own.

Under the Spotlight

Many YPs described a long-standing preference to remain unseen, framing this as the way they navigated the world even before the onset of FTs. For some, like Sasha, who spoke about "*always trying to give no one any reason to be mean to me"*, social visibility may have become internalised as some form of interpersonal threat. Conceptually, this aligns with Williams' (2009) Temporal Need-Threat Model of Ostracism, which outlines how unmet relational needs such as belonging and recognition can eventually lead to a 'resignation stage', in which individuals no longer attempt reintegration into a group, instead withdrawing to preserve psychological safety:

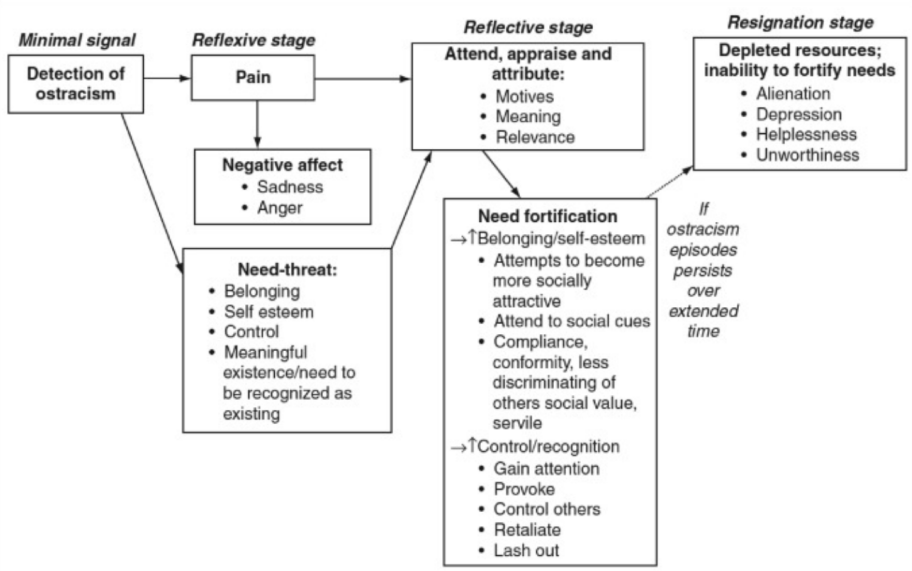

Figure 4: Temporal Need-Threat Model of Ostracism (Williams, 2009)

The FTs disrupted this strategy, suddenly making YPs hyper-visible. With that came a hyper-awareness of how they were being perceived: where they once worried they might be judged, the FTs made them certain they would be. As their visibility increased, so did their sense of inconveniencing others and being scrutinised. Their accounts align with Clark and Wells' (1995) model of social anxiety, which suggests that people engage in extensive internal monitoring and negative self-appraisal when they understand themselves to be the object of others' attention, especially if that attention may be critical (Rapee & Heimberg, 1997). To mitigate this, YPs attempted to pre-empt others' discomfort, evident in their concerns around "*impacting other peoples' learning"* (Juliette) or "*needing to not make anybody's day worse*" (Isla). Whilst these responses reflect safety behaviours to manage social anxiety, they also resemble the 'fawn' response (Walker, 2013), where, as it pertains to this context, YPs sought emotional safety by sidelining their own needs or preferences to appease others in response to perceived interpersonal threats (Brown, 2023), such as those outlined above.

Compounding these challenging dynamics was the regularly encountered suspicion that YPs were exaggerating or fabricating their symptoms, with external accusations morphing to internalised ones. This form of internalised stigma, where one becomes aware of negative stereotypes about their condition, grows to agree with them, and applies these beliefs to themselves (Corrigan et al., 2011), is prevalent within both tic conditions and FND (Foley et al., 2024; Pring et al., 2023), particularly as the aetiology of both is still not fully understood. The doubt seeded in clinical encounters was then reinforced within social interactions, intensifying YPs' uncertainty and leading them to question the legitimacy of their own experiences, something observed within FND populations (Karterud et al., 2015). Tessa captured this

poignantly when asking, "*How do I explain something I don't understand?"* This again evokes Fricker's (2007) concept of hermeneutical injustice, which shows how its insidiousness extends beyond clinical encounters into one's own understanding of themselves: without an established interpretive framework to make sense of FTs, YPs were unable to defend themselves against cultural and interpersonal messaging that framed their condition as illegitimate and found themselves questioning their own integrity.

Despite this, several YPs reached a point where they began to question the logic of their self-doubt, wondering, "*why would I be making this up?"* (Isla), gradually developing ways of managing others' responses to them, pre-empting questions with an explanation as Paige did, or challenging negative beliefs, like Avery. These can be viewed as acts of 'narrative repair', where individuals resist pathologising or delegitimising 'master' narratives by constructing counter stories that enable them to reclaim agency over their experiences and restore a more coherent understanding of themselves (Nelson, 2001; Palmer, 2007), not least following the biographical disruption discussed above. Whilst for some these became ways of empowering oneself, for most YPs these were necessary forms of self-protection which helped them navigate social settings, reduce internalised stigma, and develop a degree of co-existence with their FTs.

Coming to Terms

The findings capture co-existence with FTs as a fluctuating and dynamic process, ebbing and flowing between acceptance and despair, mirroring the same psychological rhythm that Schut and Stroebe (1999) describe as 'oscillation' in their Dual Process Model of Bereavement (Figure 5). Oscillation refers to the "alternation between loss- and restoration-oriented coping", where a person may find themselves at times confronting the distress of their loss, whilst at others, "taking time off" by shifting energy onto the aspects resulting from the loss (Schut & Stroebe, 1999). In the context of FTs, YPs oscillated between grieving the disruptive impacts of FTs, such as the loss of bodily control, autonomy, or the ability to blend in, and attending to the practical tasks of reorienting their lives around them. As Norah reflected, the goal wasn't "*trying to get back to your old body"*, but adapting to new routines, managing social environments, and navigating their 'new normal', often through trial and error. Avery's description of "*mini cycles"* is apt, capturing how acceptance could be reached, lost, and rediscovered as internal and external circumstances fluctuated.

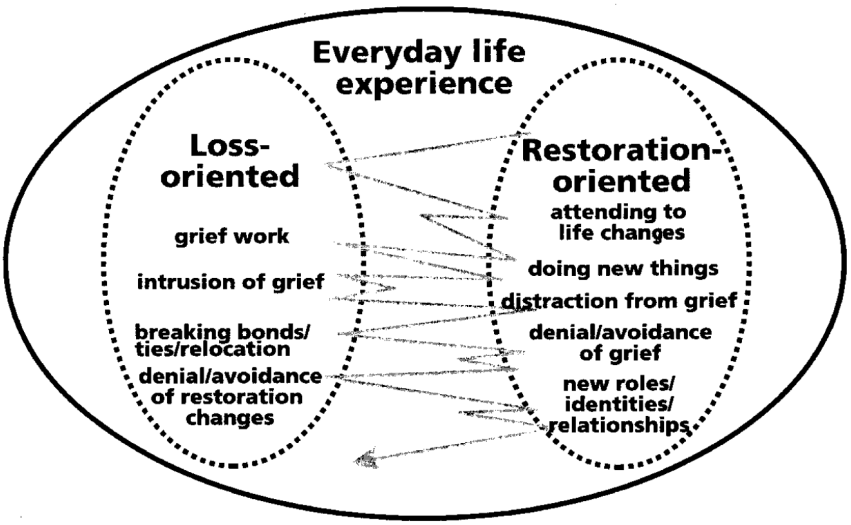

Figure 5: Dual Process Model of Bereavement (Schut & Stroebe)

This oscillation was particularly evident where YPs described experiencing some relief. Tessa, for example, recalled feeling *"freer"* from her FTs after realising that the social backlash she anticipated didn't materialise. Her experience resembles a behavioural experiment, a core cognitive-behavioural technique, in which her feared prediction was tested in a real-world situation and disconfirmed. In Tessa's case, discovering that her anticipated threat did not come to fruition reflects Rapee and Heimberg's (1997) emphasis on shifting one's attention away from internal assumptions and considering external feedback within social anxiety. Doing so also had a positive effect for her FTs, helping disrupt the feedback loop between fixation, exacerbation, and exhaustion. Other YPs described similar shifts, where discovering ways of alleviating hypervigilance or self-monitoring helped ease the frequency and intensity of their FTs, and in effect, improved their wellbeing.

Indeed, several YPs reflected on the connection between their mental health and tic severity, having experienced their own version of the above process. Many noted that the onset and intensity of their FTs coincided with periods of immense strain, emotional overwhelm, or times of "*working myself to the bone"* (Avery). The need to reduce pressure, rest, and prioritise their mental wellbeing was difficult to ignore, even if doing so meant accepting a psychological component to their FTs, something which felt invalidating and dismissive when conveyed bluntly by a clinician. A conversation analysis of FND diagnosis delivery showed that psychosocial explanations are often met with resistance, resulting in outright disagreement, unresponsiveness, and disengagement (Monzoni et al., 2011). As discussed previously, rather than overt rejection, this may reflect a protective response against the cumulative weight of invalidating experiences, cultural stigma, and fears around contending with either a new, or additional, psychiatric malady. Stone et al. (2016) suggest an additional dimension: that psychological explanations

can feel particularly difficult as they imply that the onus of recovery is placed upon the individual, rather than the clinician, a particularly onerous prospect for YPs navigating emotional turmoil, functional upheaval, and identity disruption. As such, this may be better understood as a protective response to a framing that still connotes judgment and blame.

Despite this, YPs took an active and thoughtful role in learning to co-exist alongside their FTs. They sought information and resources, adapted their daily lives, experimented with different coping methods, developed toolkits that included distraction, humour, rest, and found new ways of responding to challenges. For some, this meant becoming mindful of their physical and psychological states and prioritising self-care. For others, it entailed cognitive shifts in how they perceived and responded to social scrutiny, for example, choosing not to internalise something they came to understand they had no control over. In this context, developing insight into the interconnectedness between their mind and body was a pragmatic shift that enabled YPs to better manage their symptoms and navigate the world around them. While these adaptations do not necessarily signal an endpoint, they represent the oscillating nature of coming to terms with FTs, offering moments of relief and agency in an experience that remains complex and ongoing.

5.4 Implications & Invitations

Policy

YPs with FTs occupy somewhat of a clinical 'blind spot', falling between neurodevelopmental tics and FND and being underserved by both due to the lack of NICE guidelines for either. NICE guidelines exist to guide consistency in care, support clinical decision-making, and promote evidence-based practice (NICE, n.d.). In their absence, clinicians lack clarity around referral and treatment pathways, while YPs experience diagnostic delays, prolonged uncertainty, and even contra-indicated interventions, as in Tessa's case. As this study demonstrates, the lack of frameworks contributes to epistemic harms and institutional marginalisation. Developing such guidelines, and including FTs within them, can provide clinicians with a conceptual framework from which to respond more effectively, particularly around the onset of FTs, a period marked by significant distress and upheaval.

The current political climate offers an opportunity to make 'transformative' changes to healthcare provision, as the UK Government's 10 Year Health Plan outlines a vision for 'digital-first', community-centred healthcare (DHSC, 2025). If the needs of this population are considered, the plan's emphasis on 'digital front doors' and community hubs means support for FTs can be embedded within online platforms and local services in modern, accessible ways. Within this infrastructure, digital interventions could be

designed for YPs and the local clinicians supporting them, offering evidence-based information, psychoeducation, therapeutic exercises, and helpful signposting towards resources as YPs await further care.

Research

While emerging follow-up studies show promising outcomes for those with FTs (Cavanna et al., 2024), the drivers of improvement remain unclear. For example, longitudinal studies (Ducroizet et al., 2025; Martino et al., 2023; Mathew et al., 2023) report that over half of their clinic attendees experienced full or partial remission of FTs over time, but do not explore what facilitated this. Other follow-up studies suggest that a combination of psychotherapy (usually CBT) and SSRIs reduce FT-related distress (Howlett et al., 2022; Nilles et al., 2024; Prato et al., 2023; Tomczak et al., 2024), but the mechanisms of change, particularly within therapy, warrant exploration. Similarly, whilst it is undoubtedly positive to see good rates of symptom remission and reductions in impairment scores, assuming recovery from FTs is inevitable or a matter of time risks abandoning those whose FTs endure. This further underscores an imperative to better understand who improves, how, and why, to ensure more equitable access to effective care.

This study has highlighted the utility of online spaces for this population, which should be considered within the research agenda. These spaces, be they social media, forums, support groups, or chat servers, are, and will continue to be, widely used to seek information and advice and connect with others, particularly in the absence of timely and satisfactory clinical support. Research exploring how services might safely and ethically integrate into or utilise these spaces is warranted, particularly as it might mitigate some of the risks identified (such as correcting misinformation). Done well, this could democratise access to specialist knowledge, though ethics and governance must be carefully considered.

Clinical

There is evidence that cognitive-behavioural, psychodynamic, and third-wave approaches support wellbeing in individuals with functional symptoms (Gutkin et al., 2021), though psychotherapeutic approaches should be guided by a formulation-based understanding of what modality is most appropriate, when (Myers et al., 2021), and alongside what multidisciplinary support (Sireci et al., 2024). For FTs, consideration of contextual factors and confidence in formulation may be more valuable than specialism[14]. With specialist services both scarce and oversubscribed, therapeutic professionals may feel uncertain about how to support YPs with FTs. Yet even being outside specialist pathways, they already

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[14] *Interestingly, evidence for the efficacy of CBIT, the specialist behavioural treatment for tics, has been mixed for FTs (Maxwell et al., 2023; Tomczak et al., 2024), demonstrating that even specialist knowledge and intervention may not be best course of treatment for this group*

possess the core building blocks that can support YPs, including formulation, empathy, and the capacity to offer a containing therapeutic relationship. Many challenges experienced alongside the FTs, including anxiety, low mood, bullying, emotional and physical fatigue, academic stress, and identity disruption can be addressed using various therapeutic models. Whilst what exactly helps to reduce the FTs themselves warrants further research, results from this study indicate that supporting YPs with the factors *around* the FTs could be just as impactful, provided YPs are able, and willing, to engage in psychotherapeutic work.

YPs' experiences of care are influential in developing that willingness. Broadly speaking, medical students wish for more experiential training around complex mental health presentations, particularly ones co-designed with experts by experience (McCormack et al., 2025). This creates an opportunity to develop a workforce premised on reflective, narrative-focused, empathic practice. With regard to FND and tics, clinicians themselves identify a need for further information and training (Barnett et al., 2022; Parker et al., 2024). Particularly for FND, training which is experiential, reflective, and person-centred helps clinicians feel more confident, competent and empathetic (Fusunyan et al., 2024; Lehn et al., 2020; Medina et al., 2021).

Finally, the way symptoms are explained can either compound distress and undermine trust or become a turning point for greater understanding and direction. Stone et al. (2016) outline six principles for delivering a helpful, "functional explanation": validate symptoms; offer a clear and positive explanation; explain the rationale; convey hope for reversibility; provide written resources; and signpost next steps. These closely match the clarity, pragmatism, and kindness that some YPs found redeemed their healthcare experiences. Even partial adherence to these principles would enable YPs to feel more contained and able to engage with support.

5.5 Strengths and Limitations

This the first qualitative study to focus exclusively on the lived experiences of YPs with FTs, rather than combining or substituting them with parental perspectives. This approach addresses a significant gap in the literature and explores experiences of a marginalised and overlooked population. Several described a preference to 'blend in' and not inconvenience others, making it all the more important that their perspectives are platformed within research and considered within clinical contexts.

The flexibility of RTA, in conjunction with a Critical Realist stance, supported a layered analysis that moved between YPs' explicit narratives and underlying meanings. Semi-structured interviews offered

opportunities for YPs to describe the practical, social, and psychological impacts of FTs, as well as their experiences navigating care and support across multiple systems. The resulting analysis offers a nuanced, multifaceted examination of life with FTs, with insights relevant to a wide range of professionals. The findings are presented in a way that clearly communicates the need for systemic change in how YPs with FTs are understood and treated, reinforcing the study's social justice aims.

Limitations should also be acknowledged. As most YPs were recruited via online communities or third sector organisations, the sample may reflect perspectives shaped by limited access to formal support. While this form of naturalistic sampling enabled access to the communities where people with FTs seek support, it may have captured those with more negative experiences, particularly of conventional clinical care, thus potentially biasing results. None of the YPs had received support through specialist tic or movement disorder clinics. Extending recruitment to include those with experience of specialist NHS input may have yielded a more varied perspective on clinical care experiences.

The presence of co-occurring conditions among YPs, many of which described additional functional symptoms, introduced complexity into the analysis. While the interview structure encouraged a focused exploration of FTs, the potential for overlapping or conflated experiences is acknowledged. In addition, participants varied in terms of how long they had been experiencing FTs at the time of interview. For some, their onset had occurred within months, while others had lived with their FTs for several years. These differences likely shaped YPs' reflections and should be considered when interpreting the results; that said, this variation can also offer insights into different phases of adjustment over time.

The wide age range of YPs (13-23 years), spanning early adolescence through emerging adulthood presents another limitation, introducing developmental heterogeneity that may have shaped how FTs were experienced and interpreted. For instance, younger YPs emphasised the role and importance of parents and schools in their experience, whereas older YPs reflected more on autonomy, identity disruption, and the possible impacts on their future. These differences may, therefore, reflect developmental stages rather than the phenomenon of FTs per se. Although thematic coherence was identified across ages, it is important to acknowledge that processes such as meaning-making, responses to destabilisation, and concerns around the future are likely influenced by developmental context and should be considered when interpreting these findings.

The sample also lacked ethnic and cultural diversity as it was composed primarily of White British participants. While some gender diversity was present amongst the YPs, including three trans men, which

reflects emerging demographic trends in FT populations (Nilles et al., 2024; Prato et al., 2023), the overall demographic profile limits the generalisability of findings. The study relied on YPs having access to digital platforms which may have excluded those with reduced digital access and literacy, potentially reinforcing socio-economic barriers.

Although the study incorporated EbE consultation and co-production elements such as member reflections, lived experience involvement was less than hoped for. Earlier and more sustained co-production would have strengthened this research.

5.6 Quality Appraisal

For the same reasons relating to methodological rigour and credibility outlined in Chapter 2, the CASP Checklist (2018) was used to assess the quality of this study (Table 11). Utilising the same scoring technique as that within the SLR, this study scored 10/10.

Table 11: Study CASP Quality Appraisal

Section A: Are the results valid?	
1. Was there a clear statement of the aims of the research? *CONSIDER:* • *what was the goal of the research?* • *why was it thought important?* • *its relevance*	☒ **Yes** ☐ **No** ☐ **Can't Tell** • The aim of the study, *to understand the lived experience of young people with functional tics,* is referenced throughout the thesis; the questions guiding the achievement of the aim are clearly stated • Justified as important due to paucity of existing research on lived experience of FTs; much of the research is about functional tics and *who* experiences them, not *what it's like* to experience them and their impact
2. Is a qualitative methodology appropriate? *CONSIDER:* • *If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants* • *Is qualitative research the right methodology for addressing the research goal?*	☒ **Yes** ☐ **No** ☐ **Can't Tell** • The qualitative methodology was appropriate for exploring the lived experiences FTs, a complex subjective phenomenon, where qualitative methods are best suited to capturing subjective meaning, nuance, and context • Using RTA aligns with the study's Critical Realist stance and focus on subjective experiences within broader contexts
3. Was the research design appropriate to address the aims of the research? *CONSIDER:* • *If the researcher has justified the research design (e.g., have they discussed how they decided which method to use)*	☒ **Yes** ☐ **No** ☐ **Can't Tell** • Study design is clearly justified; qualitative research is best suited to explore subjective experiences • RTA was chosen as it facilitates flexibility, depth, and reflexivity within analysis, which are key to understanding lived experience • As an outsider researcher, RTA's emphasis on reflexivity was key to examining how personal positioning might influence

interpretation, rather than treating subjectivity as a bias to eliminate
- Alternative approaches were considered and ruled out, with rationale for why RTA was more appropriate for the study's aims provided

4. Was the recruitment strategy appropriate to the aims of the research?

☒ **Yes** ☐ **No** ☐ **Can't Tell**

CONSIDER:
- *If the researcher has explained how the participants were selected*
- *If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study*
- *If there are any discussions around recruitment (e.g. why some people chose not to take part)*

- Recruitment procedures clearly outlined, including the use of purposive sampling to identify YPs with lived experience of FTs, and by which means
- Inclusion and exclusion criteria are clearly stated, including reasons for exclusion of prospective participants
- Screening procedure and the criteria that prospective participants were screened against clearly outlined, ensuring construct validity within the study

5. Was the data collected in a way that addressed the research issue?

☒ **Yes** ☐ **No** ☐ **Can't Tell**

CONSIDER:
- *If the setting for the data collection was justified*
- *If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)*
- *If the researcher has justified the methods chosen*
- *If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)*
- *If methods were modified during the study. If so, has the researcher explained how and why*
- *If the form of data is clear (e.g. tape recordings, video material, notes etc.)*
- *If the researcher has discussed saturation of data*

- Data collection is clearly described, with semi-structured interviews used to explore YPs lived experiences in a flexible and in-depth way, and interview schedule is provided
- The interview process is clearly explained, including how the schedule was developed and refined with input from an EbE consultant
- Interviews were conducted virtually, with rationale given for accessibility, participant comfort, and safety of younger participants
- Transcriptions of interviews manually corrected to ensure accuracy
- Methodology addresses that data adequacy was assessed through information power, reflecting the study's aim to capture depth and richness over saturation

6. Has the relationship between researcher and participants been adequately considered?

☒ **Yes** ☐ **No** ☐ **Can't Tell**

CONSIDER:
- *If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location*
- *How the researcher responded to events during the study and whether they considered the implications of any changes in the research design*

- Engaged in reflexivity throughout, recognising how outsider position might shape interpretations and interactions with participants. Methodology outlines how subjectivity is treated as a resource within RTA, and researcher positionality is discussed in relation to the CR stance
- Reflexive strategies are detailed, including use of a reflexive diary, critical discussions with supervisors, and attention to potential preconceptions during coding
- Consultation with EbE informed study materials and interview style, helping ensure sensitivity and resonance
- Methodology section highlights moments of flexibility during the study, making ethically approved amendments to adapt inclusion criteria, recruitment strategies, and

	participant involvement [member reflections], ensuring alignment with participant needs and research aims • Reflections on recruitment avenues are included in the discussion, noting that platforms like Reddit and third-sector organisations may influence who feels able or motivated to participate, and acknowledges the potential for this to bias results

Section B: What are the results?

7. Have ethical issues been taken into consideration? *CONSIDER:* • *If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained* • *If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)* • *If approval has been sought from the ethics committee*	**☒Yes ☐ No ☐ Can't Tell** • Clearly states that ethical approval was obtained from the UH Research Ethics Committee, and all ethics amendments detailed and justified • Informed consent and assent processes clearly explained, with age-appropriate materials and emphasis on participant autonomy and the right to withdraw • Confidentiality, data storage, and anonymisation procedures are outlined, including use of pseudonyms and secure, GDPR-compliant data storage • Potential for participant distress was anticipated, with safeguards in place.
8. Was the data analysis sufficiently rigorous? *CONSIDER:* • *If there is an in-depth description of the analysis process* • *If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data* • *Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process* • *If sufficient data are presented to support the findings* • *To what extent contradictory data are taken into account* • *Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation*	**☒Yes ☐ No ☐ Can't Tell** • Analysis was conducted using Braun & Clarke's six-phase Reflexive Thematic Analysis framework, clearly outlined in Methodology section • Each phase of analysis is described in detail, including familiarisation, coding, theme development, and refining, with attention to both semantic and latent meanings • Coding and theme development were iterative, and excerpts were reviewed with a peer and supervisors to support reflexivity and challenge assumptions • Researcher reflexivity during analysis is explicitly discussed, including use of a reflexive diary and supervisory input to examine possible bias or over-interpretation • Data presented in findings reflect both shared and divergent experiences, with illustrative quotes selected to demonstrate the interpretive process rather than just summarise content • As above (Q6) researcher bias was considered and reflected upon
9. Is there a clear statement of findings? *CONSIDER:* • *If the findings are explicit* • *If there is adequate discussion of the evidence both for and against the researcher's arguments* • *If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)*	**☒Yes ☐ No ☐ Can't Tell** • Findings are explicitly presented through four themes and accompanying subthemes, with explicit links to the research questions. Findings are grounded in participant reflections, with quotes used throughout to illustrate both commonalities and variation across experiences • Although arguments aren't made in the traditional sense, findings are discussed in relation to relevant theory and practice, with consideration of evidence both supporting and complicating interpretations

• *If the findings are discussed in relation to the original research question*	• Credibility is supported through peer input, supervisory feedback, and participant member reflections. Triangulation is not explicitly used, but reflexivity is embedded throughout the interpretive process

Section C: Will the results help locally?

10. How valuable is the research?	☒ **Yes** ☐ **No** ☐ **Can't Tell**
CONSIDER: • *If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g., do they consider the findings in relation to current practice or policy, or relevant research-based literature* • *If they identify new areas where research is necessary* • *If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used*	• The study clearly outlines its contribution to an under-researched area, highlighting the lack of literature focused on the lived experience of YPs with functional tics • Findings are discussed in relation to relevant theory, policy, and clinical practice, particularly around stigma, diagnostic uncertainty, and access to support • Discussion considers how results could inform future service provision and practitioner awareness. Areas for further research are identified, such as need for greater understanding mechanisms of effective therapy • Limits of generalisability are acknowledged

5.7 Conclusion

This study aimed to explore the lived experience of young people with functional tics, a population overlooked in research and underserved in clinical practice. YPs described the emotional, physical, practical, and social challenges of having FTs, as well as the harm caused by stigma, invalidation, and gaps in care. However, they also shared moments of clarity, connection, resilience, and optimism, offering insights into what helps and what hurts.

These findings build on emerging literature around FTs and shed light on what it's like to experience them. They also highlight a need for more informed, coordinated, and compassionate responses across healthcare and support systems. There is a clear imperative for services to ensure that YPs with FTs are met with understanding rather than dismissal, and are offered timely, evidence-based support grounded in empathy and validation.

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Appendices

Appendix A: Full CASP Results

Study	1. Was there a clear statement of the aims of the research?	2. Is a qualitative methodology appropriate?	3. Was the research design appropriate to address the aims of the research?	4. Was the recruitment strategy appropriate to the aims of the research?	5. Was the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	9. Is there a clear statement of findings?	10. How valuable is the research?
Burn et al., 2025	✓	✓	✓	✓	✓	✓	✓	✓	✓	**Valuable** as one of the few studies exploring lived experiences of functional tics, offering insights from both parents and young people. Highlights the long and difficult path to diagnosis, gaps in post-diagnostic support, and the role of community networks as vital sources of validation and practical help for a group of people whose voices and perspectives are under-represented in research. Uses findings to call for clear clinical pathways to facilitate diagnosis and families getting support, including more specialist services, that can support with both tics and co-occurring needs, alongside research to grow understanding of the psychological pathways to developing FTs.
Coleman & Melia, 2024	✓	✓	✓	✓	✓	✓	✓	✓	✓	**Valuable** as focuses specifically on women's experiences of TS, offering a nuanced look at gendered perspectives, the importance of connecting with others for validation and belonging, and the challenges posed by stigma and gaps in adult services; sheds light on voices often missing from TS research, despite some limits to generalisability. Situates findings in relation to current treatment policies, calling for both adult and female-focused interventions to address the psychosocial factors highlighted in the results, and calls for further research on how TS might shape identities of younger women, and how certain therapies may be used to support this.
Cuenca et al., 2015	✓	✓	✓	✓	✓	✗	✓	✓	✓	**Valuable** as provides a comprehensive view of the challenges young people and parents face when seeking TS care, highlighting gaps in professional knowledge, systemic barriers like long waits and fragmented pathways, and the difficulty accessing behavioural interventions; adds weight through mixed-methods design and a large, varied sample. Considers how findings reflect on the state of treatment and makes suggestions for future research into efficacy of tailored interventions.
Hermansen & Miller, 2008	✓	✓	✓	?	✓	✗	✓	?	✓	**Somewhat valuable** as offers a novel perspective on how negative experiences in mainstream healthcare push some toward seeking alternative interventions, and for highlighting both emotional and systemic barriers in seeking support for children with TS and ADHD; however, findings are limited by potential bias towards positive views of chiropractic care and a small, clinic-based sample.

Hu et al., 2024	✓	✓	✓	✓	✓	✗	?	✓	✓	**Valuable**, as one of few studies highlighting how cultural beliefs, misconceptions, and stigma shape help-seeking for TS outside Western contexts. Offers insights into delays in diagnosis and the role of parental blame / guilt in seeking care; findings deepen understanding of how cultural context influences support pathways. Identifies future directions for research to capture perspective across various regions in China.
Ludlow et al., 2018	✓	✓	✓	✓	✓	✗	✓	✓	✓	**Valuable** as offers a holistic view of carers' experiences seeking support across professional, educational, and peer domains. Highlights both practical barriers and emotional toll of feeling dismissed or unsupported; contributes important insights into gaps in service provision and the critical role of peer networks. Calls for clearer guidance on the management of TS and raising awareness of the condition to reduce negative and stigmatising attitudes and increase knowledge.
Ludlow, et al., 2024	✓	✓	✓	✓	✓	✗	✓	✓	✓	**Valuable** as one of the first studies exploring the lived experience of families dealing specifically with functional tics. Offers varied and detailed accounts of the emotional and practical challenges faced by mothers navigating their children's functional symptoms. Findings highlight important gaps in professional awareness and service pathways, including schools, and identifies future research opportunities around the various factors that may impact symptoms and long-term outcomes in this population.
Malli et al., 2019	✓	✓	✓	✓	✓	✓	✓	✓	✓	**Valuable** as reveals how gaps in adult-specific services contribute to feelings of isolation and fragmented support; offers perspectives into both the emotional and interpersonal impacts of living with TS in adulthood. Authors link findings to practice by recommending comprehensive clinical approaches and psychoeducation to support adults with TS, call for policy development that mirror other neurodev. conditions, and highlight future research around providing anti-stigma care
Malli et al., 2022	✓	✓	✓	✓	✓	✓	✓	✓	✓	**Valuable** for highlighting how structural stigma and gaps in professional knowledge shape adult experiences of support-seeking for TS, highlighting the burden placed on individuals to self-advocate and educate others. Makes a strong contribution to research through mixed-methods design and PPI involvement. Authors link findings to current gaps in policy and practice, and call for tailored anti-stigma interventions, and better professional training.
Marino et al., 2023	✓	✓	✓	✓	✓	?	✓	✓	✓	**Valuable** for its unique emphasis on experiences of primary care, supplemented by insights into experiences of secondary care; highlights specific experiences in good detail, capturing both practical and psychological aspects. Offers clear recommendations for improving GP knowledge and treatment pathways, calling for further research into referral processes and experiences of secondary care.
O'Hare et al., 2017	✓	✓	✓	✓	✓	✗	✓	✓	✓	**Valuable** as adds unique perspective on TS within an Australian context and offers good insights into specific stressors faced by parents of children with TS, and how these can inform both clinical practice and education provision, in the context of parenting stress models. Authors suggest how findings could be used to guide policy and practice.

Perkins et al., 2020	✓	✓	✓	✓	✓	✗	✓	✓	✓	**Valuable** for being one of the first study to specifically explore experiences of online TS communities. Adds new insights around the functions of these communities, the benefits they provide for members, balanced alongside challenges. Authors link findings to practice by exploring how online communities can be a complementary / alternative option for those who struggle to access offline care. Authors also highlight ongoing gaps in knowledge about non-English speaking groups and those who disengage from online communities and call for further research.
Pine et al., 2024	✓	✓	✓	✓	✓	✗	✓	✓	✓	**Valuable** for its unique contribution to TS awareness and clinical guidance in NZ, specifically in the education context. Clearly links results to current gaps in practice and policy, making parent-informed recommendations on how to best implement good quality education provision nationally. Authors explicitly discuss how findings could inform training and resources and invite future research looking specifically into young people's perspectives, and possible regional differences to improve generalisability across contexts.
Rivera-Navarro et al., 2009	✓	✓	✓	✓	✓	✗	✓	✓	✓	**Valuable** as focuses on how communication during TS diagnosis drives stigma, confusion, and delays in care, and offers suggestions that could shape more effective and informed communication from professionals to families. Also adds a holistic perspective by triangulating views of individuals, carers, and professionals.
Soós et al., 2022	✓	✓	✓	✓	✓	✗	✓	✓	✓	**Valuable** for its demonstration of how online communities provide emotional validation, connection, and practical guidance. One of few papers looking into the use of online spaces in tic populations and suggests directions for future research across multiple platforms and user groups, though findings are limited to one community without clear information on who is posting.
Taylor et al., 2022	✓	✓	✓	✓	✓	✗	✓	✓	✓	**Valuable** for its unique focus on tic-related pain, an under-researched but significant factor in tic conditions, adding depth to understanding both the physical and emotional impacts of tics. Makes clear implications in practice and guidance for improving clinical practice, pain management, and service pathways.
Travis & Juarez-Paz, 2020	✓	✓	✓	✓	✓	✗	✓	✓	✓	**Valuable** as demonstrates how carers experience communication in both supportive and harmful ways, with clear implications for improving professional practice and suggestions for how to interact with carers in ways that feel more supportive based on feedback highlighted in results. Authors link findings to gaps in current services and call for more research to include diverse carers (such as fathers).

Appendix B: Example of CASP

Paper: Using Online Support Communities for Tourette Syndrome and Tic Disorders: Online Survey of Users' Experiences

Authors: Perkins et al., 2020

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research? *CONSIDER:* • *what was the goal of the research?* • *why was it thought important?* • *its relevance*	☒ **Yes** ☐ **No** ☐ **Can't Tell** • Aim is clearly stated and multi-faceted: to explore users' experiences of online communities and to gain insight into their participation within them, including its impact on aspects of 'offline' life • The authors recognise and name the relevance, importance and prominence of online spaces as support-tools and name that no other study has yet explored the way people with tic conditions utilise them and how they might help / hinder them
2. Is a qualitative methodology appropriate? *CONSIDER:* • *If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants* • *Is qualitative research the right methodology for addressing the research goal?*	☒ **Yes** ☐ **No** ☐ **Can't Tell** • Use of qualitative method is justified and aligns with aims of the study which want to explore subjective, but shared, experiences across this population of online community users • Qualitative design enables collection of richer, more nuanced subjective data, which would be less possible with quantitative methods
3. Was the research design appropriate to address the aims of the research? *CONSIDER:* • *If the researcher has justified the research design (e.g., have they discussed how they decided which method to use)*	☒ **Yes** ☐ **No** ☐ **Can't Tell** • Open-ended surveys allow participants to elaborate on their experiences in a focused, but open way; good substitute for semi-structured interview, which also allows for greater number of participants • Choice of thematic analysis enables identification of patterns across narratives • Research design is based upon previous successfully executed study (by one of the co-authors) given little research and framework around conducting a study using members of specific online communities
4. Was the recruitment strategy appropriate to the aims of the research? *CONSIDER:* • *If the researcher has explained how the participants were selected* • *If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study* • *If there are any discussions around recruitment (e.g. why some people chose not to take part)*	☒ **Yes** ☐ **No** ☐ **Can't Tell** • Recruitment procedures clearly outlined (as above, based off previous study); users of active, user-led tic-condition support communities which is the focus of study • Inclusion criteria ensured participants had relevant lived experience, either personal or as supporter of someone with tic condition, again reflecting the aims of the study • Some mention re: communities that declined / DNR'd but with an explanation that those who declined did not stipulate why, but authors do comment on what may have driven this (wanting to keep externals out of user-led spaces). Does not speak to why people may have disengaged on individual level.

5. Was the data collected in a way that addressed the research issue?

☒ Yes ☐ No ☐ Can't Tell

CONSIDER:

- *If the setting for the data collection was justified*
- *If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)*
- *If the researcher has justified the methods chosen*
- *If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)*
- *If methods were modified during the study. If so, has the researcher explained how and why*
- *If the form of data is clear (e.g. tape recordings, video material, notes etc.)*
- *If the researcher has discussed saturation of data*

- Data collection procedures clearly described and justified; collected via open-ended survey; accessible and pragmatic approach that stands to reach many potential participants without geographical limitations
- Interview schedule provided, and rationale for selection of questions articulated, basing off previous research that has been adapted for this population; describes the use of PPI to shape interview questions prior to administration
- Does not speak to data saturation, goal in terms of number of participants, or why 90 was selected as cut-off

6. Has the relationship between researcher and participants been adequately considered?

☐ Yes ☒ No ☐ Can't Tell

CONSIDER:

- *If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location*
- *How the researcher responded to events during the study and whether they considered the implications of any changes in the research design*

- By nature of the study design, researcher is not technically 'connected' to participants [i.e., same research group]; authors do not state whether they are involved in these communities or have their own lived experience of either tics or using online spaces
- No meaningful discussion of researcher positionality and how personal views, contexts, or background may have influenced data collection, interpretation, or reporting
- PPI input is valuable, but does not comment on how it contributed toward researcher reflexivity
- No events to respond to mentioned

Section B: What are the results?

7. Have ethical issues been taken into consideration?

☒ Yes ☐ No ☐ Can't Tell

CONSIDER:

- *If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained*
- *If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)*
- *If approval has been sought from the ethics committee*

- Ethical approval granted and clearly stated
- Authors speak to providing participants with 'comprehensive' study information sheets but does not detail contents, however, does speak to addressing matters such as confidentiality, data handling and storage, right to withdraw
- No issues raised and thus no commentary on handling

8. Was the data analysis sufficiently rigorous?

☒ Yes ☐ No ☐ Can't Tell

CONSIDER:

- *If there is an in-depth description of the analysis process*
- *If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data*
- *Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process*

- Thematic analysis followed as per Braun & Clarke's six-step framework, with steps outlined and explained how they were followed in data analysis process
- Details iterative nature of process how codes and clusters were rearranged to get to theme
- Themes and subthemes were data driven and reviewed by co-authors
- Analysis of themes and subthemes is driven by good use of illustrative quotes and offers some degree of contradiction, highlighting both shared and diverging experiences

- *If sufficient data are presented to support the findings*
- *To what extent contradictory data are taken into account*
- *Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation*

- Researcher bias / influence within interpretation is not addressed, or not commented upon if co-authors facilitated any reflexivity when checking over themes

9. Is there a clear statement of findings?

☒ **Yes** ☐ **No** ☐ **Can't Tell**

CONSIDER:

- *If the findings are explicit*
- *If there is adequate discussion of the evidence both for and against the researcher's arguments*
- *If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)*
- *If the findings are discussed in relation to the original research question*

- As above, analysis of themes and subthemes is driven by good use of illustrative quotes and offers some degree of contradiction, highlighting both shared and diverging experiences
- No arguments per se, as this research is primarily exploratory
- Whilst more than one analyst was involved in looking over themes, how this impacted credibility is not discussed
- Findings are constantly linked back to original question

Section C: Will the results help locally?

10. How valuable is the research?

☒ **Yes** ☐ **No** ☐ **Can't Tell**

CONSIDER:

- *If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g., do they consider the findings in relation to current practice or policy, or relevant research-based literature*
- *If they identify new areas where research is necessary*
- *If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used*

- Valuable for being one of the first study to specifically explore experiences of online TS communities.
- Adds new insights around the functions of these communities, the benefits they provide for members, balanced alongside challenges.
- Authors link findings to practice by exploring how online communities can be a complementary / alternative option for those who struggle to access offline care.
- Authors also highlight ongoing gaps in knowledge about non-English speaking groups and those who disengage from online communities and call for further research.

Appendix C: SLR Study and Theme Tabulation

	Struggling Through Systems				The Emotional Gamut			Bridge to the Outside World		
	Knowledge Gaps	*Reluctant Experts*	*Service Gaps*	*Beyond Healthcare*	*Barriers to Seeking Help*	*Emotional Battles*	*Personal Strains/Supports*	*Filling Gaps*	*Building Communities*	*Use With Caution*
Burn et al., 2025	✓	✓	✓	✓		✓	✓	✓	✓	✓
Coleman & Melia, 2024	✓		✓		✓			✓	✓	
Cuenca et al., 2015	✓	✓	✓							
Hermansen & Miller, 2008	✓		✓	✓	✓	✓				
Hu et al., 2024	✓		✓		✓	✓				
Ludlow et al., 2018	✓	✓	✓	✓		✓	✓	✓	✓	
Ludlow, et al., 2024	✓	✓	✓	✓		✓		✓	✓	
Malli et al., 2019	✓		✓		✓		✓	✓	✓	
Malli et al., 2022	✓	✓	✓	✓			✓			
Marino et al., 2023	✓	✓	✓	✓		✓		✓		
O'Hare et al., 2017	✓	✓	✓	✓		✓	✓	✓	✓	
Perkins et al., 2020	✓	✓	✓		✓			✓	✓	✓
Pine et al., 2024	✓	✓		✓		✓				
Rivera-Navarro et al., 2009	✓		✓			✓	✓			
Soós et al., 2022	✓				✓		✓	✓	✓	✓
Taylor et al., 2022	✓		✓		✓		✓			
Travis & Juarez-Paz, 2020			✓	✓		✓	✓	✓	✓	

Appendix D: Excerpts of Reflexive Diary

Date	Entry
26/07/2024	And so the thesis journey begins. I wish I could say that I was radiating with excitement, but truly what I feel is tiredness and trepidation. There's no glossing over it… what should feel like the exciting launch of a meaningful project just feels quite heavy. I'm coming off the back of an intense year, and all I can really register is how behind I already feel. Reading feels like wading through concrete. I know I need to immerse myself in the literature to get a feel for the field, but I'm very tired. I know, academically, that MRP demands deep engagement with context and theory, so I know I need to take small, manageable steps (much like you support clients on placement to do). I keep circling the idea of FTLBs tics as a gendered, stigmatised, and "psychologised" phenomenon, and think it'll be important to tell this story. The SLR is on my mind, but the prospect of a narrative synthesis feels a bit daunting. Martindale's existing review feels intimidating; 119 papers included, and mine would be three years of literature later. Have I bitten off more than I can chew? Okay overall, I still feel a bit that I'm in the middle of a stormy ocean, but I do at least feel I've found a paddle. I think next steps for sure will be to: • Understand what I've signed up for in terms of conducting a *narrative* review • Do the PROSPERO registration and nail down the question • Establish my search terms • Understand the degree to which I can *build upon* what Martindale and Mink have written, rather than rewriting it. And also, maybe look on the bright side, some of the work has been done for you! • As I go, begin formulating an outline of your thesis so you can feel a bit more grounded and organised in terms of where you're going with it all
08/08/2024	Came back from the TaNDEM clinic visit today, was nice to see both Tamsin and Tammy in action, and also to meet families. It's very special to see families. I see parents desperately seeking answers. And they're exhausted, yes, but also ready to advocate for their child at all costs, waiting (as this one family did) for over a year to attend this specialist meeting. What really strikes me is the contrast between those at the beginning of their journey and those whose time with the clinic is coming to an end. The young people further along in treatment walk in more relaxed. The change is subtle, but powerful, and it makes me think about what good, timely support can actually do. How these kids can go from distressed to calm by being contained and looked after. Why are there only a handful of clinics like TaNDEM in the UK? Why have this family had to come all the way from Wales to be seen for a one-hour appointment? A huge testament to their resilience for managing without any support… I'm also struck by how big of a role dad played… he has Tourette's himself and said he had no one to help him growing up, and that he'd do anything for his boy. I'm grateful to have witnessed this particular dynamic; it'll be really important to explore the role of parents (or other family members) when I come to interview my participants.
12/20/2024	Recruitment has gotten off to a bit of a rocky start. I've worked hard to set things up with FND Hope and Tourette's Action… radio silence. I thought I'd have people to speak with over half term. I can definitely sense a slight feeling of dread and concern that the project not going to get off the ground. At the same time, the SLR topic and its focus on online support in particular is showing me something very obvious: that I myself might need to pivot to online spaces (dare I say, TikTok or Instagram… or maybe even Reddit or MumsNet for parents… or Facebook groups) given they seem to be support

	groups, diagnostic tools, and venting spaces all rolled into one. Happy to have Amanda and Tammy's blessing for this. Increasing age criteria to 25 makes sense also. Am a bit daunted by the prospect of putting 'myself' out there, even if it is for research purposes. This is doubtless fuelled by my worry that no one will respond. But as [fellow trainee] said, recruitment is quiet… until it's not. Just do it.
12/03/2025	Now that I've done a handful of interviews, I'm starting to notice the lingering emotions after pressing the 'end meeting' button. Some interviews stay with me more than others, although I can't always pin down why. It's not necessarily what's said… sometimes it's the tone, the pacing, the pauses that I feel like I don't pick up on. I'm not sure I'm always brave enough to ask the follow-up questions I want to… maybe I'm playing it safe, or feeling like I'm prying? It's jarring to listen to yourself back whilst correcting the transcripts, being like 'should have asked this'… 'how could I have missed that'? For upcoming interviews, try to slow down a bit. Fully take in what they're saying. It's 'semi-structured' for a reason, you don't need to hit all questions if there's a valuable thread to untangle, as [participant] said. I'm also continuously struck by how strong these young people are…. in this quiet, unrelenting way. Navigating their lives with symptoms that are so misunderstood, dismissed, disbelieved… and still doing their thing, still living their life as best they can…still trying to advocate for themselves, often when no one else will. It's very humbling to hear what some have gone through. And then the flip side of that: *why is this the reality?* Why does so much of their wellbeing hinge on whether they happen to get a decent, compassionate clinician? Why are we still so bad at supporting people with functional symptoms? It doesn't take a fancy intervention or cutting-edge approach, it just takes listening and seeing that the person in front of you is suffering. This feels so basic it barely counts as an assumption, but maybe that's the point… I assume that medical decency shouldn't be a luck of the draw experience. I didn't expect this research to make me angry, ha.
22/04/2025	Coding started out feeling clean and satisfying…colour-code, label, cluster. I like the neatness of it, it makes my perfectionist, Virgo brain happy to see things coming together. But then the contradictions and overlaps start to show, and it gets messy. And then I walk away, and come back, and it's still messy, but maybe I guess it's a good thing to notice the tensions and the way that things don't necessarily fit into a singular, specific box. Maybe I need to watch out for inadvertently 'tidying' the messiness too much and glossing over nuance. Some of the contradictions sound familiar. Not literally, but emotionally. That tension between needing space and fearing abandonment… wanting to be seen but not wanting to worry others… Also, I keep seeing paradoxes. Wanting to hide and becoming super seen. Wanting help but being hurt in the process. The more I want the tics to go away, the worse they become… and conversely, when I stopped giving the tics so much of my care and attention, they seem to go away…. Maybe these are my themes? Or is this too reductionist, would I be trying to wedge everything into said box?
09/05/2025	In supervision yesterday, Amanda challenged one of my preliminary subtheme names, saying it sounds too neutral. Having gone back and reread some transcripts… she's right. I've called it *Adjusting to a new way of life*, but what the participants are describing is not mild inconvenience. It's having to be fed by parents because they can't hold cutlery. It's dropping out of school… not being able to walk. Like, life upending things. Going back to the transcripts, I start to see what I've potentially missed. Sometimes, participants downplay things, like life with tics 'is not that bad,' or, 'they're not even my worst symptoms' then follow with examples that have completely derailed life… Maybe they're protecting themselves from the pain

of the devastation? Especially for the neurodivergent participants, that emotional language may not always be that direct, but that doesn't mean emotions aren't there.

Maybe that's where some aspect of the resilience stems from, a sort of manifestation of keep calm and carry on? I think I had assumed that the devastation would be front and centre and easy to convey, but maybe this sort of flattening of the distress is a signal of feeling unable to open up about their vulnerabilities fully (I am just a stranger on a screen, after all).

I think I get what latent coding is?!

Appendix E: UH Ethics Approval

University of Hertfordshire UH

HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO	Natasha Oates
CC	Dr Amanda Ludlow
FROM	Dr Ian Willcock, Social Sciences, Arts and Humanities ECDA Chair (on behalf of Dr Simon Trainis, Health, Science, Engineering and Technology ECDA Chair)
DATE	29/08/2024

Protocol number: **LMS/PGR/UH/05773**

Title of study: Functional Tic-Like Behaviours: Towards an Understanding of Young People's Experiences

Your application for ethics approval has been accepted and approved with the following conditions by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

Dr Tammy Hedderly: tammy.hedderly@gstt.nhs.uk

General conditions of approval:

Ethics approval has been granted subject to the standard conditions below:

Permissions: Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

External communications: Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Invasive procedures: If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

Submission: Students must include this Approval Notification with their submission.

Validity:

This approval is valid:

From: 29/08/2024

To: 15/07/2025

Please note:

Failure to comply with the conditions of approval will be considered a breach of protocol and may result in disciplinary action which could include academic penalties.
Additional documentation requested as a condition of this approval protocol may be submitted via your supervisor to the Ethics Clerks as it becomes available. All documentation relating to this study, including the information/documents noted in the conditions above, must be available for your supervisor at the time of submitting your work so that they are able to confirm that you have complied with this protocol.

Should you amend any aspect of your research or wish to apply for an extension to your study you will need your supervisor's approval (if you are a student) and must complete and submit form EC2.
Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1A. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1A may need to be completed prior to the study being undertaken.

Failure to report adverse circumstance/s may be considered misconduct.
Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately.

Appendix F: UH Ethics Amendments

Reason for Amendment Request	Protocol Approval
To expand the recruitment strategy to include social media platforms, so as to reach potential participants who may not be connected with third sector organisations such as Tourette's Action and FND Hope	**0247 2024 Nov HSET**
To allow for a risk assessment to be conducted in instances where a YP under 16 years of age may wish to take part in the interview without a parent / carer present in the same room, enabling them to speak more openly of their experiences	**0247 2024 Dec HSET**
To expand the inclusion criteria to include participants up to the age of 25, aligning with the NHS's definition of 'young person' and to include those whose tics may have developed in the early phases of the Covid-19 pandemic, when incidence was highest, and who are older but continue to experience FTs	**0247 2025 Jan HSET**
To remove the requirement that tics must have been present for at least 6 months so as to include people with a more recent onset, conditional on them receiving some form of help or support and feeling comfortable and safe in discussing their experiences	**0247 2025 Mar HSET**
To gain permission to invite participants to contribute towards member reflections of the results of the study, and to consult upon or take part in creation of any dissemination materials pertaining to the study	**0247 2025 June HSET**

To: Ms Natasha Oates

Your application for an amendment of the existing protocol listed below has been approved by the Health, Science, Engineering and Technology Ethics Committee with Delegated Authority. **Please read this letter carefully.**

Study Title: Functional Tic-Like Behaviours: Towards an Understanding of Young People's Experiences

Your UH protocol number is: **0247 2024 Nov HSET**

The Protocol Number issued from the online system replaces any previously issued protocol numbers and should be quoted on all paperwork, including advertisements for participants.

If you wish to use the UH Ethics Committee logo disclaimer in your communications with participants, please find it in our UH Ethics Canvas site under 'Units - Application Forms': UH Ethics Approval (instructure.com.

This ethics approval expires on 15/07/2025

Amending your protocol

Individual protocols will normally be approved for the limited period of time noted above. Application for minor amendments (including time extensions) of a protocol, may be made for a maximum of 4 working weeks after the end date of that protocol.

It is expected that any amendments proposed via the online system will be minor. Should substantial modification be required, it would be necessary to make a fresh application for ethical approval.

Note that you must obtain approval from the relevant UH Ethics Committee with Delegated Authority **prior to implementing any changes**. Failure to do so constitutes a breach of ethics regulations (UPR RE01).

Adverse circumstances
Any adverse circumstances that may arise because of your study/activity must be reported to ethicsadmin@herts.ac.uk as soon as possible.

Permissions
Any necessary permissions for the use of premises/location and accessing participants for your study/activity must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

Ethics Administration Team

ethicsadmin@herts.ac.uk

To: Ms Natasha Oates

Your application for an amendment of the existing protocol listed below has been approved by the Health, Science, Engineering and Technology Ethics Committee with Delegated Authority. **Please read this letter carefully.**

Study Title: Functional Tic-Like Behaviours: Towards an Understanding of Young People's Experiences

Your UH protocol number is: **0247 2024 Dec HSET**
This reference must be quoted on all paperwork, including advertisements for participants.

If you wish to use the UH Ethics Committee logo disclaimer in your communications with participants, please find it in our UH Ethics Canvas site under 'Units - Application Forms': UH Ethics Approval (instructure.com.

This ethics approval expires on 15/07/2025

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Ethics Administration Team

ethicsadmin@herts.ac.uk

To: Ms Natasha Oates

Your application for an amendment of the existing protocol listed below has been approved by the Health, Science, Engineering and Technology Ethics Committee with Delegated Authority. **Please read this letter carefully.**

Study Title: Functional Tic-Like Behaviours: Towards an Understanding of Young People's Experiences

Your UH protocol number is:

0247 2025 Jan HSET

This reference must be quoted on all paperwork, including advertisements for participants.

The Protocol Number issued from the online system replaces any previously issued protocol numbers and should be quoted on all paperwork, including advertisements for participants.

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Permissions
Any necessary permissions for the use of premises/location and accessing participants for your study/activity must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

Ethics Administration Team

ethicsadmin@herts.ac.uk

To: Ms Natasha Oates

Your application for an amendment of the existing protocol listed below has been approved by the Health, Science, Engineering and Technology Ethics Committee with Delegated Authority. **Please read this letter carefully.**

Study Title: Functional Tic-Like Behaviours: Towards an Understanding of Young People's Experiences

Your UH protocol number is: **0247 2025 Mar HSET**
This reference must be quoted on all paperwork, including advertisements for participants.

If you wish to use the UH Ethics Committee logo disclaimer in your communications with participants, please find it in our UH Ethics Canvas site under 'Units - Application Forms': UH Ethics Approval (instructure.com.

This ethics approval expires on 15/07/2025

Amending your protocol

Individual protocols will normally be approved for the limited period of time noted above. Application for minor amendments (including time extensions) of a protocol, may be made for a maximum of 4 working weeks after the end date of that protocol.

It is expected that any amendments proposed via the online system will be minor. Should substantial modification be required, it would be necessary to make a fresh application for ethical approval.

Note that you must obtain approval from the relevant UH Ethics Committee with Delegated Authority **prior to implementing any changes**. Failure to do so constitutes a breach of ethics regulations (UPR RE01).

Adverse circumstances
Any adverse circumstances that may arise because of your study/activity must be reported to ethicsadmin@herts.ac.uk as soon as possible.

Permissions
Any necessary permissions for the use of premises/location and accessing participants for your study/activity must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

Ethics Administration Team

ethicsadmin@herts.ac.uk

To: Ms Natasha Oates

Your application for an amendment of the existing protocol listed below has been approved by the Health, Science, Engineering and Technology Ethics Committee with Delegated Authority. **Please read this letter carefully.**

Study Title: Functional Tic-Like Behaviours: Towards an Understanding of Young People's Experiences

Your UH protocol number is: **0247 2025 May HSET**
This reference must be quoted on all paperwork, including advertisements for participants.

If you wish to use the UH Ethics Committee logo disclaimer in your communications with participants, please find it in our UH Ethics Canvas site under 'Units - Application Forms': UH Ethics Approval (instructure.com.

This ethics approval expires on 26/09/2025

Amending your protocol

Individual protocols will normally be approved for the limited period of time noted above. Application for minor amendments (including time extensions) of a protocol, may be made for a maximum of 4 working weeks after the end date of that protocol.

It is expected that any amendments proposed via the online system will be minor. Should substantial modification be required, it would be necessary to make a fresh application for ethical approval.

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Permissions
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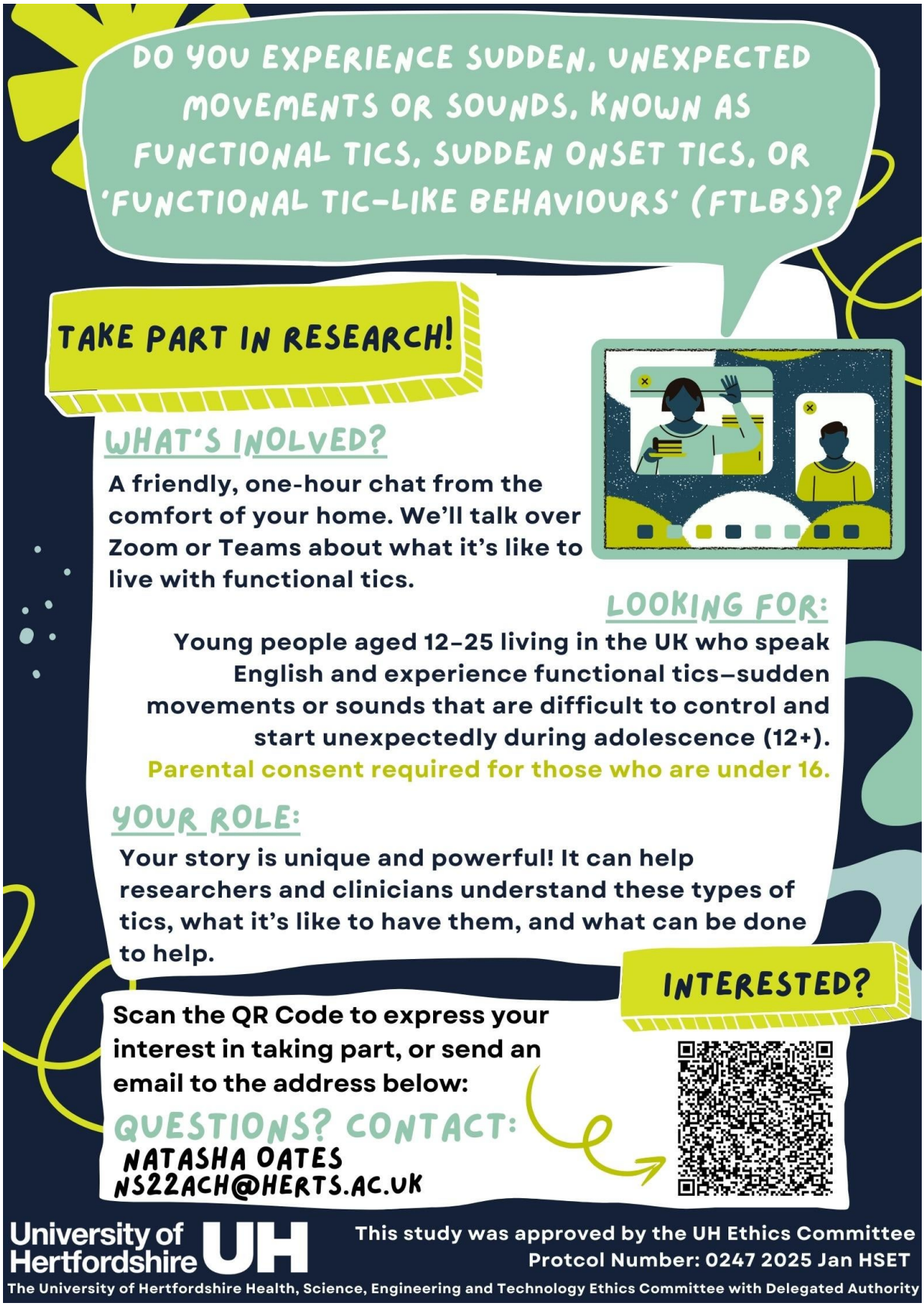
Ethics Administration Team

ethicsadmin@herts.ac.uk

Appendix G: Study Adverts (Participant + Consultant)




CONSULT ON DOCTORAL RESEARCH!
HELP SHAPE RESEARCH ON
FUNCTIONAL TICS
Are you a young person, or a parent/carer of someone with lived experience of Functional Tics (also known as 'sudden onset tics', 'tic-like behaviours' or 'functional movements')?
Share your insights to help make our study more accessible, inclusive, and meaningful for participants.
GET IN TOUCH!
NATASHA OATES
(PRINCIPAL RESEARCHER):
NS22ACH@HERTS.AC.UK
< SCAN ME TO SEND AN E-MAIL!
Do you want to participate in the study instead?
Contact Natasha for study info!
University of Hertfordshire UH
This study was approved by the UH Ethics Committee
Protcol Number: LMS/PGR/UH/05773
The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority

Appendix H: 16 & Over Study Information Sheet

University of Hertfordshire UH Ethics Committee

UNIVERSITY OF HERTFORDSHIRE

ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS ('ETHICS COMMITTEE')

FORM EC6: PARTICIPANT INFORMATION SHEET

1 **Title of study**

Understanding Young People's Experiences of Functional Tic Like Behaviours (FTLBs)

2 **Introduction**

You are being invited to participate in a study that is being carried out as part of a Doctorate in Clinical Psychology. Before you decide whether you wish to participate, it is important that you understand why the study is being conducted and what it involves. Please read the following information carefully and feel free to discuss it with others. Do not hesitate to contact us for anything that is unclear or if you require further information to help you make your decision. Please do take your time to decide whether or not you wish to take part. The University's regulation, UPR RE01, 'Studies Involving the Use of Human Participants' can be accessed via this link:

https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs
(after accessing this website, scroll down to Letter S where you will find the regulation)

Thank you for reading this.

3 **What is the purpose of this study?**

This study aims to explore what it's like to experience Functional Tic-Like Behaviours (FTLBs)—which are sudden, uncontrollable movements or vocal expressions. We are interested in hearing from young people about their experiences with FTLBs: how they impact their life, their feelings about the behaviours, their self-perception, and what has been helpful so far. Their perspective is crucial as there has been little research involving young people on living with FTLBs.

4 **Do I have to take part?**

It is entirely up to you whether you participate in this study. If you choose to participate, you will receive this information sheet and be asked to sign a consent form. Signing the consent form does not mean you are obligated to participate, nor does agreeing to start the study mean you must complete it.

You can withdraw at any stage without providing a reason. A decision to withdraw at any time, or a decision not to participate at all, will not affect any treatment or care you may receive elsewhere.

5 **Are there any age or other restrictions that may prevent participation?**

Age: We are specifically looking to understand the experiences of young people, so are seeking participants who are between 12 and 25 years of age.

Types of Tics: For this study, we are looking to speak to young people who have been told that their tics are functional. We are still learning about these tics; they are understood to be complex

University of Hertfordshire UH Ethics Committee

sounds and movements with a sudden onset during adolescence. They may cause pain or discomfort and are challenging to control. Functional tics may co-occur alongside Tourette's Syndrome or Tic Disorders, and if you hold one of these diagnoses but also experience functional tics, you are still eligible to participate. If you have questions as to whether your tics are functional in nature, the lead researcher can discuss this with you ahead of scheduling the interview.

Other Diagnoses: We know that FTLBs often occur alongside other mental health difficulties. You are eligible to participate unless such conditions significantly impair your ability to communicate or engage in a verbal conversation.

Duration: There's no minimum length of time you need to have had functional tics, but it's important you feel comfortable talking about your experiences. During the intake call, we'll discuss how you're feeling and any support you've had (either from professionals or others), to make sure participating feels safe and positive for you.

6 **How long will their part in the study take?**

If you decide to participate, you will have a conversation with the lead researcher, Natasha Oates, over Zoom or Microsoft Teams, lasting about an hour. This may extend slightly if breaks are needed. You will be asked some additional information prior to the interview, which should take no more than 10 minutes to complete.

7 **What will happen if I take part?**

You will sign a consent form acknowledging that you have read and understood this information and agree to participate. Prior to scheduling the interview, the lead researcher will call or e-mail you to obtain some general information about yourself, such as demographics, mental health history and descriptive information about your tics. You may choose which questions you answer.

The interview will be conducted online via Zoom, focusing on your experiences with FTLBs— both the challenges and helpful aspects. It's important that you are in a comfortable, safe, and private space during the conversation, which will last about an hour with breaks as needed. We will also explore how FTLBs affect your daily life, your mental health, and whether social platforms have helped you better understand FTLBs or find community support. To ensure your safety and wellbeing during the interview, you will be asked to provide an emergency contact.

The conversation will be recorded and transcribed to ensure accuracy. If you consent, you may be contacted you to confirm the accuracy of the data's interpretation. All personal contact will be deleted post-project (by September 2025).

8 **What are the possible disadvantages, risks or side effects of taking part?**

Discussing personal experiences and emotions can be challenging and may be upsetting. There will be ample opportunities for breaks. All participants will be provided with a debrief sheet which contains contact information for support services and resources.

Participation is voluntary, and you can withdraw at any time.

9 **What are the possible benefits of taking part?**

This research is important as it seeks to improve understanding and potentially enhance life for young people with FTLBs. Findings may inform clinical practice and service development, benefiting young people living with this condition.

University of Hertfordshire UH Ethics Committee

Additionally, participants who complete the interview will be reimbursed with a £10 voucher for their time.

10 **How will my taking part in this study be kept confidential?**

You will be assigned a pseudonym; real names or identifiable information will not be used in any study materials. Confidentiality will be maintained unless disclosure is necessary to prevent harm. More details on data handling can be found in section 12.

11 **Audio-visual material**

Audio-visual material is solely for record-keeping and will only be accessed by the principal researcher and supervisory team. As per UH policy, original interview recordings will be stored securely in a GDPR-compliant UH OneDrive folder, until the completion of the principal researcher's examination viva. Interview recordings will then be deleted.

12 **What will happen to the data collected within this study?**

The interview will be recorded with transcription turned on. This is to ensure that what is shared is accurately captured and can be double-checked for accuracy within the transcription.

Only the lead researcher will have access to these recordings. They will be anonymised and stored in a password protected folder on the University's GDPR compliant OneDrive. Once the transcription of the interview is complete and verified to be free of errors, the recording will be deleted following the completion of the principal investigator's examination viva in July 2025.

An anonymised written transcript of the conversation will be kept on the university's secure storage for 5 years after the study's completion (approx. 2030), as per the University's policy. This is to ensure that this research in conducted soundly and ethically.

This type of research often uses quotes or excerpts from participants' interviews. If this is the case, any quotation will be from the pseudonym and any information which could identify you would be removed.

Your name and contact information will be stored securely in a password protected file in case we need to get in touch with you at some point during the study. However, this will be deleted once the research concludes (September 2025).

13 **Will the data be required for use in further studies?**

It is common that data collected in one research study may be utilised in other, future studies to further build upon and develop research and knowledge within the field. If appropriate, data collected in this study may be used for such purposes, including further presentations or publications. As data is stored securely and anonymously to begin within, it will remain anonymous in such instances.

14 **Who has reviewed this study?**

This study has been reviewed by:

The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority

University of Hertfordshire UH Ethics Committee

The UH protocol number is **0247 2025 Mar HSET**

15 **Factors that might put yourself or others at risk**

Please note that if, during the study, any medical conditions or non-medical circumstances become apparent that might or had put yourself or others at risk, the researcher and/or the University may refer the matter to the appropriate authorities and, under such circumstances, you may be withdrawn from the study.

16 **Who can I contact if I have any questions?**

If you would like further information or would like to discuss any details personally, please get in touch by email:

Lead Researcher
Natasha Oates
Trainee Clinical Psychologist
Doctorate in Clinical Psychology
University of Hertfordshire
E-Mail: ns22ach@herts.ac.uk

Principal Supervisor:
Dr Amanda Ludlow
Head of Psychology and NeuroDiversity
Applied Research Unit
University of Hertfordshire
E-Mail: a.ludlow@herts.ac.uk

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar
University of Hertfordshire
College Lane
Hatfield
Herts
AL10 9AB

Thank you very much for reading this information and giving consideration to taking part in this study.

Appendix I: 16 & Under Study Information Sheet

Appendix 6: EC6 Young Person Participant Information Sheet

UNIVERSITY OF HERTFORDSHIRE

ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS ('ETHICS COMMITTEE')

FORM EC6: PARTICIPANT INFORMATION SHEET

1 **Title of study**

Understanding Young People's Experiences of Functional Tic Like Behaviours (FTLBs)

2 **Introduction**

You are being invited to take part in a study that is part of a Doctorate in Clinical Psychology. Before you decide whether to do so, it is important that you understand the study. Please take the time to read this information carefully. Do not hesitate to ask us anything that is not clear or if you have questions.

Please do take your time to decide whether you wish to take part.

The University's regulation, UPR RE01, 'Studies Involving the Use of Human Participants' can be accessed via this link:
https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs
(after accessing this website, scroll down to Letter S where you will find the regulation)

Thank you for reading this.

3 **What is the purpose of this study?**

This study is about what it's like to live with functional tics, sometimes called Functional Tic-Like Behaviours (FTLBs). These are sudden movements or vocal expression that happen outside of your control. In this research, we want to hear from young people like you about what life is like with functional tics, how you feel about them, and what has been helpful in your experience so far. Your story is very important because there hasn't been much research with young people about what it's like to have functional tics.

4 **Do I have to take part?**

Taking part in the study is totally your choice. If you do want to join, you will read this information and sign a form saying you agree to take part. As you are under 16, your parent will also need to sign a form agreeing for you to take part. Just because they've signed the form, doesn't mean you have to join the study. If you do sign up but decide that you don't want to do it anymore, you can stop without needing to explain. Stopping the study won't affect any care that you receive anywhere else.

5 **Are there any age or other restrictions that may prevent me from participating?**

Age: We are looking to understand the experiences of young people who are between 12 and 25 years old.

Types of Tics: For this study, we want to speak to people who have been told their tics are functional. We are still learning about these tics; we understand them to be painful movements or sounds that may feel hard to control and make go away. It might feel like they came out of

nowhere at some point during adolescence (from 12 years on). You might have a diagnosis of Tic Disorder or Tourette Syndrome. Even if you do, you can still take part. Your experience of tics may be different to what's described, and that's okay. If you (or your parent) are not sure if your tics are 'functional', Natasha can discuss this with you before arranging the interview.

Other Diagnoses: We know that people with functional tics can also have other mental health conditions. This won't stop you from taking part, as long as you are able to understand and answer interview questions.

Duration: It doesn't matter how long you've had functional tics, but it's important that you feel okay talking about your experiences. When Natasha speaks to your parent / carer during the intake call, we'll check in about how you're doing and any support you've had (from doctors, family, or friends). This helps make sure joining the study feels safe and comfortable for you.

6 **How long will my part in the study take?**

If you decide to take part, Natasha (lead researcher) will call or e-mail your parent to arrange the interview. She will also ask you some questions about yourself (see section 7 for details). This will take around 10 minutes. Then you will meet Natasha over Zoom / Teams. This chat will last about an hour, or a bit longer if you need to take any breaks. You might have some questions at the end, which we will have time to go over.

7 **What will happen to me if I take part?**

Before we start, you and your parent/carer will sign a consent form saying that you've read this sheet and understand this information about the study. Natasha will call or e-mail your parent to arrange the interview, and will ask some basic details about you, like your age, gender, ethnicity and whether you're currently going to school. She will also ask some questions about your mental health, including whether you have any existing mental health diagnoses, when you started experiencing tics, what kind of tics you experience, and whether you've been given a diagnosis for these tics. This is to give some general, helpful information about people who take part in the study and experience functional tics. You don't have to answer these questions if you don't want to.

As you are 12-15 years old, I will need to speak with your parent or carer to ensure that you feel safe, comfortable, and supported during the interview. Their role is to help decide whether it would be okay for you to complete the interview on your own. If they agree that you're comfortable and there's minimal risk, they may give permission for you to take part independently. Even in that case, your parent or carer will still need to remain at home while the interview takes place.

When you do the interview with Natasha, she'll ask you about your experience with tics. Make sure that you're in a comfortable, quiet, and private place for the conversation. The chat will last about an hour, and you can take breaks when you need. We'll talk about how these tics affect your day-to-day, your mental health, and if social media has helped you find support with your tics. You can request the interview questions if you want to see them before the interview.

The conversation will be recorded so that Natasha can accurately capture everything you said. *We don't have to have video turned on.* The recordings will be stored securely and anonymously, which you can read more about in section 12. After the interview, Natasha might contact you to make sure that she got everything right. Your personal data would be deleted after the project is finished (by September 2025). At the end of the study, Natasha will share an easy-to-read report of the overall results with you, but you don't have to read it.

8 **What are the possible disadvantages, risks or side effects of taking part?**

Appendix 6: EC6 Young Person Participant Information Sheet

This study does not wish to make you feel uncomfortable or upset, but, talking about personal stuff, your experiences, and your feelings may be tough. If that happens, we can take breaks and decompress, and even move on from questions. If you parent is not sitting in the room with you, your parents/carers will be asked to be home while we talk, so that they can offer you some support if needed. Remember, you can always stop or leave the study when you want.

9 **What are the possible benefits of taking part?**

Your story is really important because there hasn't been much research with young people about what it's like to have FTLBs. Finding this out could help us understand how to make things better at school or at home. Clinicians in the NHS are very interested in how they can improve the lives of young people like you, and this research could help them do that. Also, after participating and completing the interview, you will receive a £10 voucher!

10 **How will my taking part in this study be kept confidential?**

To keep everything private and confidential, we will give you a fake name (a pseudonym), and your real name won't be used in any notes or files. No one will know who you are from the study. Anything you say in the interview will stay between you and Natasha. The only exception to this is if you tell Natasha something that makes her worried that your or someone else is in danger. If that happens, Natasha may have to tell someone, so that they can help keep you or others safe. She will let you know if she needs to do this.

11 **Audio-visual material**

Our interview will be recorded, but only Natasha will have access to it. The recording is so that she can go back and make sure that everything you said is written down correctly. Once Natasha finishes her project, the recordings will be deleted.

12 **What will happen to the data collected within this study?**

Our interview will be recorded so that Natasha can make sure everything is written down correctly. Only Natasha will access it, and it will be saved in a password-protected folder under a fake name. It will be saved on the university secure storage system called OneDrive.

After Natasha presents her project to the markers (in July 2025), the recordings will be deleted. The written version of what we talked about (with your fake name) will be kept by the university for five more years, but no one will know it's you. This is to make sure that Natasha did her research correctly.

This type of research often uses quotes from interviews. If this is the case, any quote will be from your fake name (pseudonym) and any information which could identify you will be completely removed.

Your name and contact information will be stored securely in a password protected file, just in case we need to get in touch with you at some point during the study. This will be deleted when the research is finished (September 2025).

13 **Will the data be required for use in further studies?**

Sometimes, information that researchers collect in one study may be useful for other studies in the future. This can help researchers and clinicians learn more about what they're investigating.

Appendix 6: EC6 Young Person Participant Information Sheet

The information that we collect in this study might be used for other studies, presentations, or reports. If that happens, everything will still be kept private and no one will know it's you.

14 **Who has reviewed this study?**

This study has been reviewed by:

The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority

The UH protocol number is **0247 2025 Mar HSET**

15 **Factors that might put others at risk**

Please note that if something comes up during the study, like any medical conditions or something illegal that puts someone in danger, the University may need to tell someone about it and you might have to leave the study.

16 **Who can I contact if I have any questions?**

If you would like further information or would like to discuss any details personally, please get in touch with me, in writing, by phone or by email:

Lead Researcher
Natasha Oates
Trainee Clinical Psychologist
Doctorate in Clinical Psychology
University of Hertfordshire
E-Mail: ns22ach@herts.ac.uk

Principal Supervisor:
Dr Amanda Ludlow
Head of Psychology and NeuroDiversity
Applied Research Unit
University of Hertfordshire
E-Mail: a.ludlow@herts.ac.uk

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar
University of Hertfordshire
College Lane
Hatfield
Herts
AL10 9AB

Thank you very much for reading this information and giving consideration to taking part in this study.

Appendix J: Parent Study Information Sheet

University of Hertfordshire UH Ethics Committee

UNIVERSITY OF HERTFORDSHIRE

ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS ('ETHICS COMMITTEE')

FORM EC6: PARTICIPANT INFORMATION SHEET

1 **Title of study**

Understanding Young People's Experiences of Functional Tic Like Behaviours (FTLBs)

2 **Introduction**

Your child is being invited to participate in a study that is being carried out as part of a Doctorate in Clinical Psychology. Before you decide whether to allow your child to participate, it is important that you understand why the study is being conducted and what it involves. Please read the following information carefully and feel free to discuss it with others. Do not hesitate to contact us for anything that is unclear or if you require further information to help you make your decision.

Please do take your time to decide whether or not you wish for your child to take part. The University's regulation, UPR RE01, 'Studies Involving the Use of Human Participants' can be accessed via this link: https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs
(after accessing this website, scroll down to Letter S where you will find the regulation)

Thank you for reading this.

3 **What is the purpose of this study?**

This study aims to explore what it's like to live with Functional Tic-Like Behaviours (FTLBs)—sudden, uncontrollable movements or vocal expressions. We are interested in hearing from young people like your child about their experiences with FTLBs: how they impact their life, their feelings about the behaviours, their self-perception, and what has been helpful in their experience so far. Their perspective is crucial as there has been little research involving young people on living with FTLBs.

4 **Do they have to take part?**

It is entirely up to your child and you whether or not they participate in this study. If they choose to participate, they will receive this information sheet and be asked, alongside your consent, to sign their own consent form. Signing the consent form does not mean they are obligated to participate, nor does agreeing to start the study mean they must complete it.

Your child can withdraw at any stage without providing a reason. A decision to withdraw at any time, or a decision not to participate at all, will not affect any treatment or care they may receive elsewhere.

5 **Are there any age or other restrictions that may prevent participation?**

Age: We are looking to understand the experiences of young people and are seeking participants who are between 12 and 25 years of age.

University of Hertfordshire UH Ethics Committee

Types of Tics: For this study, we are looking to speak to young people who have been told that their tics are functional. We are still learning about these tics; they are understood to be complex sounds and movements with a sudden onset during adolescence, from 12 years onwards. They may cause pain or discomfort and are challenging to control. Functional tics may co-occur alongside Tourette's Syndrome or Tic Disorders, and if your child holds one of these diagnoses but also experiences functional tics, they are still eligible to participate. If you have questions as to whether your child's tics are functional in nature, the lead researcher can discuss this with you ahead of scheduling the interview.

Other Diagnoses: We know that FTLBs often occur alongside other mental health difficulties. Your child is eligible to participate provided that such conditions do not significantly impair their ability to communicate or engage in a conversation.

Tic Duration: There is no minimum duration required for your child to have experienced functional tics. However, it's important that they feel comfortable speaking about their experience. This will be explored during the intake call, including any professional or informal support your child has received to ensure that participating feels safe and supportive.

6 **How long will their part in the study take?**

If your child decides to participate, Natasha Oates, the lead researcher, will call or e-mail you to arrange the interview. She will also ask you some questions to get some background information (see section 7 for details) about your child. This will take around 10 minutes. Natasha will then meet with them over Zoom / Teams to conduct the interview, which will last about an hour, with additional time given for breaks. There will be time at the end of the interview for your child to ask questions.

7 **What will happen if they I take part?**

Both you and your child will sign a consent form acknowledging that you have read and understood this information and agree to their participation. Before the interview, you will be asked some background information about your child, including age, gender, ethnicity, and whether they're currently attending school. You will also be asked questions about their mental health history, including when they started experiencing tics, the kinds of tics they experience, whether they've been given a diagnosis for these tics, and whether they hold any other mental health diagnoses or see any mental health professionals. Your child is welcome to take part in this conversation. This general information can help enhance clinical understanding about the populations that experience functional tics; however, your child can opt out of answering any of these questions.

The interview will be conducted online via Zoom or Microsoft Teams, focusing on your child's experiences with FTLBs—the challenges and helpful aspects. We will also explore how FTLBs affect their daily life, their mental health, and whether social platforms like TikTok or Instagram have helped them understand FTLBs or find community support. *Your child does not have to turn on their video during the interview.*

It's important that they are in a comfortable, safe, and private space during the conversation, which will last about an hour with breaks as needed. To ensure their safety and wellbeing during the interview, a parent or carer will be asked to sit in with the child whilst the interview is taking place, but only their contributions will be included in the study. If your child prefers to complete the interview on their own, this can be discussed with the researcher who will assess the possible risk and safety of doing so. A parent or carer will be required to be in the home to at the time of interview to offer immediate support.

University of Hertfordshire UH Ethics Committee

The conversation will be recorded and transcribed to ensure accuracy. If you and your child consent, they may be contacted you to confirm the accuracy of the data's interpretation. All personal contact will be deleted post-project (by September 2025).

8 **What are the possible disadvantages, risks or side effects of taking part?**

Discussing personal experiences and emotions can be challenging and may upset your child. There will be ample opportunities for breaks, and you are required to be in the same building during the interview to provide support. There is very little research that centres the young peoples' voice and experience of FTLBs, and it is important that their perspectives are captured. This means that only their contributions will be transcribed and used in the study. Participation is voluntary, and your child can withdraw at any time.

9 **What are the possible benefits of taking part?**

This research is important as it seeks to improve understanding and potentially enhance life for young people with FTLBs. Findings may inform clinical practice and service development, benefiting young people living with this condition. Additionally, young people who complete the interview will be reimbursed with a £10 voucher for their time.

10 **How will my taking part in this study be kept confidential?**

Your child will be assigned a pseudonym; real names or identifiable information will not be used in any study materials (drafts or formal reports). Confidentiality will be maintained unless disclosure is necessary to prevent harm. More details on data handling can be found in section 12.

11 **Audio-visual material**

Audio-visual material is saved solely for record-keeping and will only be accessed by the principal researcher. As per UH policy, original interview recordings will be stored securely in a GDPR-compliant UH OneDrive folder, until the completion of the principal researcher's examination viva (July 2025). Interview recordings will then be deleted.

12 **What will happen to the data collected within this study?**

The interview will be recorded with transcription turned on. This is to ensure that what is shared is accurately captured and the transcription can be double-checked for accuracy. Only the lead researcher will have access to these recordings. They will be anonymised and stored in a password protected folder on the University's GDPR compliant OneDrive. Once the transcription of the interview is complete and verified to be free of errors, the recording will be deleted following the completion of the principal investigator's examination viva in July 2025.

An anonymised written transcript of the conversation will be kept on the university's secure storage for 5 years after the study's completion (approx. 2030), as per the University's policy. This is to ensure that this research in conducted soundly and ethically. This type of research often uses quotes or excerpts from participants' interviews. If this is the case, any quotation will be from the pseudonym and any information which could identify your child would be removed. Your name and contact information will be stored securely in a password protected file in case we need to get in touch with you at some point during the study. However, this will be deleted once the research formally concludes (September 2025).

13 **Will the data be required for use in further studies?**

University of Hertfordshire UH Ethics Committee

It is common that data collected in one research study may be utilised in other, future studies to further build upon and develop research and knowledge within the field. If appropriate, data collected in this study may be used for such purposes, including further presentations or publications. As data is stored securely and anonymously to begin within, it will remain anonymous in such instances.

14 **Who has reviewed this study?**

This study has been reviewed by:

The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority

The UH protocol number is **0247 2025 Mar HSET**

15 **Factors that might put others at risk**

Please note that if, during the study, any medical conditions or non-medical circumstances such as unlawful activity become apparent that might or had put others at risk, the University may refer the matter to the appropriate authorities and, under such circumstances, your child will be withdrawn from the study.

16 **Who can I contact if I have any questions?**

If you would like further information or would like to discuss any details personally, please get in touch with me, in writing, by phone or by email:

Lead Researcher
Natasha Oates
Trainee Clinical Psychologist
Doctorate in Clinical Psychology
University of Hertfordshire
E-Mail: ns22ach@herts.ac.uk

Principal Supervisor:
Dr Amanda Ludlow
Head of Psychology and NeuroDiversity
Applied Research Unit
University of Hertfordshire
E-Mail: a.ludlow@herts.ac.uk

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar
University of Hertfordshire
College Lane
Hatfield
Herts
AL10 9AB

Thank you very much for reading this information and giving consideration to taking part in this study.

Appendix K: 16 & Above Consent Form

UNIVERSITY OF HERTFORDSHIRE
ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS
('ETHICS COMMITTEE')

FORM EC3
CONSENT FORM FOR STUDIES INVOLVING HUMAN PARTICIPANTS

I, the undersigned *[please give your name here, in BLOCK CAPITALS]*

……..
of *[please give contact details here, such as a phone number or email address]*

……
hereby freely agree to take part in the study entitled

Understanding Young People's Experiences of Functional Tic Like Behaviours (FTLBs)

UH Protocol number **0247 2025 Mar HSET**

1 I confirm that I have been given a Participant Information Sheet (a copy of which is attached to this form) giving particulars of the study, including its aim(s), methods and design, the names and contact details of key people and, as appropriate, the risks and potential benefits, how the information collected will be stored and for how long, and any plans for follow-up studies that might involve further approaches to participants. I have also been informed of how my personal information on this form will be stored and for how long. I have been given details of my involvement in the study. I have been told that in the event of any significant change to the aim(s) or design of the study I will be informed, and asked to renew my consent.

2 I have been assured that I may withdraw from the study at any time without disadvantage to myself, or having to give a reason.

3 In giving my consent to participate in this study, I understand that voice, video or photo-recording will take place and I have been informed of how/whether this recording will be transmitted/displayed.

4 I have been given information about the risks of my suffering harm or adverse effects during the study. I agree to provide an emergency contact and that they may be contacted if concerns about my safety or the safety of others arise during the study. In signing this consent form I accept that requisite attention might be sought for myself, should circumstances require this. I have been informed that a debrief sheet will be provided to me after the study.

5 I have been told how information relating to myself (data obtained in the course of the study, and data provided by me about me) will be handled: how it will be kept secure, who will have access to it, and how it will or may be used.

6 I understand that my participation in this study may reveal findings that could indicate that I may require medical advice. In that event, I will be informed and advised to consult a GP and I acknowledge that, following discussion, I may be required by the University to withdraw from the study. If, during the study, evidence comes to light that I may have a pre-existing (medical) condition that may put myself or others at risk, I understand that the University will refer me to the appropriate authorities and that I will not be allowed to take any further part in the study.

7 I understand that if there is any revelation of unlawful activity or any indication of non-medical circumstances that would or has put others at risk, the University may refer the matter to the appropriate authorities.

Signature of participant……..…Date……

Signature of (principal) investigator

Form EC3 – 26 August 2021

Appendix L: 16 & Below Consent Form

UNIVERSITY OF HERTFORDSHIRE
ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS
('ETHICS COMMITTEE')

FORM EC3
CONSENT FORM FOR STUDIES INVOLVING HUMAN PARTICIPANTS

I, the undersigned *[please give your name here, in BLOCK CAPITALS]*

……..…
of *[please give contact details here, such as a phone number or email address]*

…..……
hereby freely agree to take part in the study entitled

Understanding Young People's Experiences of Functional Tic Like Behaviours (FTLBs)

(UH Protocol number **0247 2025 Mar HSET**)

1 I confirm the following:

Information Sheet: I have read the information sheet and understand what the study is about and how it will be done.

Study Team: I know that Natasha Oates is the main researcher and know how to contact her or her supervisor if I need to.

Risks and Benefits: I understand what good things that can come from the study, and what parts might be difficult.

Data Storage: I know that Natasha and her supervisor will keep the recordings of my answers from the interview safe and when they will delete them.

Personal Information: I know that Natasha will keep my personal information secure and private, and that only she will be able to see it.

My Role: I understand that I will be answering questions about my experience with tics.

Changes to the Study: If something changes in the study, I understand that Natasha will tell me, and will ask for my permission to take part again.

2 I know I can stop taking part in the study whenever I want, and I don't need to give a reason for this.

3 I understand that Natasha will record a video of our interview and write down my answers, but that she will delete this once the project is complete.

4 I know that some parts of interview might be tough or uncomfortable, but that a parent/carer will be nearby if I need them. I know I can take a break or stop the interview whenever I want.

5 I understand how my information will be kept safe, who will see it, and how it will be used.

6 If Natasha finds out that I or someone else is in danger or unsafe, she will let the university know so that they can tell people who are able to help.

Signature of participant

…… Date……

Appendix M: Parent Consent Form

University of Hertfordshire UH Ethics Committee

UNIVERSITY OF HERTFORDSHIRE
ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS
('ETHICS COMMITTEE')

FORM EC4
CONSENT FORM FOR STUDIES INVOLVING HUMAN PARTICIPANTS
FOR USE WHERE THE PROPOSED PARTICIPANTS ARE MINORS, OR ARE OTHERWISE UNABLE TO GIVE INFORMED CONSENT ON THEIR OWN BEHALF

I, the undersigned *[please give your name here, in BLOCK CAPITALS]*

……
of *[please give contact details here, sufficient to enable the investigator to get in touch with you, such as a phone number or email address]*

……
hereby freely give approval for *[please give name of participant here, in BLOCK CAPITALS]*

.....
to take part in the study entitled

Understanding Young People's Experiences of Functional Tic Like Behaviours (FTLBs)

UH Protocol number **0247 2025 Mar HSET**

1 I confirm that I have been given a Participant Information Sheet (a copy of which is attached to this form) giving particulars of the study, including its aim(s), methods and design, the names and contact details of key people and, as appropriate, the risks and potential benefits, how the information collected will be stored and for how long, and any plans for follow-up studies that might involve further approaches to participants. I have also been informed of how my child's personal information will be stored and for how long. I have been given details of his/her involvement in the study. I have been told that in the event of any significant change to the aim(s) or design of the study I will be informed, and asked to renew my consent for him/her to participate in it.

2 I have been assured that he/she may withdraw from the study, and that I may withdraw my permission for him/her to continue to be involved in the study, at any time without disadvantage to him/her or to myself, or having to give a reason.

3 In giving my consent to participate in this study, I understand that voice, video or photo-recording will take place and I have been informed of how/whether this recording will be transmitted/displayed.

4 I have been given information about the risks of his/her suffering harm or adverse effects during the study. I agree to be physically present nearby at the time his/her interview is taking place. In signing this consent form I accept that medical attention might be sought for him/her, should circumstances require this.

5 I have been told how information relating to him/her (data obtained in the course of the study, and data provided by me, or by him/her, about him/herself) will be handled: how it will be kept secure, who will have access to it, and how it will or may be used.

6 I understand that his/her participation in this study may reveal findings that could indicate that he/she may require medical advice. In that event, I will be informed and advised to consult a GP and I acknowledge that, following discussion, he/she may be required by the University to withdraw from the study. If, during the study, evidence comes to light that he/she may have a pre-existing medical condition that may put others at risk, I understand that the University will refer him/her to the appropriate authorities and that he/she will not be allowed to take any further part in the study.

University of Hertfordshire UH Ethics Committee

7 I understand that if there is any revelation of unlawful activity or any indication of non-medical circumstances that would or has put others at risk, the University may refer the matter to the appropriate authorities.

8 I declare that I am an appropriate person to give consent on his/her behalf, and that I am aware of my responsibility for protecting his/her interests.

Signature of person giving consent

…… Date……

Relationship to participant

……

Appendix N: Post-Study Debrief Sheet

Thank you for generously taking part in this research project. Hopefully, this research will help us better understand young people's experience of functional tic-like behaviours (FTLBs) and help shape services to better suit the needs of young people in the future.

Hearing young people's stories of their experience with FTLBs can help other young people in similar positions, as well as teachers, medical professionals and commissioners who make decisions about service design.

The information that you have provided will be kept confidential and the recordings will be destroyed after the interviews have been transcribed, analysed, and reviewed.

Remember:

If you feel upset after the interview and need someone to talk to, you can:

- Speak to your parent, carer, or trusted person.
- Speak to your GP, mental health team, or involved professional.
- Childline (0800 1111) and Samaritans (08457 909090) both provide confidential help for people feeling distressed.
- FND Hope (fndhope.org) and Tourettes Action (tourettes-action.org.uk) are two organisations that have resources that may be helpful in navigating FTLBs and tics.
- If you decide that you don't want me to use the information we spoke about in the interview, that is fine, and you do not have to give a reason for this. Please let Natasha know as soon as you can via e-mail.

Contact Information:

Lead Researcher:
Natasha Oates
Trainee Clinical Psychologist
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University of Hertfordshire
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Evelina Children's Hospital
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Appendix O: Interview Schedule

Introduction	Time
Hello _____; it's very nice to meet you, and thanks so much for taking part in this research project. I'm Natasha, I'm a psychologist in training completing this research as part of my doctorate, and I'm looking forward to chatting with you today. Today we're going to be talking about your experiences of functional tic-like behaviours, what life's been like for you, what their impact has been, what you've found helpful, less so, etc. There are no right or wrong answers, your experience is unique and I'm sure your answers will be too, and I'm not looking for you to answer in a specific way. You'll probably see me looking down: I've got a list of prepared questions, but we may go outside of these too, depending on the way our conversation flows. Your openness and willingness to share your experience is valuable and will hopefully yield some positive changes for young people going though similar experiences, so thanks again. Couple of house-keeping things before we start: • Just to confirm, you've read the information sheet and still agree to participate? • Is your parent or carer close by in the house right now? • Are you still happy for this conversation to be recorded and transcribed? • Remember that if you want to skip a question or need to take a break, just let me know, I'm happy to pause. • If you decide mid interview that you want to stop and withdraw, that's not a problem at all. • Also, how do you refer to FTLBs? *(Use YPs' language when referring to tics)* That's it for the practical bits – do you have any questions for me before we begin?	5MIN
Onset	
Can you tell me a little about what it was like when you first started to experience tics? • *What were your first reactions to the tics? (Feelings, thoughts)* • *How did other people around you react? (Parents, siblings, friends, peers)*	5MIN
Daily Life	
How would you say your day-to-day life changed after you began experiencing tics? • *What sort of things or activities did you have to stop or start doing?* • *What was life like at home after this?* **And how have these changes affected your school life, friendships, and hobbies?** • *How did your teachers and other people at school react to this?* o *Did you feel supported, or like they didn't understand what was going on and how to help?* • *How did other people (like friends, peers) react and how did that make you feel?* • *Did you have to explain to others what you were going through?* o *How did you find that process?* **What's been your experience of being in public spaces (like school)?** • *Are there specific situations that are particularly tricky?* o *How do you handle those?*	10MIN
Emotional Impact	
If you look back at how you felt when you first started experiencing tics, how have your emotions changed from then to now? • *Were there any significant moments that changed how you felt?* o *What caused those changes (coping mechanisms, (lack of) support streams, etc)?*	10MIN

Perception	
Has having FTLBs changed the way you think about yourself? • *Do you feel like the tics are a part of you, or something that's happening to you?* **And do you think that the tics have changed how other people see you?** • *Have you noticed that people treat you differently?* o *What are your thoughts on that?*	5MIN
Support	
What sorts of things, or people, have helped you throughout this experience? • *Can you give an example when things felt like they were getting better or going well?* o *What do you think helped about that?* **What's been your experience in getting support from teacher, doctors, or people who work in mental health?** • *Are there things you've been happy with?* • *Are there things you wish people would know, or do differently?* **Apart from medical professionals, do you access support in any other way?** • *Social media? Support groups?* **From your point of view, did / does anything help to reduce the intensity / frequency of the tics?**	10MIN
Social Media	
Do you, or have you, used social media platforms or communities to understand tics, or connect with people going through similar experiences? • *Did you find this helpful / valuable? In what way?* o *Have you found tips or strategies through platform that have helped you?* **What makes an online space helpful or unhelpful?** **Do you feel more supported, or more anxious about tics after spending time on *platform*?**	10MIN
Reflections and Future Thinking	
What do you think you've learned about yourself so far through this experience? • *Probe: strengths, abilities, resilience, things that have been conquered or achieved* **Is there any advice you would give to other young people going through this experience?**	5MIN
Debrief	
That's us done. Thanks so much for your openness and sharing your experience with me, this has been a fruitful and valuable conversation. How are you feeling after our interview? Have you got plans for the rest of the day? Do you have any questions for me? If you think of anything, you've got my contact info, feel free to get in touch. I'll also send you and your *parent* a debrief sheet with some information and some contact information for various helpful organisations if you feel you need support.	Flexible depending on support required

Appendix P: Examples of Transcripts and Codes

[P14] 13:52:30
So… So starting… Starting with when they first started, obviously very nervous then came sort of, I guess, acceptance as I realised that it was just something that was sticking around and staying… And then sort of during secondary school with that and then… sorry, words…. Throughout A level as it progressed I started to get more fearful of them and more, I guess, actively bothered by them and more and more I guess….I guess frustrated with them…

Especially… being around someone that you're close to with them, You know, it's very hard to function. And so during that period of time I was much more "oh god is this how it's going to be from now on?"

And then as time went on sort of going on to uni, not only did they not stop but they again got worse. Where I would, it was so frequent at that stage that it was really disrupting my daily life, it was disrupting my lectures, it was disrupting my friendships And… the friends that I have made again had tics…

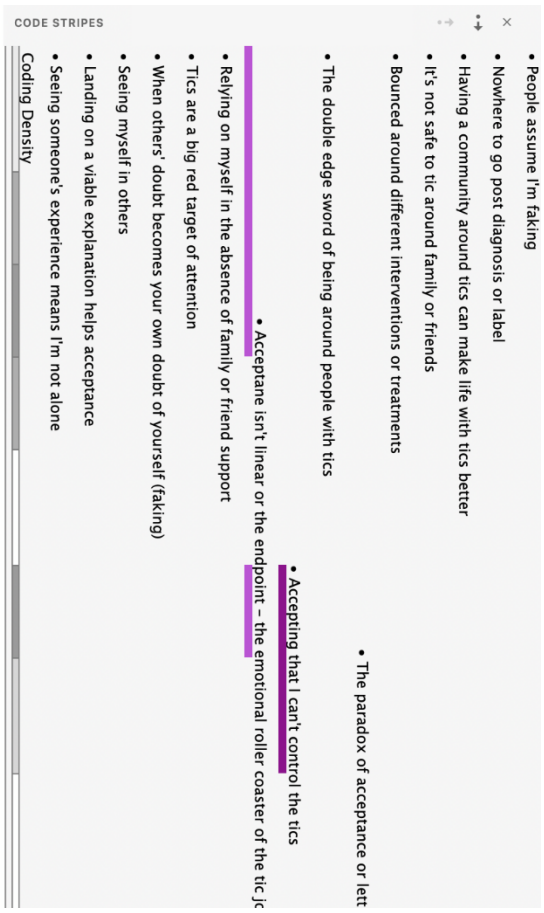
And not only that but there were multiple people who had tics now so it didn't matter *who* I was around, it sort of felt like I was surrounded by people with tics. So even when I wasn't around them it kind of had just increased my tics overall as well…

[Natasha Oates] 13:54:33
So just kind of became your life. Basically.

[P14] 13:54:37
Yeah, essentially, which was really hard because I had a lot of other stuff going on at the same time. And at that stage, I started to lean more into acceptance again. Once I got past the first few months of that, I started to go… I might as well just have a laugh about them essentially… I might as well just giggle when they happen… and just try and sort of stay confident about it, essentially.

Because at that point, my confidence… I sort of had fake confidence about them… and I guess continuing on that line, I just started to get *actually* more confident about them you know… And eventually they started to decrease in frequency and things settled back down to a manageable level again…

[Natasha Oates] 13:55:45
Okay. So can I just have a few questions to follow up because you've said so many amazing things there. The first one, that kind of fake confidence. Was it like a sort of fake it till you make it oh wait, I've made it… kind of thing?



Like I have a lot of friends who I haven't told about FND at all yet. Just 'cause... I just still haven't told a lot of people that it's even going on.

And so there was like a really bad tic day, and I hadn't had that conversation with them yet. Like I'd be like, hey, can we do a different day 'cause? I was like, I just don't want to talk to this person about it, and they're going to come over and they're going to ask, and I just don't want to do that.

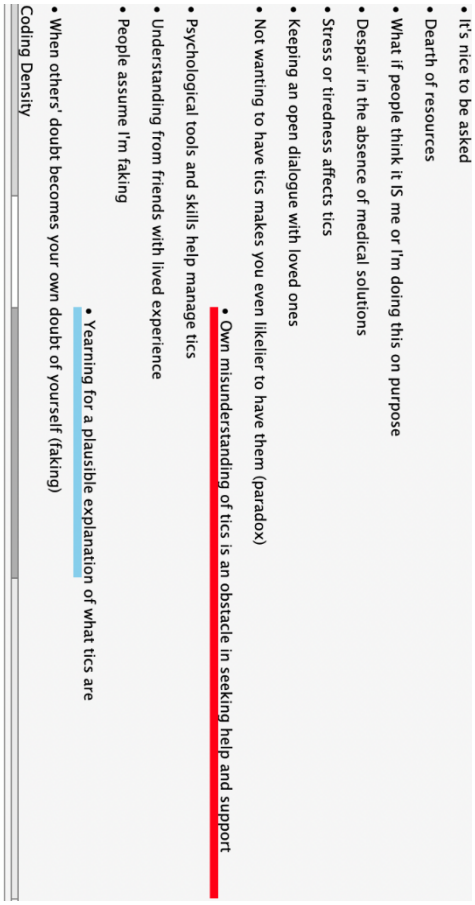
Natasha Oates [Student-LMS] 25:55
What? What do you remember? What, like what caused that feeling of not wanting to talk like what you were feeling or experiencing?

P9 26:03
I think it just was that everything about the tics and everything else is so... like from back when it really started in like September through to now.... I just have... like I've done my best to have as full a picture and understanding as I can of what's happening and what I need to be doing, but I still just like, I've still not had.... other than going to A&E and a follow up with my GP I've had....no specialist or neurologist speak to me about this at all, and I don't know what I'm supposed to be doing to manage it. And I don't know if the things that I've been doing myself are helping long term or... making it worse long term....And I feel like I can't talk to people.

Natasha Oates [Student-LMS] 26:56
We we will definitely. Oh, sorry.
Go ahead, go ahead.

P9 26:58
Just that I feel like I can't talk to people about it without them being like, "oh, like, what did the doctor say?" And I'm like I don't want to talk about the fact that I am *so* stressed about still being on the wait list for any help with this.

So I'm just like....just don't come over because you are going to ask about the tics and I'm going to have to explain it to you.



Appendix Q: Example of Thematic Clustering

An alternative to sticky-note mapping: all bullet points are codes

SUPPORT

Subtheme 2: Social Media / Online Support – Double Edged Sword

- Community of social media and online support brings comfort AND disruption at the same time (paradox)

- Engagement with tic content / online support typically comes *after* onset of symptoms

- Online support fills a gap in actual medical, NHS, professional support
  - Different social media has different functions
  - Online support- community is a repository of information

→

- MAIN FUNCTION: Seeing myself in others
  - Lived experience more valuable than clinical guidelines
  - Other people can do it, so can I
    - Seeing others' experience of tics encourages acceptance and confidence
  - Seeing someone's experience means I'm not alone
  - TikTok as a safe space for chronic illness community

- Importance of being discerning about information online
  - Content creators not always honest
    - Fine line between legitimate and faking accounts
  - Social media requires sifting through
    - Lack of balance in social media

→

- Awareness that seeing tics online can make my own tics worse
  - Suggestibility is impacted by mental state
  - Exposure to good and helpful information is worth exacerbating tics
    - The double edge sword of (physically) being around people with tics

ACCEPTANCE

Subtheme 1: The long and windy road to acceptance

- Acceptance isn't linear or the endpoint- the emotional roller coaster of the tic journey
  - The danger of holding out hope that the tics will go away on their own

- Ingredients of acceptance
  - Comfort comes with time / Duration of tics gives them a sense of legitimacy
  - Acceptance from others helps acceptance of self
    - Acceptance comes from not caring what people think
      - Relief in not hiding
  - Landing on a viable explanation helps acceptance
    - Realising a lack of danger can facilitate acceptance
  - Feeling 'normal' as an ingredient to acceptance and relief
    - The expense of trying to 'be normal' Will need to go back and see the quotations here to understand the contradiction

- THE PARADOX OF ACCEPTANCE: KEY MESSAGE: Acceptance and relief come when you stop resisting the tics
  - Accepting that I can't control the tics
    - People don't make a big deal out of it, if you don't
    - Ownership of tics grows with emotional safety

Appendix R: Thematic Gist / Definitions

EXPERIENCE

Main Message: Here I'm trying to describe the actual experience of the tics themselves, and the ways in which they affected the YP's day to day or life experiences. This has an emotional component to it definitely, but I also want to make sure it remains distinct from the theme that goes more deeply into the disruption to the sense of self that the tics caused. But, I know these are interconnected so I will need to be thoughtful about how to keep these distinct.

IDENTITY / SELF

Main Message: Tics didn't just disrupt the status quo of daily life… they caused a massive disruption to the participants' idea of who they actually are, and what the tics *say about them* as people. This is particularly underscored by the idea of 'the paradox of attention', that the tics have betrayed participants' invisibility and invited significant scrutiny from the outside world. Attempting to navigate and reconcile these feelings is what kept, and for some, keeps, them stuck in a state of distress and wondering, 'could I be doing this to myself'?

SUPPORT

Main Message: Support was spoken about in various ways: the obvious being experiences of medical support (diagnosis and getting guidance / information on tics), but also through social media, family, and friends. There was no such thing as a purely positive or negative support experience…participants expressed a duality to all of the above, that each has an 'underbelly' of sorts. What was particularly striking was that when support was bad, it wasn't just 'not good': it was actively harmful in some way.

ACCEPTANCE

Main Message: Not all of the participants have yet made it to a place of accepting their tics, but many have been contending with them for a long time and developed some valuable reflections along the way. The underlying message of all of this is release: releasing control, releasing the fight, releasing attention, releasing assumptions, releasing the care about what other people think of them. In accepting that tics aren't going away, many found some semblance of relief, or, that the distress of the tics loosened its grip on their life, at least a little bit. Acceptance was helped, to some degree, by building a toolbox of coping strategies that helped people get by in the day-to-day.

Appendix S: 16 & Above Member Reflections Information

University of Hertfordshire UH

Invitation to Review Study Results (Member Reflections)
And Participate in Dissemination Feedback

Research title:
Functional Tics: Towards an Understanding of Young People's Lived Experience

Why am I being contacted?
Thank you again for taking part in the above research. The analysis and write-up of the interview data has been completed, and you are being invited to:

1. Offer feedback on the study's results (called *member reflections*), and/or
2. Stay in touch to help guide how the study's results are shared with others (called *dissemination*)

Do I have to do this?
There is no obligation to take part in either Member Reflections or Dissemination. Your participation in the original interview is separate and will not be affected in any way.

Even if you choose not to participate further, your interview data will still be included in the final analysis (unless you have previously withdrawn your consent). You can also change your mind and withdraw from the Member Reflections or Dissemination process at any time.

What does this entail?
Member Reflections involve looking at a summary of the results, and offering your reflections, feedback, critiques, thoughts, or questions via e-mail.

You will be sent a summary of the four main themes and their subthemes (the key ideas identified through the analysis of the data). You can comment on any aspect of the results, including the way they are presented, names of the themes, or content of the themes, etc.

There are no right answers; your feedback helps Natasha make sure that the findings feel meaningful.

Dissemination refers to sharing the results with people who might benefit from them, such as teachers, doctors, the public, or organisations. This might take the form of:

- Leaflets or infographics
- Short videos
- Presentations
- Another format that may be suggested and is possible given available resources

Natasha would like to stay in touch with you (via e-mail, or video call if preferred) to get your thoughts or suggestions about: the format (what it looks like), the content (what it says), and/or the audience (who it's for). You may wish to give feedback on drafts or even contribute your own ideas or materials (for example, artwork). This is entirely up to you.

Should you wish to take part in either of these processes, you will be asked to sign a consent form.

How will my feedback be used?

Member Reflections
Your feedback will support Natasha to ensure that the findings of the study make sense to you and are felt to contribute towards a better understanding of young people's experiences of functional tics. Your anonymous feedback will be discussed with the research team. This is to foster reflections on whether any amendments may be required.

Please note that due to time constraints, it will not be possible to implement any major changes to the results. The summary points of the feedback received will be included in the final write-up for the study.

Dissemination
Your suggestions may shape what materials are created, what they contain, and how they are shared. You can also choose only to give feedback on materials Natasha will have developed.

Will I remain anonymous?
Yes, you will not be identified any shared outputs. All identifying information will be removed from feedback, and any quotes used will be attributed to your pseudonym.

Your responses will be stored confidentially on University of Hertfordshire's encrypted OneDrive system until the completion of the project (October 2025), in accordance with the University of Hertfordshire Ethics and Research integrity policy.

This study has been reviewed and approved by the University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority, under the protocol 0247 2025 May HSET.

If you would like further information or would like to discuss any details personally, please get in touch by email:

Lead Researcher:
Natasha Oates
Trainee Clinical Psychologist
Doctorate in Clinical Psychology
University of Hertfordshire
E-Mail: ns22ach@herts.ac.uk

Principal Supervisor:
Dr Amanda Ludlow
Head of Psychology and NeuroDiversity Applied Research Unit
University of Hertfordshire
E-Mail: a.ludlow@herts.ac.uk

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar
University of Hertfordshire
College Lane
Hatfield
Herts
AL10 9AB

Thank you for taking the time to support this research!

Appendix T: 16 & Below Member Reflections Information

University of Hertfordshire UH

Invitation to Review Study Results (Member Reflections)
And Participate in Dissemination Feedback

Research title:
Functional Tics: Towards an Understanding of Young People's Lived Experience

Why am I being contacted?
Thank you again for taking part in this study! Natasha has now finished looking at everyone's interviews. She would love to hear what you think about what we found. You can also help her figure out how to share the results with others in the best way.

You can choose to do:

1. *Member Reflections*: this tells Natasha what you think about the results
2. *Dissemination*: this helps Natasha share the results in a way that makes sense

Do I have to do this?
No, you do not, it's entirely up to you. Even if you don't want to give feedback on these parts of the research your interview will still be part of the study (unless you have asked to take it out). You can also change your mind any time.

What does this entail?
Member Reflections
You will get a simple summary of the study results (the main ideas that were found). You can:

- Say what you think of the results
- Share ideas or ask questions

There are no wrong answers. Your feedback will help Natasha make sure that the results make sense to those who took part. Please have your parent / carer e-mail your feedback to Natasha.

Dissemination
This means sharing the results with those who might need to know them, like teachers, doctors, or other people. Natasha might make:

- Leaflets
- Short videos
- Posters or slideshows
- Or any other ideas that are possible

You can be as involved as you like. This may mean your parent communicating with Natasha by e-mail, or we can speak by video call (if you prefer).

How will my feedback be used?

For Member Reflections, your feedback helps Natasha check if the results are clear and helpful. She'll talk about your ideas with the research team and mention them (anonymously) in the final report.

For Dissemination, your thoughts might shape what Natasha makes, what's in it, or who it's shared with.

Will my name be used?
No. Everything you share will stay anonymous. This means your real name won't be used; it will come from your fake name (pseudonym) that was used in the study. Natasha will remove anything that might show who you are.

University of Hertfordshire UH

Your responses will be stored confidentially on University of Hertfordshire's encrypted OneDrive system until the project is done (October 2025), as per the University of Hertfordshire Ethics and Research integrity policy.

This study has been reviewed and approved by the University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority, under the protocol 0247 2025 May HSET.

If you would like further information or would like to discuss any details personally, please have your parent get in touch by email:

Lead Researcher:
Natasha Oates
Trainee Clinical Psychologist
Doctorate in Clinical Psychology
University of Hertfordshire
E-Mail: ns22ach@herts.ac.uk

Principal Supervisor:
Dr Amanda Ludlow
Head of Psychology and NeuroDiversity Applied Research Unit
University of Hertfordshire
E-Mail: a.ludlow@herts.ac.uk

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar
University of Hertfordshire
College Lane
Hatfield
Herts
AL10 9AB

Thank you for taking the time to support this research!

Appendix U: Parent Member Reflections Information

University of Hertfordshire UH

Invitation to Review Study Results (Member Reflections)
And Participate in Dissemination Feedback

Research title:
Functional Tics: Towards an Understanding of Young People's Lived Experience

Why am I being contacted?
Thank you again for supporting your child to part in the above research. The analysis and write-up of the interview data has been completed, and your child is being invited to:

1. Offer feedback on the study's results (called *member reflections*), and/or
2. Stay in touch to help guide how the study's results are shared with others (called *dissemination*)

Do I have to do this?
There is no obligation for your child take part in either Member Reflections or Dissemination. Their participation in the original interview is separate and will not be affected in any way.

Even if they choose not to participate further, their interview data will still be included in the final analysis (unless they have previously withdrawn consent). They can also change their mind and withdraw from the Member Reflections or Dissemination process at any time.

What does this entail?
Member Reflections involve looking at a summary of the results, and offering their reflections, feedback, critiques, thoughts, or questions via e-mail.

You will both be sent a summary of the four main themes and their subthemes (the key ideas identified through the analysis of the data). They can comment on any aspect of the results, including the way they are presented, names of the themes, or content of the themes, etc.

There are no right answers; their feedback helps Natasha make sure that the findings feel meaningful.

Dissemination refers to sharing the results with people who might benefit from them, such as teachers, doctors, the public, or organisations. This might take the form of:

- Leaflets or infographics
- Short videos
- Presentations
- Another format that may be suggested and is possible given available resources

Natasha would like to stay in touch with your child (through you, via e-mail, or video call if preferred) to get your child's thoughts or suggestions about: the format (what it looks like), the content (what it says), and/or the audience (who it's for). They may wish to give feedback on drafts or even contribute your own ideas or materials (for example, artwork). This is entirely up to them.

Should your child wish to take part in either of these processes, both of you will be asked to sign a consent form.

How will my feedback be used?

Member Reflections
Feedback will support Natasha to ensure that the findings of the study make sense and are felt to contribute towards a better understanding of young people's experiences of functional tics. Their anonymous feedback will be discussed with the research team. This is to foster reflections on whether any amendments may be required.

University of Hertfordshire UH

Please note that due to time constraints, it will not be possible to implement any major changes to the results. The summary points of the feedback received will be included in the final write-up for the study.

Dissemination
Your child's suggestions may shape what materials are created, what they contain, and how they are shared. They can also choose only to give feedback on materials Natasha will have developed.

Will my child remain anonymous?
Yes, your child will not be identified any shared outputs. All identifying information will be removed from feedback, and any quotes used will be attributed to their pseudonym.

All responses will be stored confidentially on University of Hertfordshire's encrypted OneDrive system until the completion of the project (October 2025), in accordance with the University of Hertfordshire Ethics and Research integrity policy.

This study has been reviewed and approved by the University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority, under the protocol 0247 2025 May HSET.

If you would like further information or would like to discuss any details personally, please get in touch by email:

Lead Researcher:
Natasha Oates
Trainee Clinical Psychologist
Doctorate in Clinical Psychology
University of Hertfordshire
E-Mail: ns22ach@herts.ac.uk

Principal Supervisor:
Dr Amanda Ludlow
Head of Psychology and NeuroDiversity Applied Research Unit
University of Hertfordshire
E-Mail: a.ludlow@herts.ac.uk

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar
University of Hertfordshire
College Lane
Hatfield
Herts
AL10 9AB

Thank you for taking the time to support this research!

Appendix V: 16 & Above Member Reflections Consent Form

UNIVERSITY OF HERTFORDSHIRE
ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS
('ETHICS COMMITTEE')

FORM EC3
CONSENT FORM FOR STUDIES INVOLVING HUMAN PARTICIPANTS

I, the undersigned *[please give your name here, in BLOCK CAPITALS]*

……..…
of *[please give contact details here, such as a phone number or email address]*

……
hereby freely agree to take part in the study entitled

Functional Tics: Towards an understanding of young people's experiences

UH Protocol number **0247 2025 May HSET**

1 I confirm that I have read an understood the invitation to take part in Member Reflections and Dissemination Feedback.

2 I have been assured that I may withdraw from these activities at any time without disadvantage to myself, or having to give a reason.

3 I understand that my original interview data will still be used in the final study, even if I do not take part in Member Reflections or Dissemination.

4 I agree to the lead researcher contacting me about these activities, and that my communication with her may take place over e-mail, video call, or my preferred format.

5 I understand that the lead researcher may use their discretion to utilise and incorporate the feedback I provide through either of these activities.

6 I understand that my anonymised feedback will be stored securely until this project concludes on October 1st, 2025.

Please tick:

☐ I agree to take part in **Member Reflections**.
☐ I agree to take part in **Dissemination consultation**.

Signature of participant……..…Date……

Appendix W: 16 & Below Member Reflections Consent Form

UNIVERSITY OF HERTFORDSHIRE
ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS ('ETHICS COMMITTEE')

FORM EC3
CONSENT FORM FOR STUDIES INVOLVING HUMAN PARTICIPANTS

I, the undersigned *[please give your name here, in BLOCK CAPITALS]*

……..…
of *[please give contact details here, such as a phone number or email address]*

……
hereby freely agree to take part in the study entitled

Functional Tics: Towards an understanding of young people's experiences

UH Protocol number **0247 2025 May HSET**

1 I confirm that I have read an understood the invitation to take part in Member Reflections and Dissemination Feedback.

2 I understand that I don't have to take part in these activities, and I can stop anytime I wish.

3 I understand that my interview data will still be used, even I don't take part in these additional activities.

4 I agree to the lead researcher contacting my parent about these activities, and that my parent will then help me speak to them through e-mail or video call.

5 I understand that the lead researcher will decide whether and how to use my feedback.

6 I understand that my anonymised feedback will be stored securely until this project ends on October 1st, 2025.

Please tick:

☐ I agree to take part in **Member Reflections**.
☐ I agree to take part in **Dissemination consultation**.

Signature of participant……..…Date……

Appendix X: Parent Member Reflections Consent Form

UNIVERSITY OF HERTFORDSHIRE
ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS
('ETHICS COMMITTEE')

FORM EC4
CONSENT FORM FOR STUDIES INVOLVING HUMAN PARTICIPANTS
FOR USE WHERE THE PROPOSED PARTICIPANTS ARE MINORS, OR ARE OTHERWISE UNABLE TO GIVE INFORMED CONSENT ON THEIR OWN BEHALF

I, the undersigned *[please give your name here, in BLOCK CAPITALS]*

.....
of *[please give contact details here, sufficient to enable the investigator to get in touch with you, such as a phone number or email address]*

.....
hereby freely give approval for *[please give name of participant here, in BLOCK CAPITALS]*

.....
to take part in the study entitled

Functional Tics: Towards an understanding of young people's experiences

UH Protocol number **0247 2025 May HSET**

1 I confirm that I have read an understood the invitation for my child to take part in Member Reflections and Dissemination Feedback.

2 I have been assured that my child's participation is voluntary and they can withdraw at any time without penalty.

3 I understand that their original interview data will still be used in the final study, even if they do not take part in Member Reflections or Dissemination.

4 I agree to the lead researcher contacting me about these activities, and that subsequent communication with my child may take place over e-mail, video call, or other preferred format, as facilitated by myself.

5 I understand that the lead researcher may use their discretion to utilise and incorporate the feedback that is provided through either of these activities.

6 I understand that these activities involve gathering my child's feedback and not my own.

7 I understand that my child's anonymised feedback will be stored securely until this project concludes on October 1st, 2025.

Please tick:

☐ I agree for my child to take part in **Member Reflections**.
☐ I agree for my child to take part in **Dissemination consultation**.

Signature of person giving consent

…….. Date……

Relationship to participant

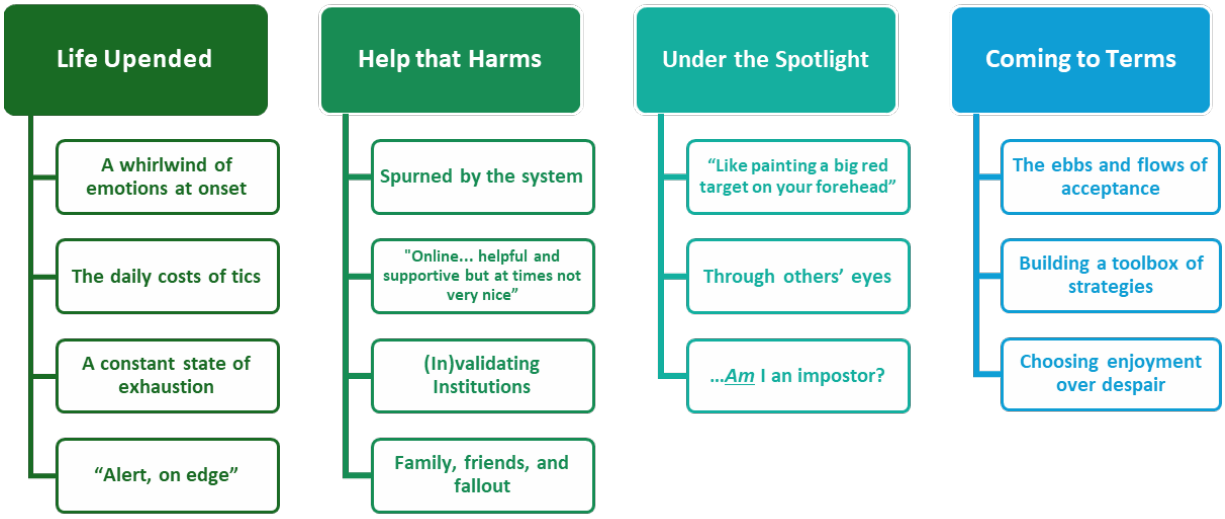
.....

Form EC4 – 1 August 2019

Appendix Y: Consolidated Results for Member Reflections

Theme and Sub-theme Summaries

A graphic of all themes – I welcome suggestions for more creative representations ☺



THEME 1: LIFE UPENDED

This theme explores the profound impact of functional tics (FTs) on participants' lives, especially in the early stages. It reflects the emotional upheaval that accompanied the sudden onset of tics, the everyday challenges of living with them, and the emotional and physical fatigue that developed over time. Across all stories, there was a sense of disruption, not just to routines, but to identity, independence, and peace of mind.

Subtheme: A Whirlwind of Emotions

For many young people (YPs), the onset of functional tics came out of nowhere, and with it, a cascade of overwhelming feelings. YPs described feeling confused, frightened, frustrated, and embarrassed, The sudden loss of control over their own bodies led to deep emotional distress, especially in the absence of a clear explanation.

> *"I just started, like, hitting myself in the face. And I couldn't stop. Like, why couldn't I make myself stop? So…scary, uncomfortable. Like, just not very nice feelings."* (Cleo)

> *"Mainly I was just kind of confused…I wanted answers about what was happening… because no one really knew."* (Juliette)

This confusion often deepened into fear. Some tried to research what was happening, only to be confronted by alarming possibilities online, which added to their anxiety.

> *"There are lots of like scary things that when you Google tics are like, oh, it could be this… I worried so much about so many different things. I thought I've got brain tumour... a neurodegenerative disorder.... schizophrenia."* (Sasha)

In many ways, the onset of FTs felt sudden and very destabilising. YPs expressed that their onset raised existential questions, about their future, their friendships, and whether they would ever feel "normal" again.

> *"It was taking so long to go away, and I was like…am I just gonna have this forever? Like have I developed like a permanent tic? Because this is really annoying and hurting my neck…"* (Kit)

> *"[Tics] definitely have a big impact on your life and your confidence… at the time when I walked into that first doctor's appointment I was thinking, how am I ever going to do anything again? How am I going to… see my friends?"* (Sasha)

Subtheme: The Daily Costs of Tics

After the initial emotional shock, participants had to learn how to live with their tics often through slow, difficult, trial and error. Though not always constant or debilitating, tics disrupted everyday life in both subtle and major ways. They made even familiar tasks feel difficult and frustrating.

> "*I was eating my lunch… and I started ticcing and I tried to throw my cheese across the room…like, I just want to be able to feed myself. A lot of the time, I can't hold cutlery, and my parents have to feed me sometimes…I just want my independence…"* (Norah)

Simple actions like eating, walking, or holding objects became unpredictable. The loss of autonomy, especially during the important period of adolescence, was especially painful.

> *"I think when my legs locked, that was probably one of the worst [tics]… because I just wanted independence… It was quite awkward because, if I wanted to go anywhere or like… move around the house…. I needed some help again."* (Brooke)

Some participants also described the emotional toll of being constantly 'on guard' around family, friends, and in public. Even small adjustments like using plastic plates, avoiding sharp objects, and rearranging furniture, became part of daily life. These changes often carried a sense of resignation or loss.

> *You know, you typically think of tics as like...movements from time to time. But it's so much more than that. It impacts so much of your life… like you're at risk when you're cooking. You're at risk if you're holding a knife. If you're holding something with just a bit of weight, it's going to hurt when you drop it… You've got the fact that you might accidentally hit someone if you're in a crowd. It just impacts so many more areas of your life than you think."* (Paige)

Subtheme: A Constant State of Exhaustion

Living with tics was described as both physically and emotionally exhausting. Most YPs spoke about the toll it took on their bodies. This exhaustion wasn't just a result of ticcing, but also of suppressing tics in public and constantly being on the lookout for someone's reactions. Many described a pattern of bottling up energy and stress during the day, only to release it all once they got home.

> *"When I come home from school… the more tired I get, the worse they get….So after a busy day or a late night…. or if I'm stressed about something, I'll be extra ticcy..."* (Juliette)

For others, the sheer mental load of trying to suppress or control tics made them worse. Suppression created a vicious cycle: the more effort they put into stopping tics, the more overwhelming they became.

> *"I become like, really aware of them and then it's just this horrible cycle. …I find that the more I try to suppress them, the more it like bubbles up and comes out a lot more aggressively."* (Riley)

The fatigue, both physical and psychological, built up over time, making it harder to cope and harder to participate in everyday life.

> *"You just wish that it could stop. You just wish that you could relax and have some time to yourself… you know when you're just sitting and trying to enjoy your food or watch a show and you're just ticcing and shouting or hitting yourself in the head and it just… you just want to break from it all…"* (Avery)

Subtheme: "Alert, On Edge"

While tics didn't always stop YPs from going out and about, they changed how safe and comfortable they felt in public. Many described becoming super aware of how their tics might look or sound to others, which led to anxiety, avoidance, or self-monitoring. In fact, the discomfort of being out in public seemed to come from the YPs' worries of how others might be affected, rather than their impact on them.

> *"If it's crowded, because there is more chance of me hitting someone or scaring them with a very loud noise, that makes me a lot more aware. More alert, on edge type of thing."* (Paige)

Participants didn't want to be seen as disruptive, dangerous, or rude, even though their tics were outside their control. Silent places like libraries or cinemas, or situations where strangers might be affected, felt especially risky.

> *"I started to avoid spaces where quietness was expected. You know, library, cinema… because I didn't want to mess up anybody else's experience of those spaces."* (Simon)

> *"I've definitely had the feeling of, 'oh God, I don't wanna go here', especially if it's a silent place where… everyone would just stare at me…. And also sometimes, if the hitting ones are quite bad, I'm like, what if I go into a crowded place and then I smack someone and I have to explain, 'It's actually just a tic', but they think I've just, like, hit them. It's worrying."* (Cleo)

Some young people found that having a friend with them made a big difference and offered some relief, because it was someone whose presence signalled to others that their tics were not something to worry about. Others used things like Sunflower Lanyards to communicate their disability and reduce misunderstandings.

> *"If I'm by myself, I'll be a little bit self-conscious…whereas, when I'm with a friend, and that person is clearly not bothered by the fact that I'm ticcing, that signals to the rest of the public that everything is fine."* (Kit)

> *"[The lanyard] makes me feel like I'm allowed to be disabled in public because I've definitely had people very rudely staring at me. And I guess knowing that I have almost like an armour…I've got something informing them that I'm disabled. And at that point, if they're continuing to make comments or stare, then they're the ones in the wrong."* (Avery)

THEME 2: HELP THAT HURTS

This theme captures participants' experiences of seeking help, whether from doctors, therapists, schools, or online spaces, and finding that help was not always helpful. Many described feeling dismissed, misunderstood, or even harmed by the very systems meant to support them. Others found moments of validation, often outside traditional pathways, and leaned on peers or digital communities when professionals failed to support them.

Subtheme: Spurned by the system

Many YPs described healthcare encounters that left them feeling frustrated, invalidated, or actively harmed. Most described being passed from one professional to another, without anyone seeming able to take responsibility for their care, or understand what was going on.

> *"With the GP… trying to explain what I was going through…felt like an argument… She was like, 'No, we don't do that. No, we can't deal with that.' [So I thought], alright. Who's actually gonna deal with me then?"* (Brooke)

Dismissiveness from professionals was a common thread. Even well-meaning clinicians often lacked understanding of FTs, or dismissed them outright. Some described actively distressing interactions that suggested not just a lack of knowledge, but a lack of compassion. Being told the tics were "just stress" or "just psychological" felt deeply invalidating to several YPs.

> *"I mean, I literally had one neurologist step over my body as I was unconscious. That's what my mum said he did… He just stepped over me and looked at me in disgust… that's the sort of attitude we get from doctors. Either they take one look at us and go, 'maybe it's FND, bye' which is what happened with my first neurologist. Or, there's people who act really concerned until they go, 'Oh, somebody's diagnosed you with functional stuff,' and then they disgustedly step over us."* (Simon)

> *"It's so frustrating… I've seen this doctor multiple times and then one day I'm [ticcing] uncontrollably, and I say, 'I'm pretty worried'. And he says, 'You're stressed and well, you <u>have</u> been depressed before, <u>did you know</u>?"* (Sasha)

A few described how even when they finally received a functional diagnosis, it was often presented with little support or explanation.

> *"I wasn't left confused, which was nice. But it was very much just, 'Right, based on your presentation, it's functional tics. This is why it's not Tourette's. No, there's no medication. If you go on this part of this website and read, it will tell you more. Have a nice life.'"* (Paige)

Still, in a small number of cases, participants did encounter professionals who made a lasting difference, offering explanations that made sense, or simply treating them with respect.

> *"The CBT I'm having… they used the phrase, 'it's a software rather than a hardware issue', which was helpful: realising that it <u>can</u> change made me believe that it <u>could</u> change."* (Tessa)

> *"[On starting therapeutic work with a supportive therapist] It used to take me a long, long time to be OK with [feeling accused of faking tics]. If I'd had those looks four years ago, I would have had a little cry in a corner. Now it's kind of like, OK...that's something that comes along with having tics. I can't change their perspective any quicker. I can't control their perspectives of me…"* (Riley)

Subtheme: "Online… helpful and supportive, but at times not very nice"

In the absence of useful medical support, many participants turned to the social media and online communities. Online spaces like Reddit, TikTok, and Instagram offered something professionals often didn't: lived experience and validation.

> *"Just to see someone else that has the same thing as me, like the same symptoms and stuff… It makes me feel happy."* (Juliette)

> *"You end up turning to online support… you know, support by people with these disorders for people with these disorders…and you can feel seen and you can feel heard. And people like to put those resources down by saying that you shouldn't be discussing these things with people who aren't professionals, but if professionals aren't willing to discuss it with you…Where else are you supposed to turn?"* (Avery)

That said, online spaces weren't always safe and helpful. Several participants described seeing content that made them feel worse, particularly when it was somebody clearly faking tics, or when others accused them of faking.

> *"Social media is… helpful and supportive, but at times not very nice." (Cleo)*

Most YPs acknowledged that seeing tic content online often made their own tics worse. However, participants also acknowledged that, in the absence of other forms of information or support, making their tics worse was a worthwhile price to pay for helpful resources and information.

> *With the chat groups, even if I do tic when I talk about it, it's for a good reason: I'm getting information... Yeah, it makes them happen more when I'm talking about them. But as I said, when I was quite unconfident, I was looking on FND Hope and some of their ambassadors… are ticcing, and it's like, yes, that provoked my tics, but then it [also showed me that it's] OK to tic."* (Brooke)

Most reflected that with time, they became selective in how they used online spaces for tics support and learned to protect themselves from the challenges that sometimes came with it.

Subtheme: (In)validating institutions

Beyond healthcare, schools, colleges, and workplaces also shaped YPs' experiences of their tics. For some, support was present and made a huge difference. For others, support was absent, or worse, institutions actively excluded or pathologised them.

> *"…We tried to approach the school, and they were just quite awkward saying they don't have the 'facilities'… we were trying to tell them what was happening and they just were either not understanding or just not willing to understand. I was… according to them, a health and safety risk."* (Brooke)

Others encountered support that was thoughtful and empowering.

> *"They absolutely love [the tics], and they've been so supportive of my disabilities. To be honest, I couldn't ask for them to do anything more, which compared to my last job, is such a breath of fresh air."* (Norah)

> *"When I started there, I was like, very nervous about disappointment with the inclusion team… The [needs assessment] call was supposed to be a half hour, but it was an hour and a half because we just yapped… It just put me at ease about the whole thing… it felt very led by what I wanted and needed."* (Kit)

Some participants had teachers or staff who quietly adjusted expectations, stood up for them, or made practical changes that helped. From YPs descriptions, it seemed that having a supportive someone in their work or education setting was luck of the draw and highly variable on individual circumstances.

Subtheme: Family, friends, and fallout

Where professionals fell short, YPs frequently relied on their families and friends for support. Some described relatives who accepted their tics without judgement, helped in practical ways, or simply didn't make a fuss.

> *"I don't know where I'd be without [parent + step-parent]… They don't make a big deal of it. One time, we were having dinner, and I… just [spilled water] all over my food… they just cleaned up… they just moved on… Like it's inconvenient, yeah, but they never let me know that it's inconvenient."* (Riley)

Sometimes, the most powerful from a loved one was simply asking, "What can I do?" But not everyone had this kind of support. A few described being left to navigate their experience of functional tics on their own, and the challenges of this experience.

> *"There were a few friends who acted as though nothing had happened and I very much appreciated that. Then there were a few even closer friends who were like 'what can we do'? And I was like, 'I don't know. I don't know what you can do. But it's very nice that you asked.'"* (Isla)

Friendships also shifted. Some friendships ended; others grew stronger. A few participants described a painful "culling process" realising which friends would stick by them, and which wouldn't.

> *I sort of realised… rather than being upset about losing some friends, maybe this is actually a good thing because maybe they were not the right kind of people to be wasting my time on..."* (Isla)

> *"My closest friend of about six years at the time… she just so casually dropped in a sentence, 'when you first had them, I thought you were faking them'…. And it was just completely crazy how she'd have known me all that time and yet she just didn't believe me… it was very…ouch, OK, I see how it is."* (Riley)

THEME 3: UNDER THE SPOTLIGHT

This theme captures what it felt like for participants to suddenly find themselves highly visible. Many described being very private before the onset of tics, and suddenly becoming extremely noticeable. Others spoke about the emotional work of trying to manage others' reactions, the fear of being disbelieved, and the uncomfortable spotlight that came with an unpredictable body.

Subtheme: "Like painting a big red target on your forehead"

Several YPs described themselves as trying to fly "under the radar" prior to the onset of tics. Many said they were used to blending in, avoiding attention, and being in control of how they were perceived. Tics disrupted that invisibility, forcing them under an unwanted spotlight.

> *"High school was pretty hard… because I was just terrified to be perceived at all… It's like, I just hate being known to people, which is weird because I have [distinguishing feature], so you know, how blended in can I get?"* (Riley)

> *"…It was genuinely sort of distressing to be going through at the time because, you know, it's like painting a big red target on your forehead and saying, 'look at me'. I definitely tried my hardest to blend in with everybody else. So to then suddenly not be able to… it was like, whoa, okay, this is even worse than before."* (Isla)

Even in supportive environments, many felt the need to manage the impact of their tics on others. Many of the YPs cared deeply about how their tics affected the people around them.

> *"I'm more worried about distracting them than anything else. I just don't want to impact other peoples' chances on learning and stuff." (Juliette)*

> *"…there is an increased fear of my actions making people uncomfortable, and I'm more aware of that. …I experienced limiting myself based on the fears of how people would react."* (Simon)

Subtheme: Through others' eyes

This subtheme speaks to the powerful and often distressing awareness of how others might judge or misinterpret their tics. Participants often described guessing what people were thinking, wondering whether they were being judged, or adjusting their behaviour to avoid stares, questions, or confrontation.

> *"It's the assumption, based on the fact that I'm visibly ticcing… that I'm mental or slow... like that's what I interpreted. And because [of that], you think it's OK to be rude to me so blatantly."* (Sasha)

> *"I was just acutely aware of everyone around me having, you know, less-than-nice thoughts about me. So then it was, 'Hmm, I need to think about everyone, and I need to be acutely aware of everything that everyone thinks, because I need to be normal and non-annoying and I need to not make anybody's day worse…'"* (Isla)

There was also a sense that people now saw their tics before they saw the rest of them. The shift from being seen as a full person to being defined by a condition was painful. To cope, many participants prepared explanations in order to get ahead of questions or reactions.

> *"Whenever I went out to like social events, I would be very aware that it would come up and I'd have a little explanation in mind…. I didn't want to make a big deal of it. It was just… something that I had, something that was part of me. I didn't want it to just be me."* (Paige)

Subtheme: …Am I an impostor?

One of the most emotionally charged aspects of being 'under the spotlight' was the fear of not being believed. Several participants described being accused of faking their tics and how these accusations cut deeply, leading to painful self-doubt.

> *"It was weird because I was quite unpopular at school as well, and then suddenly people would remember my name…So that was that was the hardest part, that people remembered me because of the functional tics and not because of me."* (Tessa)

> *"And then some people… including teachers as well… assumed that I was faking it for attention. And it was difficult to explain like, 'No, I know that this is not fake', but I've never known: how do I explain something I don't understand?"* (Tessa)

> *"There's a lot of people that look down on teenagers as a whole, especially if they're on TikTok and stuff like that, and it very much came across in the way of 'look at what these stupid teenagers are doing now' and it's like, no, hang on, this is a real thing, it has real effects!"* (Paige)

Paradoxically, some YPs said that the times they felt most out of control were also the moments that helped them realise it wasn't fake because of the 'nonsensicalness' of the idea that they would deliberately choose to fake their tics:

> *"And that's something that I think a lot of people…need to come to terms with is: if you could control [the tics], you would. I cannot emphasise enough how important that is because every single person that I've interacted with anything similar to this, has needed…to be reaffirmed and reassured. I'll even do trials with the people and be like, 'Okay if it's within your control, control it right now'. And they won't be able to and I'll say, 'So why aren't you controlling it right now?' And they're like, 'Well, because I can't!' And I'll sort of give them the look like, you know… you know what I'm getting at here. And they'll sort of do a frustrated sigh and go, 'okay, maybe that does make sense. Maybe you are onto something here.'"* (Avery)

THEME 4: COMING TO TERMS

This theme explores how some YPs moved (backwards and forwards) toward acceptance of their tics and how they began to adjust emotionally, practically, and socially. For many, coming to terms with their tics is not a linear process. It comes in ebbs and flows, and often sits alongside frustration, grief, or ambivalence. What helps varies amongst YPs; for some it's time, for others, explanation, peer support, humour, or becoming able to give themselves permission to stop fighting the tics.

Subtheme: The ebbs and flows of acceptance

YPs were clear that "acceptance" didn't mean being okay with having FTs all the time. Rather, it was a fluctuating process, rising and falling depending on energy levels, symptoms, environment, and how others responded.

> *"You sort of go through phases, like mini cycles, where one day you'll be very negative about it and the next day you'll be back to sort of normal, accepting. And it's just taught me that sometimes you just need to wait those feelings out."* (Avery)

Some said that time going by was a necessary component. Others found that having a formal diagnosis or explanation gave them a new way of understanding what was happening, and some said that realising that they didn't have control of their tics also facilitated some element of acceptance.

> *"Ironically, it's the moments of least control that make me feel most certain. The worse it is and the harder I'm fighting against myself, the more I'm like, 'oh, OK, that isn't me'. Because if it was me, I would just stop."* (Simon)

> *"I knew I wasn't going crazy eventually. It…helped seeing an actual medical professional and them going 'this is what's going on'… and that this wasn't just something… in my head I've just made up."* (Isla)

But time and understanding weren't always enough. For some, it was letting go of the idea of "fixing" themselves that was helpful. Likewise, some YPs felt relief when they stopped trying to stop their tics.

> *"I'd say is the sooner you accept that this might be the rest of your life… That's going to make it easier on you. The more time you spend trying to cure yourself and get back to your old body, the worse it's going to get..."* (Norah)

> *"I think part of the tics was that they were quite vocal... you know, the thing that you would not say in a situation... I would think 'I'm going to get quite a lot of backlash', but I didn't… so I was just [able to feel] lot more relaxed about stopping the tics...So then the tics lessened because I was freer."* (Tessa)

Subtheme: Building a toolbox of strategies

Across interviews, many YPs described how they had developed a 'toolbox' of coping strategies over time to manage their tics and to navigate life with them. These included practical adjustments, mindset shifts, and small acts of self-protection.

> *"I think it's mostly just a bunch of little things added up. You know, little things you do throughout your day to make it a bit easier, a bit safer. There's no big singular coping mechanism that has a huge difference. It's just a bunch of little differences."* (Paige)

Humour was a particularly valuable part of the toolbox, with many saying that finding opportunities to laugh about their tics added much needed comic relief.

> *"…I started to lean more into acceptance again… I might as well just have a laugh… just giggle when [the tics] happen and just try and stay confident."* (Avery)

Rest and self-care came up frequently, and even that the tics highlighted how some YPs to be more attuned to their wellbeing, and when they needed to rest. Several said they hadn't realised how little they were caring for themselves until they were forced to.

> *"Most of the things that I've learned about myself are just in regard to my self-care. I didn't realise how little I prioritised my own welfare until [the tics] started, and… that like, if I don't take care of myself, I will suffer real physical consequences."* (Kit)

Others mentioned distraction, mindfulness, and reframing their thinking. Some found this advice online, other from helpful mental health practitioners.

> *"I just kind of I try and distract myself… I might put on a film or something and like, just do something I like to do… I'll just be kind to myself."* (Cleo)

Subtheme: Choosing enjoyment over despair

Throughout their interviews, YPs were unambiguous: if they could make FTs go away, they would. Yet amidst the frustration, YPs also spoke of their resolve to not let the FTs take away their enjoyment and purpose in life:

> *"I tic and it's that's OK… it makes for a good joke every now and then, you know? So, as much as it's not a good thing to have tics, you can make light of it."* (Paige)

> *"It's hard, because if I could choose not to have them, I would…And I feel as though basically everyone who I know with tics would choose that. But at the same time, it is still possible to be able to laugh about it…if you're not laughing about it…what a miserable life, you know?"* (Avery)

Many described coming to a decision that their tics shouldn't stop them from living their life to the best of their ability. Such acts mark neither a rejection of the reality of life with FTs, nor succumbing to their symptoms. Rather, they demonstrate a resilience and dedication to continue to live, move, and find peace even while FTs persist:

> *"If you let the tics and anything else going on limit you and what you do, and you just sit around doubting yourself and doing nothing with your life, you will feel so much worse. …Even if you just like go on a little walk; if you don't feel like it, you can sit in the sun for a bit. …Actually do stuff. Don't think about doing stuff, just do it."* (Simon)

None of these shifts happened overnight. Many said they still struggled regularly, but many also chose to actively take steps towards coming to terms with their FTs.

> *"Most of the time we just laugh at them because you've got to haven't ya? 'Cause if I don't laugh again, I'm wallowing in that hole of my own self-pity. And you know… I don't want to spend the rest of my life in that hole."* (Norah)

Appendix Z: Member Reflection Responses

SIMON

I'm unsure if I'll have time to do a detailed response without it taking forever so I'll just give a short bit of feedback!

Overall I think it really accurately captures the experiences, and I was surprised by just how much of other's experience with functional tics fit into my experience considering the differences on the FND side of things.
I'd say the structure works quite well, following along chronologically definitely helps readers to understand the whole process of coming to terms with it and the first symptoms/diagnosis -> acceptance pathway for us.

Completely random suggestion for the sub theme colouring - maybe it would be a little easier to navigate quickly based on colour (treating the initial graphic as an index of sorts) if the in-text colours matched those of the graphic.
Experimentally the subtheme could have a main heading colour and then different shades of said colour for the subheadings. This might make it look too busy, though.

Sort of like this although the email text colours are limited. I'm happy to make a mockup graphic if you want.

Life Upended:
-> A whirlwind of emotions at onset
-> The daily cost of tics
-> A constant state of exhaustion
-> "Alert, on edge"

CLEO

I'm so sorry I completely forgot about this I've been busy! I've read the results and I really love the way you've laid it out with the short segments of information and findings supported by a quote or two. It makes it very easy to read and informative with clear comparisons. I don't have any suggestions for improvements! It was a fascinating read, thank you very much for letting me take part.

KIT

Here's some thoughts I had, I hope they're useful. Sorry again for how late I am with this!

I love the themes, I think they all fit incredibly well.

The Constant state of exhaustion sub theme I think is especially important, I don't think many people realise just how physically tiring it is to deal with.

Spurned by the system I also resonated with a lot (unfortunately, as expected), despite the fact that I've had somewhat more luck than others with it. The testimonials in this sub theme are really impactful, especially Sasha's. So often functional disorders are just labeled as depression/anxiety symptoms, as if it's as easy as taking a couple days to relax and recharge to fix it. Also, Paige seems to have had The Website treatment too - sooooo great that this is the standard :/

The culling process mention is very real!

The Am I an impostor theme is also a really big one for me - I haven't met a single person with a functional disorder who hasn't battled with this, and even after being told by a neurologist that I'm not faking it, I still can't quite shake the worry that I am.

Similar to above - I agree completely with Simon in The ebbs and flows of acceptance, the moments of least control are the most reassuring, because that's when I know what I'm experiencing is real and not something I'm secretly faking.

Overall, I love the way you've structured this and I think it paints a really thorough picture of the experience of living with tics. Thank you for doing this work!!