

Looking to the future of Tourette Syndrome research

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Abstract

Tourette Syndrome (TS) research and public discourse remain shaped by **binary framings that can produce epistemic and political polarisation**, including the policing of authenticity, behavioural interpretations of tics, and an over-reliance on cure-oriented narratives. While biomedical and clinical research remains vital, there is **growing need for critical, interdisciplinary approaches that foreground tourettic lived experience and attend to the social, cultural, political, and historical contexts in which TS is studied and understood**.

Building on this emerging field, we facilitated an online roundtable 'Towards Tourettic Studies' at Durham University's Institute for Medical Humanities in November 2025. The event brought together TS researchers, many with tourettic lived experience, to consider the future of TS research beyond disciplinary silos. From this discussion, we propose *Tourettic Studies* as an interdisciplinary field that actively centres tourettic people, examines TS as a lived, cultural, political, and embodied phenomenon, and supports more creative, critical, and community-led approaches to research. **This poster outlines three key themes from our emerging research agenda.**

Linguistics and Non-Standard Language in Tourette Syndrome Discourse

Many researchers use 'behavioural' to refer to volitional action, but **lay understandings of the world 'behavioural' imply an element of choice**, and contribute to the stigmatisation of the TS community. This can be used to discredit tourettic experiences; it may directly **contribute to feelings of unbelonging and minimise the already-limited access to support in treatment spaces, workplaces, or schools**¹.

It is key to acknowledge non-standard ways of writing about TS in digital spaces. **Platforms such as TikTok are known to 'shadow ban' based on specific key terms used** in produced content, and so **users bypass these algorithmic blocks by writing about TS with words such as 'TOurettes' and 'tics'**². Considering this in our research on digital experiences of TS increases the accessibility of the tourettic community's opportunity to contribute to knowledge creation. **Scientific and clinical vocabularies need to be expanded for more nuanced approaches.**

A *Tourettic Studies* would require the acknowledgement of researcher responsibility for the implications of language used when writing about and researching TS. This includes in clinical, research, and public settings.

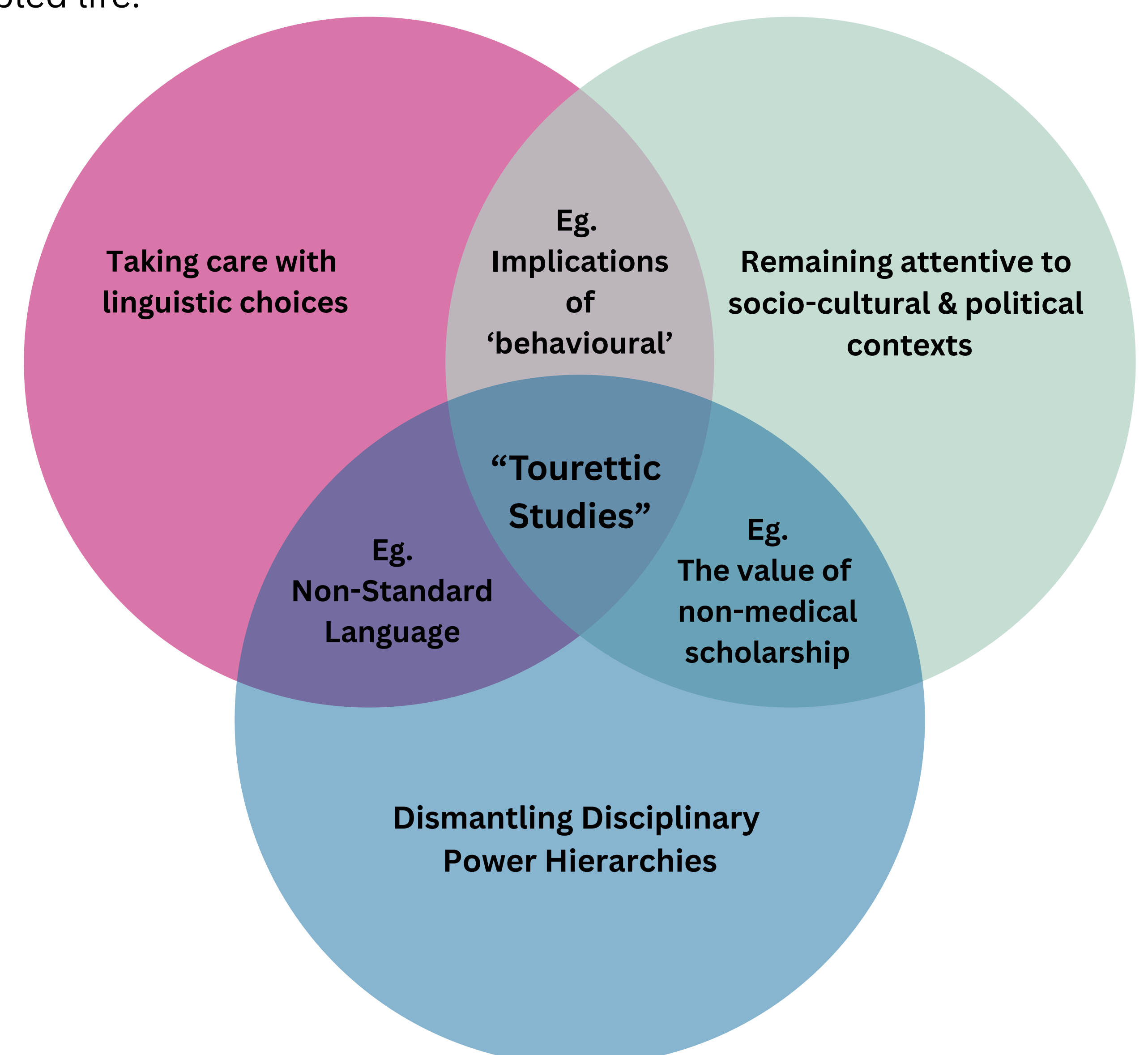
Socio-Cultural & Political Contexts: Intersectionality

Tourettic Studies attends to the **social, cultural, and political contexts in which tics are lived, interpreted, and responded to**. Tics are **never only bodily events**; their meanings shift across environments, institutions, and power relations. A tic involving words such as 'I have a gun', for example, may carry very different risks depending on national context, policing cultures, and the racialised or classed position of the person ticcing³. **TS is also increasingly politicised, including through public discourse that frames neurodevelopmental disability as suspicious, newly invented, or socially contagious**. This has material consequences for tourettic people, particularly those who are multiply marginalised. **Young people may face accusations of 'faking' or being influenced by 'TikTok tics,' while women and girls are often more likely to have their tics dismissed as behavioural**^{4,5}. *Tourettic Studies* therefore requires an intersectional approach that avoids homogenising tourettic experience and instead asks how gender, sexuality, race, class, age, disability, and geography shape distinct tourettic lives. Rather than assuming a single tourettic culture, this theme foregrounds **tourettic cultures as plural, situated, and politically contested**.

Dismantling Disciplinary Power Hierarchies

Tourettic Studies requires genuinely interdisciplinary approaches that value medical, social scientific, arts, humanities, and lived experience perspectives equally. **Current TS research remains shaped by disciplinary hierarchies, with clinical and biomedical approaches often given greater authority than arts, humanities, and social science scholarship**. We argue that these **hierarchies must be actively questioned**, while also recognising that no single discipline can fully account for TS or tourettic experience. Arts, humanities, and social science approaches offer vital conceptual, cultural, political, and methodological insights, just as biomedical research contributes important clinical knowledge.

Critical Autism Studies offers a useful model, demonstrating how neuroaffirming, interdisciplinary work can reshape services, reduce stigma, and centre those most affected⁶. Similarly *Tourettic Studies* offers a framework for radically interdisciplinary TS research that supports community wellbeing, challenges cure- and normalisation-focused narratives, and generates new understandings about embodiment and disabled life.



Conclusions

We argue for a future of TS research that moves beyond 'syndrome' alone and centres tourettic people in context. This requires greater attention to language, interdisciplinarity beyond the medical sciences, and the cultural, social, and political forces that shape TS discourse. **The three themes outlined here offer an initial framework for collaboration across medical science, social science, humanities, arts, and lived experience communities**. Such work has the potential to improve tourettic community wellbeing, increase social nuance, and reduce stigma across academic, clinical, charitable, and advocacy spaces. **Rather than simply including tourettic people within existing TS scholarship, a *Tourettic Studies* approach asks how research might be reoriented through tourettic cultures, politics, experiences, and ways of knowing**. We therefore invite response, critique, and collaboration as part of an emerging conversation about the future of TS research and *Tourettic Studies*.

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