

# Development and Evaluation of the Tourettes Action Adult Lived Experience Advisory Panel: Insights into Its Formation, Impact, and Functioning



## Authors and Affiliations

Ione Georgakis<sup>1,2</sup>, Edward Palmer<sup>1</sup>, Emma McNally<sup>1</sup>, Amanda Marples<sup>1</sup>, Samuel Sutcliffe<sup>1</sup>, Paul Stevenson<sup>1</sup>, Charlotte McGregor<sup>1</sup>, Danni Phoenix-Kane<sup>1</sup>

<sup>1</sup> Tourettes Action, <sup>2</sup> Livewell Southwest NHS Trust

## INTRODUCTION

The involvement of individuals with lived experience in shaping healthcare, research, and charitable initiatives is increasingly recognised for its potential to enhance service relevance, quality, and impact. Lived Experience Advisory Panels (LEAPs) offer a structured platform for these individuals to share their perspectives, ensuring that services genuinely reflect the priorities of those directly affected.

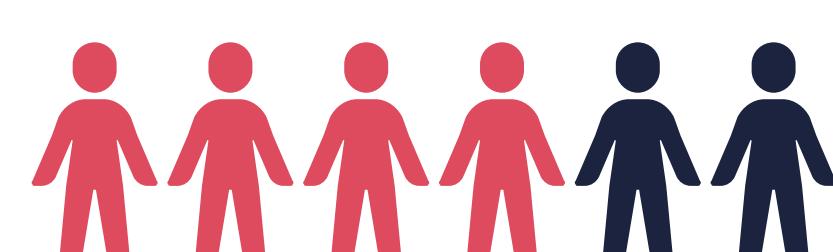
## BACKGROUND

In 2023 UK charity Tourette's Action (TA) launched its Tourette syndrome (TS) Champions Programme which brings together young people living with TS to raise awareness in their local communities. This poster describes the development and implementation of TA's Adult TS LEAP, created to support the evolution of TA by amplifying the voices of those with lived experience across the lifespan. The LEAP was developed in 2023 and is chaired by TA's Therapies and Advocacy Manager, an Occupational Therapist with lived experience of TS.

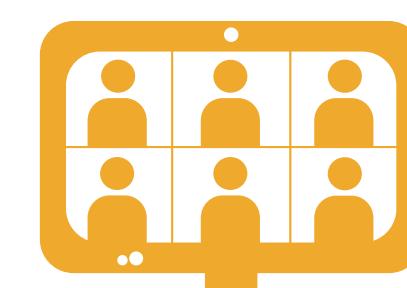
## METHODOLOGY



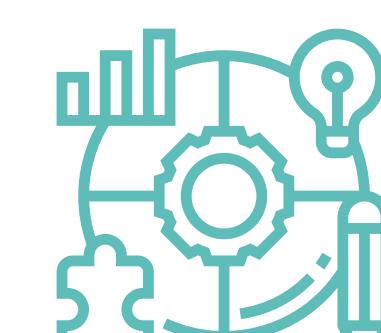
Participants were recruited through a structured application and selection process, prioritising diversity and broad representation.



The panel comprises of six adults (Female 4, Male 2) and one facilitator with personal lived experience of TS.



Members participate in four facilitated online meetings per year and one in-person session at the TA adult support weekend.



Mixed-methods approach, data collected from meeting minutes and LEAP survey feedback analysed using thematic analysis.



Member checking the final abstract was completed with all LEAP members.

## RESULTS ANALYSIS

Participant Priorities	Benefits of Engagement	Barriers to Engagement	Accessibility in design
<ul style="list-style-type: none"><li>Need for increased adult specific support services</li><li>Employment challenges</li><li>Safety during activities of daily living</li><li>The impact and value of assistance dogs</li><li>Barriers faced when applying for benefits</li></ul>	<ul style="list-style-type: none"><li>Positively contributing to the TS community</li><li>Opportunities for peer collaboration</li><li>Development of transferable professional skills</li><li>Explaining lived experiences</li><li>Guiding TA</li><li>Learning more about TS</li><li>Collaborating with others</li></ul>	<ul style="list-style-type: none"><li>Limited availability for online meetings among employed members</li><li>A desire for more frequent meetings</li><li>Health and family commitments</li><li>Minimal. 100% of members want to continue their membership</li></ul>	<ul style="list-style-type: none"><li>Email reminders sent a week before meetings</li><li>Optional WhatsApp group for social connection</li><li>LEAP members can pre submit topics via email, text, or voice note</li><li>Participants are pre informed of themes/topics</li><li>Resources for evaluation are provided at least one month in advance</li><li>Microphone/camera optional</li><li>Participants encouraged to tic freely during sessions</li><li>Participants are asked to attend a minimum of 50% of meetings per year</li></ul>
Charity Priorities	Facilitators to Engagement	Opportunities	CONCLUSION
<ul style="list-style-type: none"><li>Feedback on the TS-friendly business, employer and organisation training scheme</li><li>Feedback on live support events</li><li>Critique of existing support resources</li><li>Exploration of employment needs and effective reasonable adjustments</li></ul>	<ul style="list-style-type: none"><li>Online format</li><li>Relaxed and informal atmosphere</li><li>Feeling safe to share opinions authentically without judgement</li><li>Flexible topics</li><li>Opportunities to pre submit topics for conversation</li><li>Facilitators lived experience of TS</li><li>Facilitators healthcare background</li></ul>	<ul style="list-style-type: none"><li>One additional face-to-face meeting per year</li><li>One evening meeting for employed members per year</li><li>Guest Researchers/Speakers</li><li>Recruitment of TA youth champion graduates</li><li>Lived experience feedback for campaigns, research, resources, training content and more</li></ul>	<p>The establishment of the LEAP demonstrates the importance of integrating lived experience into charitable initiatives. The LEAP offers TA actionable feedback and recommendations to help us better meet the needs of service users across the lifespan, enhance new and existing support resources, and gather input on awareness campaigns and research priorities. The LEAP provides a structure to emulate in research offering representation of the community's needs and priorities by amplifying the voices of adults with TS. Plans for the LEAP involve recruiting two new members, graduates from our junior TS Champions programme and engaging with researchers and other LEAP's.</p>