



Background

As people living with the condition, family members, providers, and researchers, we know Tourette Syndrome and Tic Disorders and (TDs) are complex conditions. Effective treatment must be thoughtful, individualized, and comprehensive.

In the last 20 years, the TDs community has come together to develop, test, and spread the word about Comprehensive Behavioral Intervention for Tics (CBIT). CBIT is an eight-session, skills-based treatment in which a patient works with a therapist to learn skills that can help reduce the severity of that person's tics, and to reduce tic-related challenges they are experiencing in their lives.

Large research studies have shown CBIT to be safe and effective for reducing tics in both children and adults (read more about CBIT [here](#)). Given CBIT's effectiveness, the American Academy of Neurology's recent Treatment Guidelines named CBIT as the recommended first-line treatment for TDs. These experts recommend that most people with TDs who want treatment for their tics should start with CBIT, rather than with medication (read more [here](#)).

We know that CBIT is not the only tool in the toolkit for living with TDs. We are aware that there are other important issues for researchers and providers to address (for example, improving the accuracy and speed of diagnosis, continuing to study the genetics and/or biology of TDs, and managing other "comorbid" conditions that can come along with tics), but the purpose of this effort was to focus on improving CBIT.

Now that CBIT has been proven effective, researchers and providers want to conduct the "next generation" of research to improve CBIT and increase its availability. Conducting research is critical for several reasons. It helps ensure that patients receive proven and effective treatments and that clinicians select and offer the best interventions. Research can also reduce health care costs by increasing the impact of services. It can help us to know the most effective methods for sharing effective treatment with others who need it and allow us to improve equality in healthcare access and health outcomes.

Treating Tourette Together Summit

We believe that input from all members of the TDs community is vital for guiding the future of CBIT research. This approach is sometimes called "patient-centered outcomes research". In order to create a plan, we held a two-day Treating Tourette Together (TTT) Summit in Minneapolis, Minnesota in August 2019 for patients, families and caregivers, health care providers, and researchers. First, we got the word out to hundreds of people in the TDs community and collected opinions on CBIT from over 700 respondents in a survey.



Over 100 of these individuals applied to attend the TTT Summit. While we wish we could have invited all applicants to attend, we had to select a smaller group to ensure that we could build community and work flexibly at the Summit.

Ultimately, we brought together a group of 45 individuals for the Summit, with representation from youth and adults with TDs, parents of children with TDs, healthcare providers (including providers from neurology, psychiatry, psychology, pediatrics, occupational therapy, and primary care) and educators who work with people with TDs, TDs researchers, and other stakeholders.

We spent two days getting to know each other, learning from each other's experiences, and sharing thoughts about what is needed to improve the lives of people with TDs. In the second half of this two-day Summit, we worked together to identify key research questions for this next generation of CBIT research. Our aim was to develop focused research questions that:

- 1) have not yet been studied,
- 2) have the potential for high impact,
- 3) are relevant to multiple stakeholders (e.g., patients, families, clinicians, payors), and
- 4) are possible to test scientifically (e.g., the question would lead to an ethical and feasible study with a testable hypothesis and measurable outcomes).

Key Research Areas

After the Summit, we organized this input into 4 Key Research Areas that described the general types of research that attendees felt passionately about.

Domain 1: Increasing Access to CBIT

Domain 2: Increasing CBIT's Effectiveness

Domain 3: Optimizing How CBIT Fits into Individuals' Broader Care for TDs

Domain 4: Investigating CBIT's Impact on Outcomes that Matter to People Living with TDs

You can now read the full research agenda here: <https://psyarxiv.com/kd2cz/>

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