

Parent-Rated Functional Impairment Over Time in Youth with Tic and Other Movement Disorders: A Preliminary Electronic Health Record Study

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Disclosure Slide

- Grant/Research Support – clinical trials (payment to Cincinnati Children’s):
 - Emalex Biosciences (Tourette)
 - PTC Therapeutics (AADC deficiency)
 - Neurocrine Biosciences (dyskinetic cerebral palsy)
 - Quince Therapeutics (Ataxia Telangiectasia)
- Speaker’s Bureau: NA
- Consultant (payment to Dr. Gilbert):
 - Emalex Biosciences (Medical Advisor. Data interpretation, data presentation at medical/scientific meeting (travel support)). Tourette. (ongoing)
 - PTC Therapeutics (data interpretation, data presentation at medical/scientific meeting (travel support)). AADC deficiency (completed); awareness educational video (completed).
 - Noema Pharmaceuticals. Tourette (completed)
 - Illumina Inc, honorarium, education on genetic testing (completed)
 - Vima Therapeutics, Dystonia. (completed)
 - Synendos Therapeutics, Tourette (completed)
- Major Shareholder: NA
- Board of Directors or Employee: NA
- Book Royalties: Wolters Kluwer, Elsevier

Background

- Movement disorders like tics can be rated with scales
- However – the scales only tell part of the story
- Treatment decisions are more often based on impairment
- How do we quantify how impaired the patient is?

Background

- Two patients with the same YGTSS (or other motor scale) ratings might have very different levels of impairment at a point in time
- One patient with the same YGTSS rating at 2 timepoints might have very different levels of impairment at those 2 time points
- Part of the reason may be co-morbidities like anxiety
- Co-morbidities may affect movement-related impairment (as well as causing their own impairment)

**How do we quantify how
impaired the patient is?**

Objective

- Discuss our experience with a tablet-based questionnaire and impairment scale
- Examine the implementation of this scale over time
- *Examine the association of diagnostic category and psychiatric comorbidity on functional impairment over time in youth ages 10 to 17*

2009

Getting to tablets

Mar 05, 2026 Today

GILBERT, DONALD (All Depts)

Filter by Status Showing: 14 of 14

Mar 2026						
Su	Mo	Tu	We	Th	Fr	Sa
22	23	24	25	26	27	28
1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30	31	1	2	3	4

Pager	MRN	Type	Notes	No Show	Provider	FFC S...	FY
	11314237	NEU * NV MDO	Worsening tics, wanting to explore ...		Gilbert, Donald Lawrence, MD	6	
	11948417	NEU * NV MDO	referral to movement disorder clin...		Gilbert, Donald Lawrence, MD	6	
	11116701	NEU * NV MDO	Chronic nonintractable headache, ...		Gilbert, Donald Lawrence, MD	6	
	11765353	NEU * NV MDO	Maysville, Motor tic disorder, ...	No Show	Gilbert, Donald Lawrence, MD		
	11947739	NEU * NV MDO	Resc//Comple x movement disorder, ...		Gilbert, Donald Lawrence, MD	6	
	11993664	NEU * NV MDO	Head banging, mri of brain	No Show	Gilbert, Donald Lawrence, MD		
	100400		Ataxia/balance		Gilbert.		

Dept: CCM NEUR...

Create

- My Schedule
 - GILBERT, DONALD
 - GILBERT, DONALD (A)
 - Resident Clinic
 - Resident Clinic Tuesd
 - Tara I inns

Open Tasks

Challenges

- Time in clinic is short
- I don't have the money for a research assistant
- Research is not always sustainable
- I want something sustainable!
- I want something comprehensive and helpful



Volume 32, Issue 8
September 2007

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Abstract

Introduction

Method

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JOURNAL ARTICLE

A Measure of Functional Impairment in Youth with Tourette's Syndrome

Eric A. Storch, PhD, Caleb W. Lack, PhD, Laura E. Simons, PhD, Wayne K. Goodman, MD, Tanya K. Murphy, MD, Gary R. Geffken, PhD

Journal of Pediatric Psychology, Volume 32, Issue 8, September 2007, Pages 950–959,
<https://doi.org/10.1093/jpepsy/jsm034>

Published: 23 May 2007 [Article history ▾](#)

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Abstract

Objective Tourette's Syndrome (TS) during childhood is linked to varied behavioral and psychological difficulties and functional impairment. The current study was undertaken to examine both tic-related impairment and impairment from other psychological problems in 59 youth (mean age 11.4 years, 69% male) with TS. **Methods** Caretakers completed a checklist about the impact of tics and other psychological difficulties on family, school, and social functioning. In addition, a clinician administered a measure of tic severity to families. **Results** Over half of the sample reported one significant problem area due to the presence of tics, with over a third reporting two or more problem areas. Problems were heterogeneous in nature, with no report of a particular problem area in more than 25% of the children. The rate of nontic-related impairment was very high, with 70% of parents reporting at least one problem area. **Conclusions** Treating both tic and nontic-related impairments concurrently may improve functioning more so than treating the symptoms separately.

Child Tourette's Syndrome Impairment Scale – Parent Report about Child.²

The CTIM-P is a 37-item parent-rated instrument that includes school, home, and social activities that may be impaired by their child's tics or a co-morbid problem (e.g., obsessive-compulsive symptoms, depressed mood, anxiety, oppositional/disruptive behavior, hyperactivity, inattentiveness).



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Research 59 youth,
caregiver report

Different than non-TS?

37*2=74: too time
consuming

Caretaker report – what
about our patients?

Preliminary evaluation of child self-rating using the Child Tourette Syndrome Impairment Scale

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PUBLICATION DATA

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Published online

ABBREVIATIONS

CTIM-P Child Tourette Syndrome
Impairment Scale - Parent

AIM To evaluate and compare how children with Tourette syndrome and parents rate tic and non-tic behavioral related impairment in home, school, and social domains; to compare these with clinician tic ratings; and to identify factors that may predict greater impairment.

METHOD In a sample of 85 Tourette syndrome and 92 healthy control families, the Child Tourette Syndrome Impairment Scale, designed for parent-report and which includes 37 items rated for tic and non-tic impairment, was administered to parents and, with the

Parent and Patient Perceptions of Functional Impairment Due to Tourette Syndrome: Development of a Shortened Version of the Child Tourette Syndrome Impairment Scale

Journal of Child Neurology

2017, Vol. 32(8) 725-730

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Jordan F. Garris, MD¹, Alyssa R. Roeckner, BS¹, Paul S. Horn, PhD¹,
Michael D. Guthrie, BS¹, Steve W. Wu, MD¹, and Donald L. Gilbert, MD, MS, FAAN, FAAP,¹

Abstract

The Child Tourette Syndrome Impairment Scale (CTIM) rates 37 problems in school, social, and home domains separately for tics and for comorbid diagnoses. However, a shorter version would be easier to implement in busy clinics. Using published data from

A step forward

- Now we add a “mini CTIM” to our intake questionnaires!

Implementation of the Mini-Child Tourette Syndrome Impairment Scale: Relationships to Symptom Severity and Treatment Decisions

Journal of Child Neurology
2021, Vol. 36(4) 288-295

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Jordan F. Garris, MD^{1,2,3} , David A. Huddleston, BA¹, Hannah S. Jackson, BA¹, Paul S. Horn, PhD^{1,2}, and Donald L. Gilbert, MD, MS^{1,2} 

Please fill out any specific sections that apply to your child or teenager. This information is extremely helpful in allowing us to provide the best care for your child.

Chief Complaint – Why have you come to see us in clinic?

Describe the movement(s) of greatest concern and tell us what problems these movements are causing:

To the child or teenager: What are the main problems or symptoms that upset or disturb YOU? Tics? Other Movements? Anxiety or mood issues? Attentional or learning problems? Please circle any that are a problem and rank them. For example, put "1" for the top problem, 2 for the second, etc. Please write in any comments.

- Tics
- Other Movements
- Anxiety
- Obsessive/Compulsiveness
- ADHD
- Impulse control problems
- Hyperactivity
- Inattention
- Other (Please describe)

To the parent or guardian: What are the main problems or symptoms that upset or disturb you or others? What are you worried about? Please circle any symptoms below that are a problem for the top problem, 2 for the second, etc. Please write in any comments.

- Tics
- Other Movements
- Anxiety
- Obsessive/Compulsiveness
- ADHD
- Impulse control problems
- Hyperactivity
- Inattention
- Other (Please describe)

History of Present Symptoms – TICS (tics are repetitive movements that look the same or sound the same each time.)

Tic Symptom Checklist: Please check the boxes below indicating if your child has ever had (past) or currently has (this week) any of the following tics, at what age the tics began, and whether your child has any sensations or urge to do this tic?

Motor Tic Checklist				
Past	Current	Age of Onset	Sensation/urge? Yes/no	Motor Tics
				Eye blinking or eye rolling
				Nose, mouth, tongue or facial grimaces (nose twitch, nasal flaring, chewing lip, teeth grinding, sticking out tongue, mouth stretching, lip licking)
				Head jerks or movements (neck stretching, touching chin to shoulder)
				Shoulder jerks/movements (shoulder shrugging, jerking a shoulder)
				Arm or hand movements (flexing or extending arms or fingers)
				Leg, foot or toe movements
				Abdominal/trunk/pelvis movements
				Others:

Vocal Tics:

Age of first vocal tic? _____ years old.

Describe first vocal tic: _____

Was tic onset sudden or gradual? Sudden Gradual

Age of worst vocal tics? _____ years old.

Motor and Vocal Tics:

Are there times when the tics are increased or worse? Circle any that apply: Illnesses, Allergies, Fatigue, Stress, School, Extracurricular activities, Other. Please explain: _____

Are there times, other than sleep, when the tics are decreased or better, for example during sports, reading, sleeping? Yes No If yes, please explain: _____

Has your child ever had any sensation, mental or physical awareness ("an urge", "a feeling", "an awareness") before or during a tic? Yes No If yes, please describe this sensation or awareness: _____

Age of these sensations? _____ years old

Do you or your child ever feel a sense of relief or a feeling of "relief" after having a tic? Yes No If yes, please describe these feelings briefly: _____

Do you or your child ever feel any "urge" to do tics? Yes No If yes, please explain: _____

If yes, please explain: _____

Is your child able to stop or hold in his/her tics for a period of time? Yes No

If yes, how long can he/she hold in the tics? _____

How does it make him/her feel to hold in the tics (i.e. anxious, annoyed, painful)? _____

Any major stressors in the past 12 months? Yes No If yes, please explain: _____

~25% completion rate

				Coughing
				Throat clearing
				Sniffing or Snorting
				Grunting
				Barking
				Humming
				Breathing out sound
				Repeating what someone else said (echolalia)
				Persistent, obscene, inappropriate words (coprolalia)
				Others:

Are the stressors making the tics worse? Yes No If yes, please explain: _____

Problems related to tics

Does your child have any pain or discomfort from the tics? Yes No Unknown

If yes, please describe the location and type of pain: _____

History of Present Symptoms – Obsessions, Compulsions, Worries, Anger

problems - Checklist: This section asks about obsessive-compulsive behaviors. Please check the boxes below indicating if your child has ever had (past) or currently has (during the past week) any of the following symptoms listed below and indicate the approximate age of onset (in years).

Past	Current	Age of Onset	Obsessions:
			are repetitive and intrusive thoughts that continue even when a person tries to ignore or suppress them. Please circle any that apply:
			Contamination Obsessions: Concern with dirt, germs, certain illnesses
			Concerns or disgust with bodily waste or secretions (e.g. urine, feces)
			Excessive concern with household items (e.g. cleaners, solvents)
			Excessive concern about animals/insects
			Excessively bothered by sticky substances or residues
			Aggressive Obsessions: Fear might harm self or others, or harm will come

Other Habits

Has your child ever had or currently have hair pulling (eye lashes, scalp, eyebrows)? Yes No

If yes, please explain: _____

Has your child ever had or currently have any habits (nail biting, lip licking, picking skin)?

Yes No If yes, please explain: _____

Other Worries, Depressive symptoms

Has your child ever had or currently have any specific fears or phobias (dark, heights, water)?

Yes No If yes, please explain: _____

Does your child "worry" or feel anxious often? Yes No If yes, please explain: _____

Limitations in cross sectional studies

- Non-random missingness

Limitations in clinical utility

- We had to add up the score ourselves

Enter: the tablets in Epic Electronic Health Record

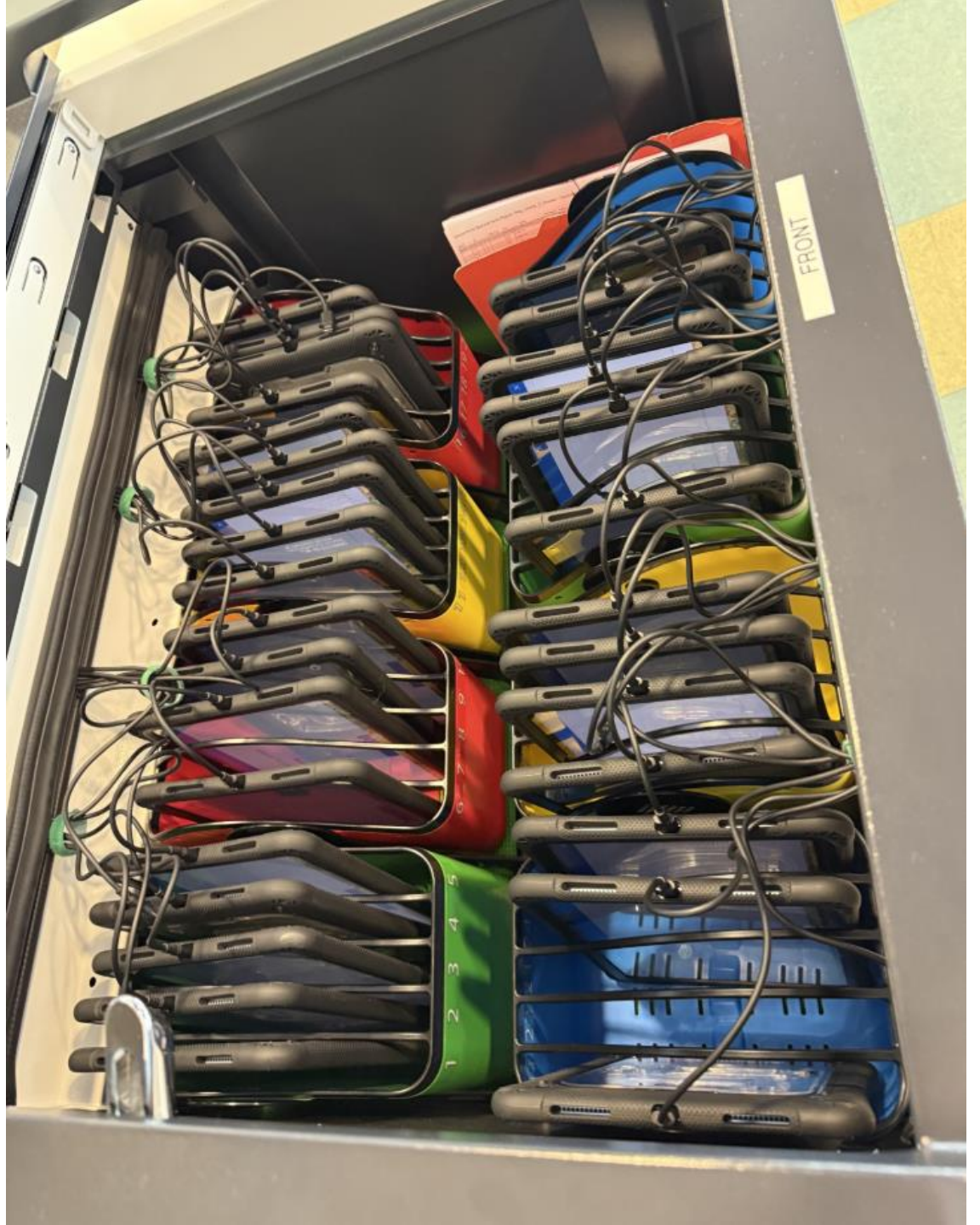
Parent and child complete new questionnaire before the visit (~10%) OR at the start of the visit on tablet provided at check in

Directly imported into EPIC *as it is being filled out* so clinician can assure completion and review before going in to room

Scores at the bottom:

ADHD-RS – parent
Mini CYBOCS
CTIM impairment

For Tic disorders – clinician does tic inventory and YGTSS total tic score

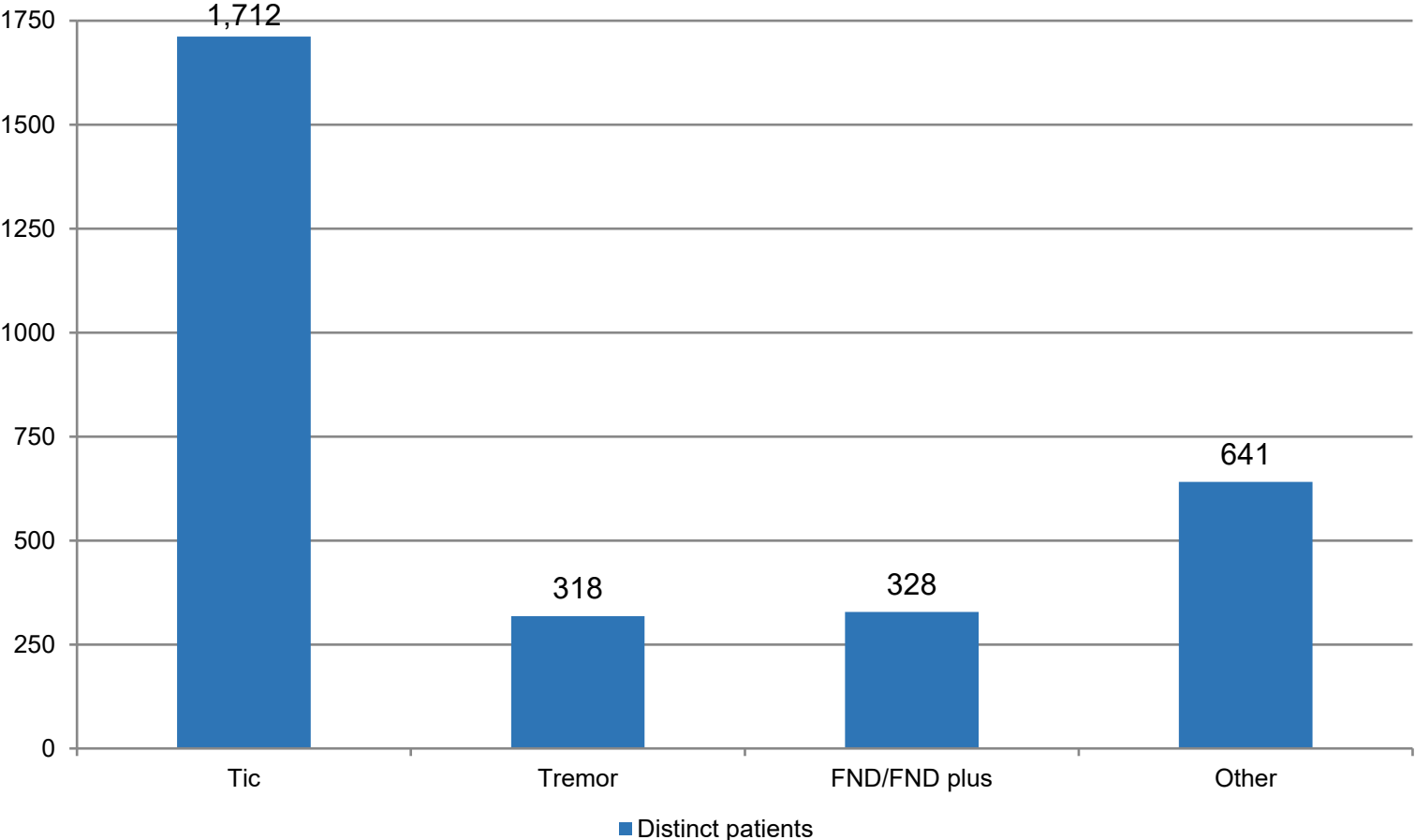


CTIM-P completion in the movement disorder clinic

EHR-derived counts, ages 10–17, 2022–2025

Analysis converts count tables to percentages at the encounter and distinct-patient levels; fully and mostly completed questionnaires are combined as the clinically useful completion endpoint.

Distinct-patient counts by diagnosis, summed across 2022–2025. Ages 10 to 17 years at time of first visit

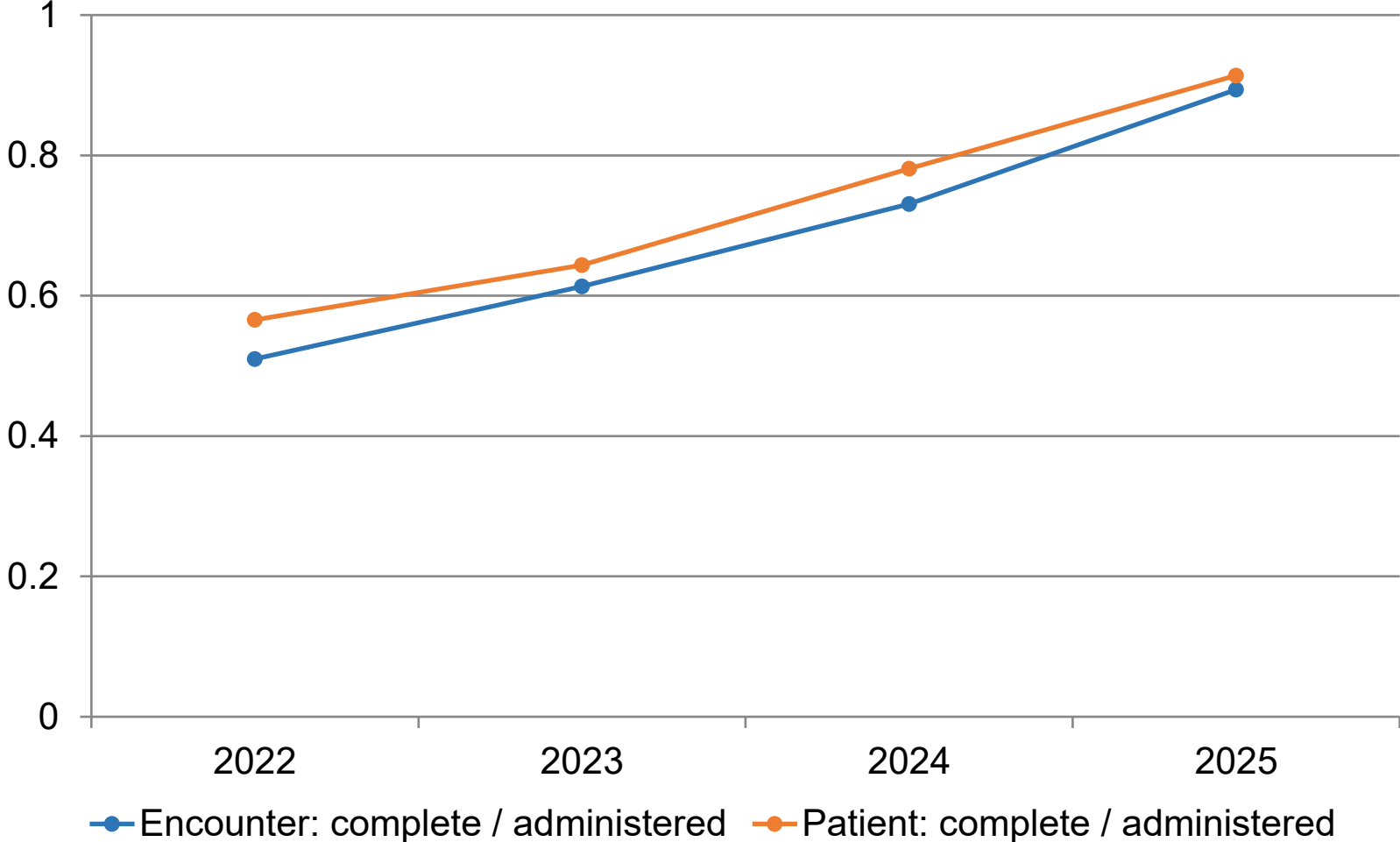


Diagnosis	2022–2025 count	Share
Tic	1712	57.1%
Tremor	318	10.6%
FND/FND plus	328	10.9%
Other	641	21.4%
Total	2999	100.0%

- Tic is the largest diagnosis group (1712 distinct patients).
- Other is the second-largest group (641 distinct patients).
- FND and FND plus are combined here, matching the main diagnosis-stratified slides.

Counts are summed from workbook row 12 across 2022, 2023, 2024, and 2025; FND/FND plus combines the FND and FND plus source columns.

CTIM-P completion improved substantially from 2022 to 2025.













Year	Enc complete/ admin	Enc complete/ total	Patient complete/ admin
2022	51.0%	38.3%	56.6%
2023	61.3%	50.2%	64.4%
2024	73.1%	58.5%	78.1%
2025	89.4%	69.9%	91.4%

- Encounter completion among administered records increased from 51.0% to 89.4%.
- Patient-level completion showed the same direction: 56.6% to 91.4%.
- The trend suggests workflow adoption improved over the observation window.




Percentages use yearly denominators from the source workbook.

6/4/2026
1:21 PM




MDO CLINIC INTAKE 10 AND OLDER QUESTIONNAIRE

What is your relationship to the patient?	Parent 
Please describe movement-related problems or symptoms you would like us to address today. If none, leave blank.	Tics 
Please describe any other problems you would like us to address today (if any)	Self harm: hitting 
The movements cause pain	Yes 
The movements injure my child's body	Yes 
My child can suppress or control the movements	Yes 
I home school my child because of the movements	No 
I have taken my child to the Emergency Department because of the movements	No 
Is your child currently being treated by a psychiatrist (MD)?	Yes 
If your child currently being treated by a psychologist or therapist?	No 




ADHD scores

Inattention Score (inattentive ADD)	7 
Hyper/Impulsive subscore (hyper/impulsive subtype)	3 
Total ADHD rating score (combined type ADHD)	10 







Time, interference, distress

How much time each day does your child do these compulsive behaviors?	> 8 hours 
How much does performing these compulsions interfere with daily life?	Substantially impairing 
How much distress do these compulsive behaviors cause your child?	Definitely but manageable 









OCD scores

Obsession Score	8	
Compulsion Score	9	
OCD Total Score	17	









14 impairment questions: home, school, social

Doing household chores ...due to ADHD, OCD, anxiety, or other?	Not at all  Pretty much 
Getting ready for bed ...due to ADHD, OCD, anxiety, or other?	Just a little  Very much 
Getting along with parents ...due to ADHD, OCD, anxiety, or other?	Pretty much  Very much 

Impairment scores – parent – tic and comorbid









Move School - Parent	3		Tics concern the parent
Move Family/Home - Parent	4		
Move Social - Parent	4		
Total mCTIM - Move - Parent	11		
Comorbid School - Parent	8		OCD concerns the parent more
Comorbid Family/Home - Parent	9		
Comorbid Social - Parent	4		
Total mCTIM - Comorbid - Parent	21		

Impairment scores – child – tic and comorbid

Move School - Child	0		Tics barely concern the child
Move Family/Home - Child	0		
Move Social - Child	2		
Total mCTIM - Move - Child	2		
Comorbid School - Child	10		OCD concerns the child – at school
Comorbid Family/Home - Child	3		
Comorbid Social - Child	2		
Total mCTIM - nontic - Child	15		

















		Parent	Child
Move	School	3	0
	Family	4	0
	Social	4	2
	TOTAL	11	2
CoDx	School	8	10
	Family	9	3
	Social	4	2
	TOTAL	21	15

Motor stereotypy age 10

Move School - Child	0		Movement: does not care
Move Family/Home - Child	0		
Move Social - Child	0		
Total mCTIM - Move - Child	0		
Comorbid School - Child	0		Non – motor: does not care, or no insight??
Comorbid Family/Home - Child	0		
Comorbid Social - Child	0		
Total mCTIM - nontic - Child	0		

Motor stereotypy age 10 vs age 15

Movement: does care now!

Move School - Child	0 	5 
Move Family/Home - Child	0 	3 
Move Social - Child	0 	8 
Total mCTIM - Move - Child	0 	16 
Comorbid School - Child	0 	0 
Comorbid Family/Home - Child	0 	0 
Comorbid Social - Child	0 	0 
Total mCTIM - nontic - Child	0 	0 

Scores pulled into note: current, most recent

YGTSS versus CTIM Impairment

YGTSS 21 ; CTIM-M-P 4

Boy

Age 8 years

YGTSS M 15; Ph 6.

YGTSS Total 21.

CTIM *Motor Parent* = 4.

Scoring of Tics based on parent's history

<u>MOTOR</u>	<u>VOCAL</u>
Number Current Number Motor Tic: 2	Number Current Number Vocal Tic: 1
Frequency Current Frequency Motor Tic: 5 Intensity Current Intensity Motor Tic: 3	Frequency Current Frequency Vocal Tic: 3 Intensity Current Intensity Vocal Tic: 2
Complexity Current Complexity Motor Tic: 3 Interference Current Interference Motor Tic: 2	Complexity Current Complexity Vocal Tic: 0 Interference Current Interference Vocal Tic: 0

YGTSS 21 → 24; CTIM-M-P 4 → 40

Same Boy

Age 12 years

YGTSS M 13; Ph 11.

YGTSS Total 24.

CTIM-Motor-Parent 40

CTIM-Motor-Child 27

Scoring of Tics based on parent's history

<u>MOTOR</u>		<u>VOCAL</u>	
Number Current	Number Motor Tic: 2	Number Current	Number Vocal Tic: 2
Frequency Current	Frequency Motor Tic: 4	Frequency Current	Frequency Vocal Tic: 4
Intensity Current	Intensity Motor Tic: 3	Intensity Current	Intensity Vocal Tic: 3
Complexity Current	Complexity Motor Tic: 3	Complexity Current	Complexity Vocal Tic: 1
Interference Current	Interference Motor Tic: 1	Interference Current	Interference Vocal Tic: 1

Longitudinal Data

- Pulled automatically from EPIC by “people who have the keys to EPIC”
- “People who have the keys to EPIC” are not the clinicians
- It is apparently not as easy as you might think
- **Validation of comorbidity diagnosis**
- Missingness - telehealth
- I have been struggling with this now since March

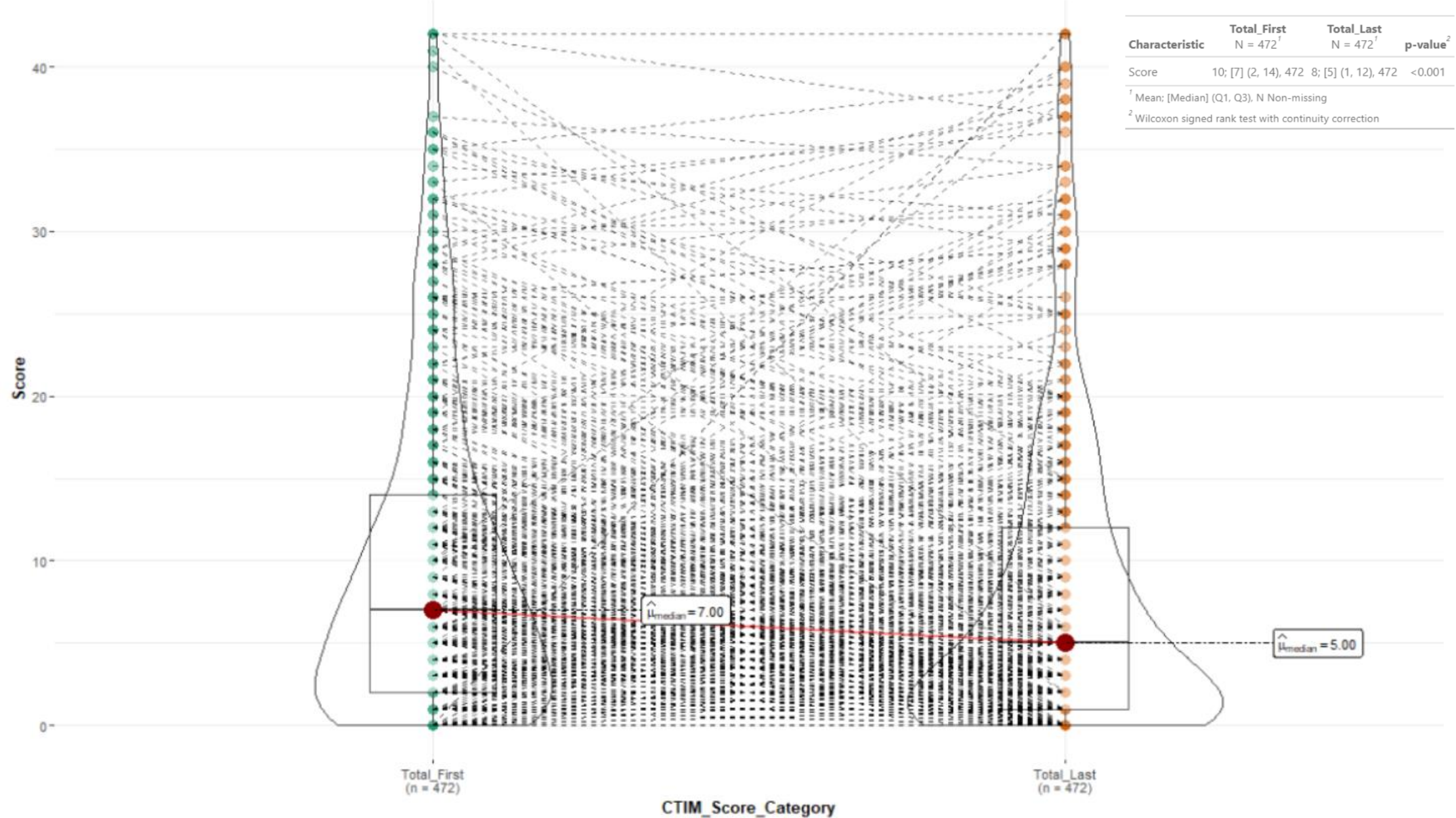
REGRESSION

Y	Impairment change	CTIM_M_P last minus first
X1	movement group Dx	Tic, Tremor, other
X2	CoDx Anx/OCD	yes, no
X1*X2	MDO and CoDx	moderation of Dx effect by Anx/OCD
X3	time between visits	continuous
X4	number of visits	between first and last visit
X5	sex	male, female
X6	age at first visit	continuous
X1*X5	Dx sex	moderation of age effect by sex?
X1*X6	Dx age	moderation of Dx effect by age?
higher order interaction		age sex Dx CoDx

Change in CTIM Total Score between First-Last Visit within MRN

All MDO

$V_{Wilcoxon} = 56475.50$, $p = 8.87e-08$, $\hat{r}_{biseri}^{rank} = 0.30$, $CI_{95\%} [0.20, 0.40]$, $n_{pairs} = 472$



Characteristic	Total_First N = 472 ¹	Total_Last N = 472 ¹	p-value ²
Score	10; [7] (2, 14), 472	8; [5] (1, 12), 472	<0.001

¹ Mean; [Median] (Q1, Q3), N Non-missing
² Wilcoxon signed rank test with continuity correction

Conclusions

- The CTIM / Tablets have already changed our practice at the individual level
 - They help us quickly compare movement versus comorbidity impacts
 - The movement scores are still useful, but are complementary
 - They help us quickly compare youth versus adult assessments
- Tablet Questionnaire Completion rates are high – still some room for improvement
- We do not know yet whether longitudinal data analysis may teach us something about our patients and about how to improve our practice

Thank you!
More to come (I hope!)

Don Gilbert – Cincinnati Children's Movement Disorders Program