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ANNOTATION SCHEMA

FINAL ANNOTATION SCHEMA

Patient-Centered Outcomes for Pediatric ADHD: Draft Annotation Schema and Guidelines

Prepared for
The Office of the Assistant Secretary for Planning and Evaluation (ASPE)
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by
NORC at the University of Chicago

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Office Of The Assistant Secretary For Planning And Evaluation

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1. Overview

The goal of this project is to develop and validate an annotation schema for identifying patient-centered outcomes in pediatric attention-deficit/hyperactivity disorder (ADHD) clinical notes. These outcomes include functional domains, symptom-related outcomes, emotional and psychosocial factors, caregiver-related outcomes, patient-important priorities, and care-related outcomes. By systematically annotating these concepts, we aim to create structured data that can inform clinical decision-making and research on pediatric ADHD management, with a focus on underrepresented clinical settings such as primary care and federally qualified health centers.

The annotation process involves defining clear entity categories, creating detailed guidelines for handling ambiguity, and training annotators to apply these rules consistently. Additionally, clinical expertise will play a central role in the development and validation of this annotation schema. Their domain knowledge helps ensure that outcome definitions are clinically meaningful, that ambiguous language is interpreted appropriately, and that annotations reflect real-world practice patterns.

Clinical notes will be pre-processed and segmented into relevant sections, and annotations will be applied at the phrase level but aggregated to the note level for analysis. Inter-annotator agreement will be monitored and refined through iterative training and adjudication.

Children with ADHD frequently experience one or more co-occurring conditions—such as anxiety, learning disorders, behavioral challenges, or mood difficulties—which can shape their day-to-day functioning and overall well-being.[1] Because these comorbid conditions often interact with ADHD in complex ways, the outcomes described below should be understood as relevant to children with ADHD regardless of whether the outcomes are directly attributed to ADHD itself in the clinical notes. In many cases, these outcomes reflect broader aspects of a child's functioning, family dynamics, or caregiving experience.[2] As such, they offer a holistic view of the challenges and strengths present in the lives of children with ADHD, independent of the specific source of those experiences.

2. Sampling

The annotation schema encompasses pediatric patients aged 4-17 diagnosed with ADHD, regardless of medication status or visit type, to ensure inclusion of a broad and representative population.

3. Annotation Guidelines/Handling Edge Use Cases

When annotating clinical notes, prioritize clarity and consistency by following these principles:

- For ambiguous language, rely on contextual clues such as surrounding sentences, comparative terms (e.g., "better," "worse"), and explicit links to patient-centered outcomes.
    - If ambiguity persists**,** default to "no mention" rather than inferring intent.

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[1] National Institute of Mental Health. Attention-deficit/hyperactivity disorder (ADHD). National Institutes of Health. https://www.nimh.nih.gov/health/topics/attention-deficit-hyperactivity-disorder-adhd

[2] Mahdi S, Viljoen M, Massuti R, et al. An international qualitative study of ability and disability in ADHD using the WHO-ICF framework. Eur Child Adolesc Psychiatry. 2017;26(10):1219-1231. doi:10.1007/s00787-017-0983-1

- For overlapping categories, annotate the most specific entity that captures the documented outcome. If a phrase legitimately fits multiple entities (e.g., academic functioning and school attendance), apply both labels only when each is clearly supported by context.
- For unusual data patterns, such as contradictory statements within the same note or atypical phrasing, annotate based on the most recent or clinically emphasized statement, and flag the note for review.
- Always document edge cases and rationale in annotation logs to maintain transparency and improve inter-annotator agreement.

4. Inter-Annotator Agreement

To ensure reliability and consistency across annotators, agreement will be measured at the level of each patient-centered outcome. Because the schema encompasses numerous outcomes, agreement will be calculated separately for each outcome, allowing identification of areas where definitions or guidelines may require clarification. For each outcome, annotators will assign one of five mutually exclusive labels:

- **PCO_absent = no mention of patient-centered outcome**
- **PCO_noted = patient-centered outcome noted but no mention of direction**
- **PCO_worse = decrease/worsening of patient-centered outcome**
- **PCO_same = no change or no new mention of patient-centered outcome**
- **PCO_better = increase/improvement in patient-centered outcome**

Discrepancies should be documented with rationale and reviewed during adjudication sessions. Consistent logging of disagreements and their resolutions will help improve schema clarity and annotator performance over time.

5. Annotation Schema

This schema focuses on identifying primary care provider (PCP) documentation of patient-centered outcomes in children with ADHD. Relevant phrases will be annotated for each entity; however, the annotation label will apply at the note level.

The entities to be captured are listed as follows:

- Symptom-Related Outcomes
    - Inattention
    - Hyperactivity-Impulsivity
- Functional Outcomes
    - Bodily Functions/Bodily Structures
    - Activities and Participation
- Behavior-Related Outcomes
- Emotional/Psychosocial Outcomes
- Care-Related Outcomes
- Patient Priorities
- Caregiver Outcomes

5.1 Primary Entity: Symptom-Related Outcomes

Two sub-types of symptom-related outcomes, adapted from the DSM-V criteria for ADHD diagnosis,[3] will be captured (as detailed in tables below). When available, numerical indicators, such as raw scores from parent or teacher questionnaires, will be incorporated. When such scores are not documented, annotators will assess the level of improvement or worsening based on clinical documentation using the structured scale described in the ***Annotation Schema*** description.

The table below (**Exhibit 1**) presents the **inattention** sub-type, which documents difficulties involving the regulation of attention (e.g., maintaining focus, listening, being easily distracted).

Exhibit 1. Symptom-Related Outcomes: Inattention

Entity	Goal: What is trying to be captured	Example Annotation Units	Examples of Ambiguity (If Applicable)
SO_I_attention_level	PCP documents ability to give close attention to details or avoid careless mistakes	"Homework is error-free; no careless mistakes in math problems this week" "Teacher notes omits punctuation despite reminders"	Mention of accuracy without detail related to attention level (e.g., "work is better"; "doing well academically")
SO_I_attention_sustainment	PCP documents ability to sustain attention during tasks or play activities	"Stayed focused during 20-minute check-in" "Loses focus halfway through homework"	Generic mention of focus without task context (e.g., "better concentration"; "improved attention")
SO_I_listening	PCP documents ability to listen when spoken to directly	"Follows verbal directions first time" "Seems distracted when spoken to"	Mention of inattentiveness without listening context (e.g., "more focused now"; "less distracted")

[3] American Psychiatric Association. (2022). Diagnostic and statistical manual of mental disorders (5th ed., text rev.). https://doi.org/10.1176/appi.books.9780890425787

Entity	Goal: What is trying to be captured	Example Annotation Units	Examples of Ambiguity (If Applicable)
			See ***SO_I_attention_level & SO_I_attention_sustainment***
SO_I_disorganization	PCP documents difficulty organizing tasks and activities	"Struggles to keep materials organized"	
SO_I_distraction	PCP documents being easily distracted by extraneous stimuli	"Gets sidetracked by noises" "Distracted by unrelated thoughts during class"	Generic mention of poor focus without distraction context (e.g., "hard to concentrate"; "attention is better")
SO_I_forgetfulness	PCP documents forgetfulness in daily activities	"Forgets to do chores" "Missed scheduled appointment despite calendar reminder"	
SO_I_task_persistence	PCP documents ability to sustain effort and complete tasks	"Stays focused until task is done" "Cannot finish chores; abandons halfway despite reminders"	Generic mention of effort without persistence context (e.g., "tries harder"; "more motivated")
SO_I_sustained_mental_effort	PCP documents avoidance or reluctance to engage in tasks requiring sustained mental effort	"Completed long reading passage without complaints" "Avoids homework requiring sustained effort; complains about long assignments"	Mention of initiating task as opposed to ongoing effort
SO_I_losing_objects	PCP documents losing things necessary for tasks or activities	"Frequently misplaces school supplies" "Lost eyeglasses twice this month"	Generic mention of forgetfulness without object context (e.g., "more forgetful"; "memory issues")

The following table (**Exhibit 2**) presents the **hyperactivity-impulsivity** sub-type, which documents difficulties involving excessive motor activity and behavioral regulation (e.g., fidgeting, excessive talking).

Exhibit 2. Symptom-Related Outcomes: Hyperactivity-Impulsivity

Entity	Goal – What is trying to be captured	Example Annotation Units	Examples of Ambiguity (If Applicable)
SO_HI_leaving_early	PCP documents leaving seat in situations where remaining seated is expected	"Leaves desk during lessons" "Gets up during dinner at restaurant"	Mentions of standing up without context (e.g., "gets up sometimes"; "moves around a bit")
SO_HI_fidgeting	PCP documents fidgeting, tapping, or squirming in seat	"Frequently taps feet during class" "Squirms and cannot sit still"	Generic "restless" without observable fidgeting
SO_HI_restlessness	PCP documents being "on the go," acting as if "driven by a motor"	"Always on the move" "Always on the move; paces classroom during quiet work time"	Generic mention of energy without hyperactivity context (e.g., "very energetic"; "full of energy")
SO_HI_running	PCP documents running/climbing in inappropriate situations	"Runs in the hallway" "Runs in the hallway between classes; 2 incidents this week"	Age-appropriate active play (recess, sports)
SO_HI_quiet_play	PCP documents inability to play or engage in leisure activities quietly	"Plays loudly despite reminders" "Cannot engage quietly with board games"	
SO_HI_talking_excessively	PCP documents excessive talking beyond situational norms	"Talks continuously in class" "Talks continuously in class; teacher notes 15+ interruptions"	Mentions of sociability without excess (e.g., "likes to talk"; "more social")

Entity	Goal – What is trying to be captured	Example Annotation Units	Examples of Ambiguity (If Applicable)
SO_HI_talking_early	PCP documents blurting out answers before questions are completed / finishing others' sentences	"Answers before teacher finishes asking" "Completes people's sentences	Mentions of eagerness without interrupting (e.g., "answers quickly"; "enthusiastic in class")
SO_HI_waiting_turns	PCP documents difficulty waiting turn (e.g., in conversation, lines, games)	"Struggles to wait in line" "Does not wait turn in board games"	Mentions of impatience without disruption (e.g., "gets frustrated waiting"; "doesn't like waiting")
SO_HI_interruptions	PCP documents interrupting or intruding on others' activities or belongings	"Respects peers' space during group work" "Takes over tasks peers are doing despite reminders"	Mentions of assertiveness without intrusion (e.g., "takes initiative"; "likes to help others")

5.2 Primary Entity: Functional Outcomes

Two sub-types of functional outcome mentions will be captured (as detailed in tables below). Functional outcomes encompass the child's ability to perform and succeed in everyday roles and tasks.

Exhibit 3 captures **bodily functions and structures**, which encompass sensory, bodily, and mental functions (e.g., cognitive processes like planning, decision-making, and self-control) and their associated structures

Exhibit 3. Functional Outcomes: Bodily Functions/Bodily Structures

Entity	Goal: What is trying to be captured	Example Annotation Units	Examples of Ambiguity (If Applicable)
FO_BFBS_calculating	PCP documents ability to perform calculations or math-related tasks	"Improved ability to solve math problems" "Needs help for simple arithmetic"	Mention of problem solving unrelated to mathematical tasks See ***FO_BFBS_executive_function***

Entity	Goal: What is trying to be captured	Example Annotation Units	Examples of Ambiguity (If Applicable)
FO_BFBS_executive_function	PCP documents planning, organizing, problem-solving, decision-making, or managing tasks	"Able to plan and organize daily tasks more effectively" "Struggles to break complex tasks into manageable steps"	Generic mention of ADHD symptoms without executive function context (e.g., "ADHD symptoms improving")
FO_BFBS_fine_hand_use	PCP documents fine motor skills	"Improved handwriting" "Still has trouble writing legibly"	Mention of gross motor skills only (e.g., "improved motor skills;" "better coordination")
FO_BFBS_reaction_time	PCP documents response speed or accuracy	"Quick, accurate responses during time-pressured tasks" "Delayed response time observed during cognitive testing"	Discussion of attention or focus without timing context (e.g., "more attentive"; "improved focus") See ***SO_I_Attention***

The following table (**Exhibit 4**) describes the outcomes within the **activities and participation** sub-type, which include outcomes related to the quality of interactions with peers, family, and others and ability to manage routines, self-care, and household responsibilities (e.g., daily activities).

Exhibit 4. Functional Outcomes: Activities and Participation

Entity	Goal: What is trying to be captured	Example Annotation Units	Examples of Ambiguity (If Applicable)
FO_AP_academic_functioning	PCP documents academic performance, behavior, and schoolwork	"Reprimanded by teacher during class" "Passed exams at school"	
FO_AP_autonomy	PCP documents the child's ability to make choices, act independently for their age, and manage tasks appropriate for their age without assistance	"child is able to complete their homework without prompting" "parent reports that child is able to dress themselves in the morning"	Generic mention of autonomy with no specific examples provided (e.g., "acting independently")

Entity	Goal: What is trying to be captured	Example Annotation Units	Examples of Ambiguity (If Applicable)
FO_AP_engagement_in_play	PCP documents engagement in play activities	"More engaged in preferred leisure activities weekly" "Resumed hobbies that were previously avoided"	
FO_AP_family_relationships	PCP documents quality of family relationships and their interactions	"Frequent arguments with family" "Communicates more effectively with close family"	Mention of home life dynamic without specific mention of relationships (e.g., "home life improved")
FO_AP_following_social_rules	PCP documents ability to act in social interactions with accordance to social conventions	"Plays cooperatively with peers" "Difficulty respecting boundaries during conversations"	Mention of following social rules within formal/informal/family relationships ***See FO_AP_family_relationships, FO_AP_formal_relationships, FO_AP_informal_relationships***
FO_AP_formal_relationships	PCP documents relationships with teachers, coaches, or clinicians and their interactions	"Good rapport with teacher" "Worsened collaboration with psychologist"	Discussion of improved experiences at school without specific relationships mentioned (e.g., "school is going better")
FO_AP_handling_responsibility	PCP documents ability to take responsibility for tasks or actions	"Accepts accountability for missed commitments" "Avoids taking ownership of personal errors"	Mention of social responsibilities; may overlap with relationship entities
FO_AP_household_tasks	PCP documents ability to complete household tasks, including chores and preparing meals	"Completes trash duty without reminders" "Avoids assigned tasks, requiring repeated prompting"	Mentions of resistance to completing household tasks due to not wanting to do the tasks (as opposed to being unable to)

Entity	Goal: What is trying to be captured	Example Annotation Units	Examples of Ambiguity (If Applicable)
FO_AP_informal_relationships	PCP documents relationships with friends or neighbors and their interactions	"Maintains several strong friendships" "Reports difficulty forming new connections"	
FO_AP_mobility	PCP documents ability to move around safely	"Rides bus independently" "Has difficulty navigating public spaces without assistance"	
FO_AP_normalcy	PCP documents child's experience of feeling typical or similar to peers in their daily life	"child participates in recess daily like their other classmates" "Parent notes that child feels like other kids since starting treatment"	Unclear specification of context, activities, or behaviors (e.g., "seems normal"; "acts like peers")
FO_AP_self_care	PCP documents ability to manage personal hygiene, grooming, health, and safety	"Brushes teeth independently" "Does not monitor safety effectively"	

5.3 Primary Entity: Coexisting Behavioral-Related Outcomes

Behavioral-related outcomes refer to regulating actions, emotions, and interactions that interfere with functioning in everyday settings, particularly school and social settings. Behavioral challenges include disruptive behaviors (e.g., classroom interruptions, distracting peers during lessons) and oppositional defiant behaviors (e.g., arguing with adults, deliberately breaking rules).

Exhibit 5. Coexisting Behavioral-Related Outcomes

Entity	Goal: What is trying to be captured	Example Annotation Units	Examples of Ambiguity (if Applicable)
B_defiant	PCP documents defiant behaviors towards authority or rules	"Deliberately breaks classroom rules after multiple warnings multiple times per week"	Generic mention of oppositional defiant behavior without context (e.g., "breaks rules")

		"Lies to teachers and parents about completing homework daily"	
B_disruptive	PCP documents behaviors that interfere with normal functioning across environments	"Yells during teacher lessons at least once per day" "Leaves seat during lessons without permission at least once per week"	Generic mention of being disruptive without context (e.g., "yells") or specifying behavior (e.g., "hard to manage")

5.4 Primary Entity: Coexisting Emotional/Psychosocial Outcomes

Emotional/psychosocial outcomes refer to experiences that affect a child's mood, emotional regulation, and daily functioning. These challenges include anxiety, depressive symptoms, difficulties with emotional regulation, and mood changes.

Exhibit 6. Co-Existing Emotional/Psychosocial Outcomes

Entity	Goal: What is trying to be captured	Example Annotation Units	Examples of Ambiguity (if Applicable)
EP_anxiety	PCP documents mentions of excessive worry, fear, or other symptoms of anxiety	"child feels nervous before school everyday" "child has daily stomach aches linked to worry"	Generic mention of being anxious without context or specificity of severity (e.g., "reports worrying") or behavior (e.g., "anxious")
EP_depression	PCP documents in symptoms related to depression such as sadness or loss of interest	"Child feels sad most days of the week" "Child no longer enjoys favorite activities like recess"	Unclear specification of duration, symptoms, or context (e.g., "seems down")
EP_regulation	PCP documents managing emotional responses	"Has daily emotional outbursts when frustrated" "Has difficulty calming down after conflict with peers"	Unclear specification of context, frequency, or severity (e.g., "emotional issues"; "struggles with emotion")
EP_mood	PCP documents fluctuations in mood that are disruptive to functioning	"Mood shifts from happy to irritable within minutes" "Multiple teachers report frequent mood changes	Unclear specification of context, frequency, or severity (e.g., "mood changes"; "mood unstable")

		during class especially when asked to complete assignments"	
EP_wellbeing	PCP documents overall emotional health	"Parent notes fewer emotional meltdowns and that child is calmer" "Teacher observes the child has a positive affect at school compared to last month"	Unclear regarding source and context (e.g., "seems happier"; "better mood")

5.5 Primary Entity: Caregiver Outcomes

Caregiver outcomes refer to the experiences and perceptions of caregivers that influence their ability to support a child with ADHD, including caregiver perceived burden, family cohesion, and chaos.

Exhibit 7. Caregiver Outcomes

Entity	Goal: What is trying to be captured	Example Annotation Units	Examples of Ambiguity (if Applicable)
CO_burden	PCP documents caregiver stress or strain related to ADHD management	"Parent reports feeling overwhelmed by daily behavioral challenges" "Caregiver expresses stress about frequent school calls"	Cause of frustration unclear and severity unspecified (e.g., "parent stressed"; "difficulty managing")
CO_cohesion	PCP documents family unity, cooperation, and ability to work together despite ADHD challenges	"family collaborates on homework routines" "parent reports that siblings help child with organization tasks"	Specific behaviors not described or relationship not specified (e.g., "good family"; "family close")
CO_chaos	PCP documents chaos within the home environment	"family is getting along" "family argues due to ongoing stress"	Specific dynamics or relationships not specified (e.g., "there's tension")