



OFFICE OF THE SECRETARY  
PATIENT-CENTERED OUTCOMES  
RESEARCH TRUST FUND

## PROJECT REPORT

### FINAL REPORT

# Pediatric ADHD Use Case for Applying NLP Methods to Extract Patient-Centered Outcomes from Clinical Notes

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Prepared for  
The Office of the Assistant Secretary for Planning and Evaluation (ASPE)  
at the U.S. Department of Health and Human Services

by  
NORC at the University of Chicago

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## Executive Summary

The Office of the Secretary Patient-Centered Outcomes Research Trust Fund (OS-PCORTF) supports efforts to strengthen data infrastructure for patient-centered outcomes research (PCOR), including advancing natural language processing (NLP) and other artificial intelligence (AI) methods to improve the capture and analysis of outcomes that matter most to children with attention-deficit/hyperactivity disorder (ADHD) and their caregivers.

ADHD affects over 11% of U.S. children and has wide-ranging impacts on daily functioning, emotional well-being, academic performance, and family life. Many outcomes that matter most to children and caregivers are documented only in unstructured clinical notes, making them difficult to analyze at scale; NLP offers a promising way to transform this free text into structured data that captures these patient-centered outcomes, enabling comparative effectiveness research (CER).

## Key Findings

This report synthesizes current evidence from an environmental scan of 60 sources to help researchers, policymakers, and health systems strengthen data capacity for PCOR. The report identifies patient-centered outcomes relevant to children with ADHD and their caregivers, outlines challenges and opportunities for extracting these outcomes from clinical notes using NLP, and identifies candidate datasets containing clinical notes suitable for such work.

**Patient-Centered Pediatric ADHD Outcomes.** The environmental scan identified 44 patient-centered outcomes across five domains (Exhibit ES-1), which were validated by a subject matter expert in developmental behavioral pediatrics. These outcomes reflect a holistic view of ADHD's impact and provide guidance for what researchers may wish to extract from clinical notes.

### Exhibit ES-1. Domains of Patient-Centered Outcomes for Pediatric ADHD Identified in Literature

| Domain                                            | Description                                                                                                                                                                                    |
|---------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>ADHD Symptom-Related Outcomes</b>              | Core ADHD symptoms, inattention and hyperactivity-impulsivity, reflect DSM-V criteria and are central to diagnosis and treatment monitoring.                                                   |
| <b>Functional Outcomes</b>                        | Everyday abilities related to bodily functions, activities, and participation that show how ADHD affects real-world performance across home, school, and community settings.                   |
| <b>Coexisting Behavior-Related Outcomes</b>       | Observable/external disruptive or defiant behaviors, including those associated with oppositional defiant disorder, that commonly co-occur with ADHD and affect family and school functioning. |
| <b>Coexisting Emotional/Psychosocial Outcomes</b> | Internal emotional experiences such as anxiety, depression, and difficulty with emotional regulation that influence overall psychological well-being.                                          |
| <b>Caregiver Outcomes</b>                         | Parent or caregiver experiences, including burden, cohesion, and household dynamics, that affect family well-being and the management of ADHD.                                                 |

**Extracting Patient-Centered Outcomes for ADHD from Clinical Notes.** The scan identified several challenges with extracting patient-centered outcomes from the clinical notes of pediatric patients with ADHD:

- **Lack of data standardization:** There is wide variation in terminology, style, and structure across providers, settings, and note types. Notes may integrate information from clinicians, teachers, caregivers, and behavioral specialists, each using different language or documentation styles.
- **Unclear or incomplete data:** Clinical notes can be ambiguous with difficulties distinguishing past from current symptoms, unclear temporal markers, and inconsistent reporting across clinicians and caregivers.
- **Use of uploaded documents:** Many rating scales that measure progress of outcomes or reports that contain information regarding outcomes are stored as PDFs or images, requiring specialized preprocessing before they can be analyzed.

Challenges in extracting pediatric ADHD patient-centered outcomes data from electronic health records (EHRs) may disproportionately affect resource-constrained clinical settings, such as federally qualified health centers (FQHCs), given their limited technical infrastructure, staffing, and financial resources, as well as limited data exchange across systems. NLP techniques can address the above challenges by supporting terminology normalization and contextual awareness, thus making sense of clinical notes.

**Candidate Datasets for Extraction.** Four datasets met the criteria for containing clinical notes and supporting pediatric ADHD outcome extraction. Each dataset varies in accessibility, population coverage, and the extent of structured versus unstructured outcome documentation:

- **American Family Cohort (AFC):** Nationally representative primary care dataset with clinical notes.
- **NeuroBlu:** Large behavioral health dataset including pediatric ADHD encounters and symptom/treatment data.
- **Partners Health Care Research Patient Data Registry (RPDR):** Multi-hospital clinical data warehouse with clinical notes (access currently limited).
- **PEDSnet:** Pediatric hospital network with EHR data relevant to ADHD diagnosis and follow-up. PEDSnet does not include clinical notes as part of its centralized data repository. However, the network has workflows to obtain and analyze unstructured clinical notes.

**Areas for Future Research.** Strengthening data capacity in the following key areas can help address barriers to extracting patient-centered outcomes from clinical notes.

- **Quality of Patient-Centered Outcome Documentation:** To address variability, conduct qualitative research with key stakeholders to develop standardized documentation practices for patient-centered ADHD outcomes in EHR data, specifically clinical notes, followed by Delphi panel consensus-building on priority outcomes and practices.
- **Data Availability to Conduct PCOR:** Expand access to EHR data that can be used to conduct PCOR on pediatric ADHD outcomes using NLP.
- **Prototype Annotation Schema:** Develop and validate a prototype annotation schema to ensure consistent labeling of patient-centered ADHD outcomes, then assess its reliability and utility through inter-rater studies and NLP benchmarking.

# 1. Introduction

Attention-deficit/hyperactivity disorder (ADHD) is a developmental disorder<sup>1</sup> characterized by symptoms of inattention, hyperactivity, and impulsivity.<sup>2</sup> ADHD can impact many aspects of daily functioning, including executive functioning, motor skills, social skills, and emotion regulation.<sup>3</sup> It is one of the most common pediatric neurodevelopmental conditions; approximately 7 million (11.4%) of children in the US (aged 3-17 years) have been diagnosed with ADHD,<sup>4</sup> and the estimated lifetime prevalence of ADHD in U.S. adults (aged 18-44 years) is 8.1%.<sup>1, 5,6,7,8</sup> Much of the evidence guiding treatment and management of ADHD is derived from structured data elements that may not capture the full scope of patient-centered outcomes most important to children and their caregivers.<sup>9,10</sup> Capturing patient-centered outcomes in pediatric ADHD can provide clinicians and patients with the data needed to develop tailored treatment plans that positively affect functional outcomes and quality of life, leading to improved treatment adherence.<sup>11,12,13</sup>

There are limitations for leveraging electronic health record (EHR) data to extract patient-centered outcomes for pediatric ADHD.<sup>14</sup> For pediatric ADHD, unstructured data also includes assessments and observations from parents, teachers, and other adults in addition to the clinical notes, uploaded into the EHR in various formats.<sup>15</sup> These data often include rich insights beyond clinical symptoms—such as patient functioning and quality of life—yet their volume, lack of standardization, and data quality issues make them difficult to process without specialized expertise and sophisticated tools.<sup>16,17</sup>

Natural language processing (NLP) is a branch of artificial intelligence (AI) used to analyze unstructured EHR data (also referred to as “clinical notes”) to extract informative clinical information, including patient-centered experiences.<sup>18</sup> NLP can enable improved understanding of patient-centered ADHD outcomes and a more holistic patient view beyond structured data.<sup>19</sup> Leveraging NLP to extract patient-centered outcomes for ADHD from clinical notes offers an opportunity to expand the evidence base and better align care with what matters most to children and their caregivers.

The goals of this report are to provide a list of patient-centered ADHD outcomes for extraction from clinical notes, discuss common gaps and challenges in behavioral health documentation that limit the scope of patient-centered outcomes for ADHD that can be extracted from free-text EHR data, and provide a short list of candidate datasets for extraction, along with their strengths, limitations, and access details.

## 1.1 Objectives and Structure of the Report

This report synthesizes environmental scan findings to determine patient-centered outcomes for pediatric ADHD and to identify challenges and considerations for extracting such outcomes from EHR data (especially in underrepresented clinical settings) and applicable datasets. This report is guided by the following research aims:

1. Identify a set of pediatric ADHD outcomes that are meaningful to patients, caregivers, and clinicians.
2. Identify key gaps in current research and practices in extracting patient-centered outcomes for ADHD from free-text EHR data, with a focus on underrepresented clinical settings (e.g., primary care, federally qualified health centers [FQHCs], etc.).
3. Identify candidate data sources for conducting pediatric ADHD PCOR and describe strengths, limitations, and access details.

This report is intended for a PCOR researcher audience, including governmental and non-governmental researchers, who are interested in using EHR data and NLP methods to extract information about patient-centered outcomes for ADHD.

## 2. Methods

We conducted an environmental scan to identify patient-centered outcomes for pediatric ADHD, understand considerations for extracting these data from EHR for research, and assess the availability and characteristics of datasets that could support NLP-based extraction of these outcomes from clinical notes.

We conducted targeted searches of peer-reviewed and grey literature in PubMed and Google Scholar. Search terms and inclusion/exclusion criteria covering publication years, document type, language, source, population, and focus are detailed in **Appendix A**. We supplemented the literature review with a scan of web resources, prioritizing U.S. Department of Health and Human Services (HHS) agency websites. In addition, we reviewed references of included articles to identify additional relevant sources through backward citation searching. A full list of websites reviewed is provided in **Appendix A**.

We applied a two-step screening process: (1) title and abstract review, followed by (2) full-text review for eligibility. In total, 60 data sources were included after screening and abstraction. Information from included sources was abstracted into a structured matrix to ensure consistency and transparency across the team. The abstraction captured details such as resource metadata, patient-centered outcomes in pediatric ADHD, challenges in clinical documentation of patient-centered outcomes, NLP methods used, barriers in data extraction, and pediatric ADHD datasets (see **Appendix A** for details).

Patient-centered outcomes were defined as outcomes reflecting what matters most to patients and caregivers, including those reported or contributed by them. Based on the literature, outcomes were grouped into five categories: ADHD symptom-related, functional, coexisting behavior-related, coexisting emotional/psychosocial, and caregiver-related (see **Section 3.1**). Groupings were validated by an ADHD subject matter expert (SME).

For candidate datasets, we included U.S.-based (or international datasets with U.S. data) that contained clinical notes and provided ADHD-related outcome data. These datasets were assessed for accessibility, data types, and relevance to NLP-based extraction (see **Section 3.4**). Findings were reviewed by the ADHD SME and a clinical informatician.

## 3. Findings

This section lists the 44 patient-centered pediatric ADHD outcomes across each of the key outcome domains, the six most commonly used instruments to assess them, and considerations for extracting outcomes from clinical notes. This section also describes the characteristics, strengths, and limitations of the three identified candidate datasets that can support NLP-based research.

### 3.1 *Patient-Centered Pediatric ADHD Outcomes*

Patient-centered outcomes for pediatric ADHD encompass a broad range of functional, symptomatic, emotional, and care-related dimensions that reflect what matters most to children, their caregivers, and



clinicians. These outcomes provide a holistic view of ADHD’s impact beyond symptom reduction, emphasizing daily functioning and quality of life. Importantly, patients’ and caregivers’ access to quality healthcare services for ADHD, including trust in clinicians, feeling understood by clinicians, and the level of shared decision-making, may also influence these outcomes by impacting treatment adherence, satisfaction, and overall care outcomes.<sup>20,21</sup>

This section highlights the patient-centered outcomes identified across each domain, along with considerations for why they are important to measure. Behavioral and emotional/psychosocial outcomes are designated as coexisting to reflect their broader impact on functioning beyond core ADHD symptoms. A table defining each outcome is available in **Appendix B**.

**ADHD Symptom-Related Outcomes.** ADHD symptom-related outcomes refer to the core features of ADHD as defined by the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5)*: inattention and hyperactivity-impulsivity.<sup>22</sup> While these symptoms are often the primary targets of pharmacological and behavioral interventions, measurement challenges contribute to both underdiagnosis and overdiagnosis among certain subgroups, including those defined by gender and age.<sup>23,24</sup> Variability in symptom presentation and caregiver, teacher, and self-reporting further complicates accurate assessment in real-world clinical settings.

Nevertheless, these outcomes provide critical insight into treatment effectiveness and functional impact. Symptom severity influences academic performance, social relationships, and emotional well-being, making it a key driver of overall functioning. These symptoms form the foundation of ADHD diagnosis and are central to treatment monitoring. Their associated outcomes, derived from the DSM-5, are listed in **Exhibit 1**.

**Exhibit 1.** Symptom-Related Outcomes

| Inattention                                                                                                                                                                                                   |                                                                                                                                                                             | Hyperactivity-Impulsivity                                                                                                                                                                                                   |                                                                                                                                               |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------|
| <ul style="list-style-type: none"> <li>• Reduced Attention to Detail</li> <li>• Difficulty Maintaining Attention</li> <li>• Difficulty Listening</li> <li>• Disorganization</li> <li>• Distraction</li> </ul> | <ul style="list-style-type: none"> <li>• Forgetfulness</li> <li>• Difficulty with Tasks</li> <li>• Difficulty Sustaining Mental Effort</li> <li>• Losing Objects</li> </ul> | <ul style="list-style-type: none"> <li>• Leaving Early</li> <li>• Fidgeting</li> <li>• Restlessness</li> <li>• Excessive Running</li> <li>• Difficulty Engaging in Quiet Activities</li> <li>• Excessive Talking</li> </ul> | <ul style="list-style-type: none"> <li>• Interruptive Speech</li> <li>• Difficulty Waiting Turns</li> <li>• Frequent Interruptions</li> </ul> |

**Functional Outcomes.** Functional outcomes represent a child’s ability to perform and succeed in everyday roles and tasks, which is central to understanding the real-world impact of ADHD beyond symptom reduction. These outcomes are based on the World Health Organization’s *International Classification of Functioning, Disability, and Health (ICF)* framework,<sup>25</sup> which emphasizes the interplay between body functions, activities, and participation, as well as environmental factors.<sup>26</sup> While not outcomes, environmental factors that reflect physical, social, and attitudinal context can influence a child’s functioning and participation. Below we expand on the outcomes categories in the ICF framework, which are summarized in **Exhibit 2**:

- **Bodily Functions and Structure.** This subdomain focuses on sensory, bodily, and mental functions that underpin a child’s capacity to engage in tasks. ADHD frequently affects cognitive processes such

as attention regulation, planning, decision-making, working memory, and self-control.<sup>27,28</sup> Motor coordination challenges may also influence participation in physical activities and fine motor tasks like handwriting.<sup>29</sup> Deficits in executive functioning, particularly in terms of planning and inhibitory control, are among the most persistent barriers to achieving age-appropriate independence and academic success.<sup>30</sup>

- **Activities and Participation.** This subdomain refers to a child’s ability to perform tasks and engage in life situations and interactions across home,<sup>31,32</sup> school,<sup>33,34,35</sup> and community settings.<sup>31</sup> This domain emphasizes execution of daily routines<sup>20,31,36</sup> and social involvement,<sup>31,32,33,34,37,38,39,40,41,42</sup>, which are areas of vulnerability for children with ADHD and require sustained attention and sequencing skills.<sup>31</sup> Social functioning is particularly salient, as difficulties with impulse control and emotional regulation can lead to peer rejection or conflict, which in turn affects self-esteem and mental health.<sup>43</sup> Evidence suggests that interventions targeting organizational skills and social competence can significantly improve participation outcomes, reinforcing the need to measure these domains alongside symptom severity.<sup>44</sup>

## Exhibit 2. Functional Outcomes

| Bodily Functions and Structures                                                                                                                 | Activities and Participation                                                                                                                                                                                                  |                                                                                                                                                                                                         |
|-------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <ul style="list-style-type: none"> <li>• Calculating</li> <li>• Executive Function</li> <li>• Fine Hand Use</li> <li>• Reaction Time</li> </ul> | <ul style="list-style-type: none"> <li>• Academic Functioning</li> <li>• Autonomy*</li> <li>• Following Social Rules</li> <li>• Engagement in Play</li> <li>• Family Relationships</li> <li>• Formal Relationships</li> </ul> | <ul style="list-style-type: none"> <li>• Household Tasks</li> <li>• Informal Relationships</li> <li>• Handling Responsibility</li> <li>• Mobility</li> <li>• Normalcy *</li> <li>• Self-Care</li> </ul> |

\* These outcomes were identified in the literature as being specifically important to patients.<sup>45,46,47</sup> They may overlap with other outcomes in the list (e.g., normalcy and following social rules), but are retained as distinct constructs to reflect differences in patient priorities, lived experience, and the aspects of functioning they represent.

**Coexisting Behavior-Related Outcomes.** Behavior-related outcomes capture observable patterns of disruptive<sup>37</sup> or oppositional behaviors<sup>48</sup> that often co-occur with ADHD symptoms. These include:

- Disruptive behaviors
- Defiant behaviors

Oppositional Defiant Disorder (ODD) is the most common comorbid condition in children with ADHD, characterized by persistent patterns of irritability, argumentativeness, and refusal to comply with authority figures.<sup>49</sup> These behaviors are associated with increased issues in school and heightened family stress.<sup>50,51</sup> Evidence suggests that these behaviors, if unaddressed, can escalate over time, leading to academic underachievement and social isolation.<sup>52</sup>

**Coexisting Emotional/Psychosocial Outcomes.** Emotional and psychosocial outcomes focus on the child’s internal experiences and overall psychological well-being. Children with ADHD frequently experience heightened emotional reactivity, difficulty regulating frustration, and persistent feelings of stress, which can interfere with daily functioning and quality of life.<sup>53</sup> Relevant outcomes include:

- Anxiety
- Depression
- Emotional Regulation

- Mood Changes
- Emotional Wellbeing

Anxiety and depression are among the most common comorbid conditions in children with ADHD.<sup>32</sup> These internalizing symptoms often arise from repeated academic struggles, social rejection, and negative feedback from caregivers and teachers.<sup>54</sup> Emotional regulation is another key challenge as children with ADHD may become easily overwhelmed by setbacks, leading to emotional outbursts or withdrawal.<sup>55</sup> Emotional well-being is also central to quality of life.<sup>36</sup>

**Caregiver Outcomes:** The caregiver outcomes domain captures the experiences and well-being of parents or caregivers managing a child with ADHD.<sup>36</sup> It includes their perceived burden and family dynamics.<sup>33</sup> Outcomes captured in this domain include:

- Caregiver Burden
- Family Cohesion
- Family Chaos

By considering these outcomes, researchers can better understand the interplay between caregiver well-being and the management of pediatric ADHD, as well as which treatments best support the family holistically.

### ***3.2 Tools for Assessing Patient-Centered Pediatric ADHD Outcomes***

Assessing ADHD outcomes requires reliable, validated instruments that capture symptom severity, functional performance, emotional well-being, and related domains across multiple settings. Standardized tools play a critical role in clinical care and research by providing structured measures that inform diagnosis, monitor treatment progress, and evaluate patient-centered outcomes. These tools, along with clinical interviews and broad-based symptom screening, are the cornerstone of measurement-based care, the standard for ADHD treatment.<sup>56</sup> Measurement-based care is especially essential in ADHD because it quantifies symptom patterns and functional impairments in ways that directly inform medication selection and dosage adjustments, where even small changes can meaningfully affect clinical and functional outcomes.<sup>57</sup>

These components of measurement-based care rely on input from parents, teachers, and clinicians to provide a comprehensive picture of the child's functioning across home, school, and community environments. Common instruments include symptom-focused rating scales, behavioral inventories, and quality-of-life measures.

**Appendix C** summarizes the most used instruments identified in the literature, highlighting their purpose and scope. Together, these tools provide a multi-dimensional framework for assessing ADHD outcomes, ensuring that treatment decisions and research priorities reflect clinical, behavioral, and psychosocial symptoms, as well as the lived experiences of children and their caregivers.

### ***3.3 Extracting Patient-Centered Outcomes for ADHD from Clinical Notes***

While standardized tools provide structured approaches to measurement, much of the relevant information resides in clinical notes. Clinical notes, however, are unstructured records of patient encounters created for many purposes (e.g., clinical communication, documenting decision-making,

meeting legal and billing requirements, and care coordination) and therefore vary widely in content, emphasis, and level of detail.<sup>58</sup> Manually extracting patient-centered outcomes for pediatric ADHD from clinical notes presents several challenges:

- **Lack of data standardization.** There is variation across providers and sites in format and structure (e.g., use of shorthand or abbreviations) regarding how non-clinical services or observations, such as education support, are documented.<sup>59</sup> This lack of data standardization makes it difficult for researchers to extract information reliably across providers. Particularly for pediatric ADHD, care frequently involves multidisciplinary inputs in addition to clinicians (e.g., teachers, caregivers, behavioral specialists). Observations from these individuals may all be recorded differently with inconsistent terminology, making harmonization difficult.
- **Unclear or incomplete data.** Clinical notes often contain ambiguities, making contextual details and timing of events unclear (e.g., “history of disruptive behavior” vs. “current disruptive behavior”). For pediatric ADHD, this challenge can be particularly pronounced as documentation spans multiple domains (e.g., medical, behavioral, educational) and requires tracking improvement or worsening of different symptoms over time.
- **Use of uploaded documents.** The format of ADHD outcomes data may make extraction difficult, as they may be housed in PDF uploads of completed tools or instruments. Information uploaded as a PDF or other file format may appear as an image in the EHR rather than as discrete, readable text.<sup>60</sup> Such uploaded documents cannot be easily parsed through direct querying, and additional preprocessing steps (e.g., transforming scanned files into machine-readable text) must be completed to extract usable data for research.<sup>61</sup> Additionally, tools for assessing patient-centered pediatric ADHD outcomes originate from multiple informants and formats and are often stored in different parts of the EHR—such as structured fields, narrative clinical notes, or scanned and uploaded documents.<sup>59</sup> This fragmentation can make outcome data difficult to retrieve consistently and can hinder efforts to triangulate information across sources for effective measurement-based care.

Extracting pediatric ADHD patient-centered outcomes data from EHRs is an issue across settings that may disproportionately affect resource-constrained clinical settings, such as FQHCs. These organizations often face limited technical infrastructure, staffing, financial resources, and limited data exchange across systems, making it difficult to implement advanced data integration tools.<sup>62</sup>

NLP techniques can address the above challenges by supporting terminology normalization and contextual awareness, thus making sense of clinical notes.<sup>62</sup> For example, NLP can be used to standardize different ways of stating the same thing (e.g., standardizing variations in medication names).<sup>63</sup> NLP can also help researchers understand context by modeling linguistic cues such as tense, temporality, negation, and clinical modifiers within clinical notes. For example, NLP can clarify whether a note is stating a child currently has symptoms or has had them in the past.<sup>64</sup> **Exhibit 3** below presents examples from the literature of NLP applications for analyzing clinical notes of patients with ADHD to examine outcomes.

#### **Exhibit 3. Example NLP Applications for Analyzing Clinical Notes for Patients with ADHD**

Measure how often outpatient primary care physicians talk with patients/caregivers about educational support and how often they collect educational records.<sup>17</sup>

Identify high-value terms indicative of ADHD symptoms.<sup>65</sup>

### Exhibit 3. Example NLP Applications for Analyzing Clinical Notes for Patients with ADHD

Evaluate clinical notes to identify whether they included recommendations for behavioral treatment.<sup>66</sup>

Identify whether clinicians documented side-effect monitoring in notes as a measure of quality of ADHD medication management.<sup>67</sup>

Extract references to mood instability and cannabis use to determine whether mood instability was associated with increased cannabis use among youth with ADHD or depression.<sup>68</sup>

Recent efforts to extract information from clinical notes have shifted towards open-source large language models (LLMs).<sup>66,69</sup> Modern LLMs are general-purpose foundation models capable of performing diverse tasks across multiple domains, often without additional training, that can leverage advanced NLP capabilities through methods such as in-context learning, retrieval-augmented generation, and domain-specific fine-tuning. LLMs can enhance efficiency and scalability by processing large volumes of clinical notes and improving accuracy, often outperforming traditional NLP methods.<sup>70</sup> Additionally, LLMs have made it easier to parse documents uploaded in the EHR (including PDFs and scanned forms); these tools can preprocess and standardize terminology within these documents without requiring structured templates.<sup>71</sup> FHQCs and other resource-constrained settings may particularly benefit from open-source LLMs, given that they are free to license, and customizable to meet local needs. However, important considerations regarding these models include data privacy and governance concerns, potential hallucinations (i.e., fabricated output), and computational costs.<sup>70</sup>

### 3.4 Candidate Datasets for Extraction

Identifying effective NLP-based methods for extracting patient-centered ADHD outcomes requires access to appropriate datasets. However, there are limited datasets available that capture pediatric ADHD outcomes in sufficient detail. Through our literature review and consultation with a SME, we reviewed 16 unique datasets and identified four candidate datasets that meet key inclusion criteria.

The four identified datasets vary in accessibility, scope, and data richness. For example, some require formal data use agreements (DUAs) and institutional review board (IRB) approval, whereas others provide more streamlined request processes. Additionally, the American Family Cohort<sup>72</sup> and NeuroBlu<sup>73</sup> datasets offer limited coverage of patient-reported outcomes (PROs) through diagnostic instruments (e.g., Patient Health Questionnaire-9 [PHQ-9]),<sup>74,75</sup> while others primarily include clinician-documented notes. **Exhibit 4** summarizes these candidate datasets, including descriptions and access details.

**Exhibit 4.** Candidate Datasets for Pediatric ADHD Outcomes Extraction

| Dataset                                                                  | Description                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         | Access Details                                                                                                                                                                                                                         |
|--------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| American Family Cohort (AFC) <sup>72</sup>                               | AFC is a large research dataset derived from the American Board of Family Medicine’s PRIME Registry, the largest primary care clinical data registry in the U.S. It contains de-identified EHR data from more than eight million patients (pediatric and adult) from 2010–2024 spanning all 50 states. The dataset includes demographics, diagnoses, medications, procedures, encounters, clinical notes, and PROs, all standardized into the Observational Medical Outcomes Partnership (OMOP) Common Data Model. <sup>76</sup> Additionally, the dataset includes patients on private insurance plans, Medicare, and Medicaid. <sup>77</sup>      | Access requests can be made via Stanford Center for Population Health Sciences website:<br><a href="https://phsdocs.developerhub.io/start-here/getting-data-access">https://phsdocs.developerhub.io/start-here/getting-data-access</a> |
| NeuroBlu <sup>73</sup>                                                   | NeuroBlu is a real-world data (RWD) platform developed by Holmusk that aggregates de-identified EHR data from U.S. mental health providers using the MindLinc EHR system. It is designed to support research and analytics in psychiatry and behavioral health. This database allows for extraction of pediatric ADHD outcomes related to symptom severity and treatment patterns. <sup>78</sup>                                                                                                                                                                                                                                                    | Access requests can be made via website:<br><a href="https://www.neuroblu.ai/#Contact-Us">https://www.neuroblu.ai/#Contact-Us</a>                                                                                                      |
| Partners Health Care Research Patient Data Registry (RPDR) <sup>79</sup> | RPDR is a clinical data warehouse developed by Partners Health Care to support research and quality improvement. It integrates data from multiple hospital systems, including Massachusetts General Hospital and Brigham and Women’s Hospital, providing researchers with access to de-identified patient information. RPDR enables extraction of symptom- and care-related information from clinical notes. <sup>80</sup>                                                                                                                                                                                                                          | Access requests can be made via DUA & IRB approval:<br><a href="https://rpdrssl.partners.org/register">https://rpdrssl.partners.org/register</a><br><br><i>*Access temporarily unavailable</i>                                         |
| PEDSnet <sup>81</sup>                                                    | <p>PEDSnet aggregates EHR data from leading U.S. children’s hospitals. It examined children aged 3–5 years with ADHD-related encounters and at least six months of follow-up. This database allows for the extraction of outcomes related to diagnosis and treatment.<sup>82</sup></p> <p>PEDSnet does not currently include clinical notes as part of its centralized data repository. However, the network has established workflows with participating institutions to obtain and analyze unstructured clinical notes for natural language processing, and this capability has been leveraged in multiple published studies.<sup>83 84</sup></p> | Request can be made via PEDSnet website:<br><a href="https://pedsnet.org/database/access-to-data/">https://pedsnet.org/database/access-to-data/</a>                                                                                    |

## 4. Discussion

Patient-centered outcomes data for pediatric ADHD are often captured in clinical notes. These data, which often come from multiple sources (e.g., clinicians, teachers, parents), include critical information on aspects of a patient's life that can indicate how well they are responding to treatment such as their interactions with peers and their level of independent functioning.

In this report, we have identified patient-centered outcomes for pediatric ADHD from the literature and examined the challenges with extracting patient-centered outcomes from clinical notes. Measurement-based care in pediatric ADHD often relies on diverse inputs (e.g., clinical interviews, free-text notes, standardized rating scales). As a result, data are stored inconsistently across the EHR in terms of how and where they are documented (e.g., appearing in various places in the EHR, scanned or uploaded documents). This fragmentation makes it difficult to access patient-centered outcomes in a standardized, reproducible way. Extracting these data is further complicated by variability in terminology and ambiguity within clinical notes.

Opportunities to expand this work and help address the challenges we identified include the following:

- **Improve Quality of Patient-Centered Outcome Documentation.** Patient-centered outcomes for ADHD are often unstructured. Qualitative research (e.g., interviews or focus groups) with stakeholders such as patients, caregivers, teachers, primary care providers, and behavioral health providers could be beneficial in understanding how different stakeholders define, prioritize, and document meaningful outcomes related to ADHD. These stakeholders could then be involved in co-designing standards for how these outcomes should be documented in the EHR. Qualitative findings could be refined using a Delphi panel process to reach consensus on priority outcomes and documentation practices.
- **Expand Data Availability to Conduct PCOR and CER.** Future efforts could focus on expanding the availability of de-identified clinical notes and candidate datasets to conduct PCOR regarding pediatric ADHD, including the development, training, and validation of NLP methods. In addition, expanding data resources would support future opportunities to demonstrate proof-of-concept applications of NLP for both PCOR and CER. High-value candidate datasets for this use case would include longitudinal clinical documentation that captures symptom trajectories, treatment changes, and functional outcomes over time, as well as multi-informant data reflecting input from clinicians, parents, teachers, and behavioral health providers.
- **Develop Prototype Annotation Schema for Patient-Centered ADHD Outcomes.** To provide a consistent structure for labeling and categorizing patient-centered ADHD outcomes, a future step for research could be to create and validate a prototype annotation schema. This could ensure that different researchers or clinicians consistently annotate data on patient-centered outcomes, enabling the data to be reliably used to evaluate and train AI models. Once the schema is developed, the next step could be to conduct inter-rater reliability studies and benchmark NLP models using the schema to assess reproducibility.

## 5. Conclusion

Pediatric ADHD is a condition that impacts millions of children in the U.S. and requires a coordinated approach across multiple settings, including clinical, academic, and social. This report emphasizes the

importance of studying patient-centered outcomes data in pediatric ADHD research, provides detailed examples from the literature, describes challenges in extracting these data, and outlines how NLP methods can help address those challenges. Further, the report highlights available EHR datasets that researchers can use to extract patient-centered ADHD outcomes data using NLP methods. These findings can support the use of EHR data to conduct pediatric ADHD PCOR, ultimately ensuring that future research on treatments reflects the outcomes that matter most to patients and their caregivers.



## Appendix A. Environmental Scan Details

**Exhibit A1.** Inclusion and Exclusion Criteria

| Category                | Inclusion Criteria                                                                                                                                                                                                                                                                                                | Exclusion Criteria                                                                                      |
|-------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------|
| <b>Publication Year</b> | Peer-reviewed journal articles: 2015-present<br><br>Grey literature: 2015-present                                                                                                                                                                                                                                 | Peer-reviewed journal articles: Before 2015<br><br>Grey literature: Before 2015                         |
| <b>Document Type</b>    | Peer-reviewed journal articles: Primary and secondary data analyses, scoping review, meta-analyses/systematic reviews<br><br>Grey literature: Reports, working papers, evaluation studies, white papers, conference proceedings, presentations, case studies, fact sheets, issue briefs, and government documents | Peer-reviewed journal articles: Conference abstracts/proceedings<br><br>Grey literature: Opinion pieces |
| <b>Language</b>         | English                                                                                                                                                                                                                                                                                                           | Non-English                                                                                             |
| <b>Source</b>           | Academic, expert, evaluator                                                                                                                                                                                                                                                                                       | News outlet                                                                                             |
| <b>Population</b>       | Pediatric ADHD (ages 4-18)                                                                                                                                                                                                                                                                                        | Adult ADHD (older than 18 years)                                                                        |
| <b>Focus</b>            | Discusses pediatric ADHD in terms of patient-centered outcomes, clinical documentation of patient-centered outcomes, NLP application to pediatric ADHD clinical notes, data extraction challenges in FQHC or primary care settings, or potential pediatric ADHD data sets.                                        | Discusses adult ADHD, no patient-centered outcomes discussed                                            |

**Exhibit A2.** Literature Review Search Terms

| Search Term Category             | Example Terms                                                                                                                                                               |
|----------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Pediatric ADHD</b>            | "Attention Deficit Disorder with Hyperactivity"[MeSH]; "Child"[MeSH]; "Adolescent"[MeSH]                                                                                    |
| <b>Patient-Centered Outcomes</b> | "Patient Outcome Assessment"[MeSH]; "Quality of Life"[MeSH]; "functional outcomes"; "patient-centered outcomes"[MeSH]; "patient-reported outcomes"[MeSH]; "treatment goals" |

| Search Term Category                   | Example Terms                                                                                                                                                                                                                                                        |
|----------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Clinical Documentation</b>          | <b>Documentation:</b> “Documentation practices”; “note quality”; “clinical notes”; “clinical documentation”; “documentation challenges”<br><br><b>EHR Data:</b> "Electronic Health Records"[MeSH]; “health information exchange”; health records”; “medical records” |
| <b>NLP Application</b>                 | "Natural Language Processing"[MeSH]; "Machine Learning"[MeSH]; “clinical notes”; annotation schema”; “free text analysis”                                                                                                                                            |
| <b>Primary Care and FQHCs Settings</b> | “federally qualified health center”; “community health centers[MeSH]”; “rural health[MeSH]”; “low-resource settings”; “primary health care[MeSH]”                                                                                                                    |
| <b>Pediatric ADHD Datasets</b>         | <b>Data Sets:</b> "Databases, Factual"[MeSH]; "Registries"[MeSH]; dataset                                                                                                                                                                                            |

**Exhibit A3.** Key Fields for Data Abstraction

| Field Type/Category                                                                  | Specific Fields                                                                                                                                                                               |
|--------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Resource Metadata                                                                    | Reference details [author_pubyear_pubsource]<br>Article name<br>Full citation with hyperlink to the DOI if available                                                                          |
| Patient-Centered Outcomes in Pediatric ADHD                                          | Outcomes identified<br>Patient or caregiver perspective provided<br>Measures used, if applicable (e.g., Patient-Reported Outcomes Measurement Information System)<br>Documentation of outcome |
| Challenges in Clinical Documentation of Patient-Centered Outcomes for Pediatric ADHD | Documentation inconsistencies noted<br>Use of structured vs. unstructured clinical data<br>Setting-specific challenges noted                                                                  |
| NLP Application to Pediatric ADHD Clinical Notes                                     | NLP methods used (e.g., sentiment analysis)<br>Annotation schema details<br>Outcomes extracted<br>Performance metrics, if available<br>Limitations and edge cases identified                  |
| Limited Extraction in Primary Care and FQHCs                                         | Setting type<br>Barriers to data extraction (e.g., note quality, EHR variability)<br>Representation of underserved populations<br>NLP feasibility discussed                                   |
| Pediatric ADHD Datasets                                                              | Dataset name<br>Population characteristics<br>Data types available (e.g., free-text notes)<br>Strengths                                                                                       |

| Field Type/Category | Specific Fields                                                                       |
|---------------------|---------------------------------------------------------------------------------------|
|                     | Limitations<br>Access requirements<br>Relevance to patient-centered outcomes research |

## Appendix B. List of Pediatric ADHD Outcome Descriptions

### Exhibit B1. Pediatric ADHD Outcome Descriptions

| Pediatric ADHD Outcome                                                 | Description                                                                         |
|------------------------------------------------------------------------|-------------------------------------------------------------------------------------|
| <b>Symptom-Related Outcomes (<i>Inattention</i>)</b>                   |                                                                                     |
| <b>Reduced Attention to Detail</b>                                     | Difficulty giving close attention to details or avoiding careless mistakes          |
| <b>Difficulty Maintaining Attention</b>                                | Difficulty sustaining attention during tasks or activities                          |
| <b>Difficulty Listening</b>                                            | Difficulty listening when spoken directly to                                        |
| <b>Disorganization</b>                                                 | Difficulty organizing tasks and activities                                          |
| <b>Distraction</b>                                                     | Easily distracted by extraneous stimuli                                             |
| <b>Forgetfulness</b>                                                   | Forgetfulness in daily activities                                                   |
| <b>Difficulty with Tasks</b>                                           | Difficulty sustaining effort and completing tasks                                   |
| <b>Difficulty Sustaining Mental Effort</b>                             | Avoidance or reluctance to engage in tasks requiring sustained mental effort        |
| <b>Losing Objects</b>                                                  | Losing things necessary for tasks or activities                                     |
| <b>Symptom-Related Outcomes (<i>Hyperactivity-Impulsivity</i>)</b>     |                                                                                     |
| <b>Leaving Early</b>                                                   | Leaving seat in situations where remaining seated is expected                       |
| <b>Fidgeting</b>                                                       | Fidgeting, tapping, or squirming in seat                                            |
| <b>Restlessness</b>                                                    | Being “on the go,” acting as if “driven by a motor”                                 |
| <b>Running</b>                                                         | Running/climbing in inappropriate situations                                        |
| <b>Difficulty Engaging in Quiet Activities</b>                         | Difficulty playing or engaging in leisure activities quietly                        |
| <b>Excessive Talking</b>                                               | Occurrence of excessive talking beyond situational social norms                     |
| <b>Interruptive Speech</b>                                             | Blurting out answers before questions are completed and finishing others’ sentences |
| <b>Difficulty Waiting Turns</b>                                        | Difficulty waiting turns in certain situations (e.g., conversations, lines, games)  |
| <b>Frequent Interruptions</b>                                          | Interrupting or intruding on others’ activities and/or belongings                   |
| <b>Functional Outcomes (<i>Bodily Functions/Bodily Structures</i>)</b> |                                                                                     |

| Pediatric ADHD Outcome                                           | Description                                                                                                                    |
|------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------|
| <b>Calculating</b>                                               | Ability to perform age-appropriate mathematical calculations and engage in math-related tasks                                  |
| <b>Executive Function</b>                                        | Ability to plan, organize, problem-solve, make decisions, and manage tasks effectively                                         |
| <b>Fine Hand Use</b>                                             | Ability to use hands and fingers for precise, coordinated movements required for tasks such as writing or manipulating objects |
| <b>Reaction Time</b>                                             | Ability to respond accurately and in a timely manner to stimuli or task demands                                                |
| <b>Functional Outcomes (<i>Activities and Participation</i>)</b> |                                                                                                                                |
| <b>Academic Functioning</b>                                      | Ability to participate in learning activities, meet academic demands, and function effectively in school settings              |
| <b>Autonomy</b>                                                  | Ability to make age-appropriate choices, act independently, and manage daily tasks without assistance                          |
| <b>Engagement in Play</b>                                        | Ability to participate in and sustain involvement in age-appropriate play or leisure activities                                |
| <b>Family Relationships</b>                                      | Quality of interactions and relationships with family members                                                                  |
| <b>Following Social Rules</b>                                    | Ability to behave in accordance with social expectations and norms during interactions                                         |
| <b>Formal Relationships</b>                                      | Ability to interact effectively with authority figures such as teachers, coaches, or healthcare providers                      |
| <b>Handling Responsibility</b>                                   | Ability to take responsibility for actions, obligations, and assigned tasks                                                    |
| <b>Household Tasks</b>                                           | Ability to complete household chores and daily responsibilities within the home                                                |
| <b>Informal Relationships</b>                                    | Ability to establish and maintain relationships with peers, friends, or neighbors                                              |
| <b>Mobility</b>                                                  | Ability to move safely and independently within home, school, and community environments                                       |
| <b>Normalcy</b>                                                  | Ability to participate in daily activities in ways that are typical for age and peer group                                     |
| <b>Self-Care</b>                                                 | Ability to manage personal hygiene, health, safety, and basic self-maintenance tasks                                           |
| <b>Coexisting Behavioral-Related Outcomes</b>                    |                                                                                                                                |

| Pediatric ADHD Outcome                            | Description                                                                                |
|---------------------------------------------------|--------------------------------------------------------------------------------------------|
| <b>Defiant Behaviors</b>                          | Quality of defiant behaviors towards authority or established rules                        |
| <b>Disruptive Behaviors</b>                       | Quality of behaviors that interfere with normal functioning                                |
| <b>Coexisting Emotional/Psychosocial Outcomes</b> |                                                                                            |
| <b>Anxiety</b>                                    | Level of excessive worry, fear, or other symptoms of anxiety                               |
| <b>Depression</b>                                 | Symptoms related to depression such as sadness or loss of interest                         |
| <b>Emotional Regulation</b>                       | Ability to manage emotional responses                                                      |
| <b>Mood Changes</b>                               | Level of fluctuations in mood that are disruptive to functioning                           |
| <b>Emotional Wellbeing</b>                        | Quality of overall emotional health                                                        |
| <b>Caregiver Outcomes</b>                         |                                                                                            |
| <b>Caregiver Burden</b>                           | Quality of caregiver stress or strain related to ADHD management                           |
| <b>Family Cohesion</b>                            | Quality of family unity, cooperation, and ability to work together despite ADHD challenges |
| <b>Family Chaos</b>                               | Level of chaos within the family environment                                               |

## Appendix C. Pediatric ADHD Outcome Assessment Tools

**Exhibit C1.** Instruments Used Across Settings to Assess Pediatric ADHD Outcomes

| Tool/Instrument                                                                 | Description                                                                                                                                                                                                                                                                                                                                           |
|---------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Symptom-Related Outcomes</b>                                                 |                                                                                                                                                                                                                                                                                                                                                       |
| <b>ADHD Rating Scale (ADHD-RS / ADHD Rating Scale-IV)<sup>85</sup></b>          | A standardized questionnaire used to measure the severity of ADHD symptoms based on DSM criteria. It typically includes items assessing inattention, hyperactivity, and impulsivity, and can be completed by parents, teachers, or clinicians.                                                                                                        |
| <b>Behavior Rating Inventory of Executive Function (BRIEF)<sup>86</sup></b>     | An instrument designed to measure executive functioning in everyday settings. It assesses areas like inhibition, working memory, planning, and emotional control, typically through parent or teacher reports.                                                                                                                                        |
| <b>Conners Rating Scale<sup>87</sup></b>                                        | This scale includes a widely used set of questionnaires with data collected by teachers, parents, and other individuals to assess symptoms of ADHD and related behavioral and emotional issues. It is used by clinicians to help diagnose and track treatment effectiveness.                                                                          |
| <b>NICHQ Vanderbilt Assessment Form<sup>88</sup></b>                            | This scale is widely used by clinicians to diagnose and monitor ADHD symptoms in children ages 6-12. The information in this form is collected from teachers and parents.                                                                                                                                                                             |
| <b>Pediatric Quality of Life Inventory (PedsQL)<sup>89</sup></b>                | A tool for assessing health-related quality of life in children and adolescents. It covers domains such as physical, emotional, social, and school functioning, and can be reported by both the child and their caregiver.                                                                                                                            |
| <b>Strengths and Difficulties Questionnaire (SDQ)<sup>90</sup></b>              | A brief behavioral screening tool that evaluates emotional symptoms, conduct problems, hyperactivity/inattention, peer relationships, and prosocial behavior. It is commonly used in both clinical and research settings.                                                                                                                             |
| <b>Functional Outcomes</b>                                                      |                                                                                                                                                                                                                                                                                                                                                       |
| <b>Developmental Disability Children's Global Assessment Scale<sup>91</sup></b> | A clinician-rated measure that assesses overall daily functioning in children with developmental disabilities, accounting for cognitive and adaptive differences across home, school, and community settings.                                                                                                                                         |
| <b>Behavior Rating Inventory of Executive Function<sup>92</sup></b>             | A standardized assessment tool used to evaluate executive functioning in children and adolescents ages 5–18. It captures everyday behaviors related to planning, organization, working memory, and self-regulation through parent and teacher report forms and helps identify executive function difficulties commonly associated with ADHD and other |

| Tool/Instrument                                                       | Description                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
|-----------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Weiss Functional Impairment Rating Scale (WFIRS)<sup>93</sup></b>  | neurodevelopmental conditions and provides insight into functioning across home and school settings.<br><br>A validated measure designed to assess functional impairment related to ADHD across multiple life domains, including family, school, social functioning, life skills, self-concept, and risky behaviors. Available in both parent-report (WFIRS-P) and self-report (WFIRS-S) versions, the scale evaluates how emotional and behavioral symptoms affect day-to-day functioning and is sensitive to changes over the course of treatment. |
| <b>Coexisting Behavior-Related Outcomes</b>                           |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Affective Reactivity Index<sup>94</sup></b>                        | A brief measure that assesses irritability in children and adolescents, focusing on the frequency and severity of angry or irritable mood as reported by the child or caregiver.                                                                                                                                                                                                                                                                                                                                                                     |
| <b>Swanson, Nolan, and Pelham Rating Scale (SNAP) IV<sup>95</sup></b> | A brief rating scale used to assess ADHD symptoms and oppositional behaviors in children. It evaluates inattention, hyperactivity/impulsivity, and oppositional defiant traits based on parent or teacher reports.                                                                                                                                                                                                                                                                                                                                   |
| <b>Coexisting Emotional/Psychosocial Outcomes</b>                     |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>ICHOM Revised Child Anxiety and Depression Scales<sup>96</sup></b> | A questionnaire that assesses symptoms of anxiety and depression in children and adolescents, aligned with DSM criteria. It includes child and caregiver versions and helps monitor emotional health across clinical and research settings.                                                                                                                                                                                                                                                                                                          |
| <b>Patient Important Outcomes</b>                                     |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>KIDSCREEN-10<sup>97</sup></b>                                      | A short measure of health-related quality of life in children and adolescents, covering overall physical, psychological, and social well-being through child or caregiver report.                                                                                                                                                                                                                                                                                                                                                                    |
| <b>Caregiver Outcomes</b>                                             |                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      |
| <b>Family Strain Index<sup>98</sup></b>                               | A brief caregiver-reported measure that assesses the stress and burden experienced by families managing a child's chronic health or behavioral challenges.                                                                                                                                                                                                                                                                                                                                                                                           |



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