

POSITION STATEMENT

NASPGHAN position statement: Enabling quality pediatric gastroenterology care through electronic health record data capture and visualization



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Abstract

Clinical practice guidelines are structured recommendations, derived from evidence-based research, aiming to inform, improve, and standardize patient care. This position paper considers the critical role the electronic health record (EHR) plays in data collection and implementation of guidelines. We describe EHR functionalities necessary to make guidelines actionable within the EHR and provide overview of data storage to inform design of data capture tools to reduce overall clinician workload. After reviewing current knowledge and practices, we have formulated the recommendation that NASPGHAN committees should develop clinical guidelines that identify specific and relevant health assessment measures with strong validity evidence, including patient-reported outcome measures. Guidelines should also outline clinical pathways, incorporating clinical decision support algorithms to provide feedback to users, and order sets to ensure the right guidance is provided for the right patient at the right time. Patient populations should be defined by using standard code sets. Committees should identify disease-specific health assessment measures with strong validity of evidence and identify areas where measures are still needed. Committees should offer guidance on population-based disease management and data visualization tools.

For affiliations refer to page 863.

CME module may be found at <https://learnonline.naspgghan.org/jpgn2>

[Correction added on 6 August 2025, after the first online publication: Article format has been updated.]

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Improving the Data Infrastructure of Electronic Health Records to Advance Pediatric Gastroenterology Care

Clinical practice guidelines rely on Electronic Health Records (EHRs) for effective implementation, data collection, and decision support



Enhancing EHR infrastructure can streamline workflows, improve guideline adherence, and ensure high-quality pediatric gastroenterology care

Development of the North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition (NASPGHAN) position statement



Recommendations for enhancing the data infrastructure for EHR



Optimizing EHR data collection protocols, tools, and infrastructure is essential for developing evidence-based guidelines and ensuring the quality of pediatric gastroenterology care

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1 | INTRODUCTION

Clinical practice guidelines serve as structured recommendations, derived from evidence-based research, aiming to inform, improve and standardize patient care.¹ While pediatric gastroenterology, hepatology, and nutrition (abbreviated heretofore as PGI) guidelines exist for a range of topics, lack of high-quality evidence in many areas limits development of evidence-informed guidelines. Additionally, when guidelines are generated, it has historically taken upwards of 17 years for clinical practice to change.^{2–6}

Electronic health records (EHRs) are digital records of patient health information that capture and store data. These systems are dynamic repositories capable of integrating guidelines to provide real-time decision support to ensure providers get the *right* information at the *right* time to perform the *right* action. Furthermore, EHR integration of guidelines has the potential to foster continuous improvement by collecting process and outcomes data which can be analyzed to inform modification of guidelines based on real-world evidence. This synergy between clinical practice guidelines and EHRs has the potential to enable a more adaptive and patient-centered approach to care.

Although EHRs hold promise in bridging the gap between guideline development and practical application, this potential has yet to be realized.⁷ The purpose of this North American Society for Pediatric Gastroenterology, Hepatology, and Nutrition (NASPGHAN) Position Paper is to provide an overview of the EHR data infrastructure necessary to enable multicenter data compilation for guideline development and to generate clinical decision support (CDS) based on clinical practice guidelines to inform and ensure quality clinical care. Additionally, it aims to establish recommendations to help ensure data informed NASPGHAN guidelines are computer interpretable and actionable to

What is Known

- Development of evidence-based guidelines in pediatric gastroenterology, hepatology and nutrition is limited by the relative rarity of associated health conditions and inefficiencies in collection of high-quality data.
- Electronic health records (EHRs) are digital records of patient health information that capture and store data.
- While EHRs hold promise in bridging the gap between guideline development and practical application, this potential has yet to be realized.
- EHRs can integrate guidelines to provide real-time decision support to ensure providers get the *right* information at the *right* time to perform the *right* action.

What is New

- Prioritizing investment in data infrastructure and architecture is crucial to support clinical care, research, and quality improvement endeavors.
- Evidence-based guidelines should define relevant patient populations using EHR code sets, identify health assessment measures and outline clinical pathways alongside clinical recommendations to fully realize the potential of the EHR to ensure high-quality care for all patients.
- All members of NASPGHAN, from clinicians to Committee members, have a role in contributing to the EHR investments necessary to support high-quality pediatric gastroenterology care, required research, and the effective implementation of evidence-based guidelines in clinical practice.

facilitate clinical implementation. By offering a roadmap leveraging EHR functionalities, this Position Paper endeavors to enhance the applicability and impact of NASPGHAN guidelines within PGI practice and streamline the generation of real-world evidence essential for informing the development and revision of PGI guidelines.

2 | METHODS

The Initial content was developed by the NASPGHAN EHR Special Interest Group (SIG), with a writing group established for the Position Statement and approved by NASPGHAN. Relevant literature was reviewed using the PubMed/MEDLINE databases with search terms including learning health systems, health informatics, data management, pediatrics, gastroenterology, hepatology, nutrition. Non-English literature was excluded. Of the 14 references initially reviewed for relevance, two were selected for inclusion. A subsequent search without the restrictions of gastroenterology, hepatology, and nutrition, yielded 121 references, from which four additional relevant sources were included, bringing the total to six.

The authors developed recommendations for each section based on available literature and expert opinions. These recommendations were then voted on by the nine authors, with options to approve, disapprove, or abstain. Given the limited quantity and quality of data, no formal grading method was used to appraise the quality of evidence for each recommendation. Each section was drafted by individual authors, reviewed, and edited by coauthors. The final manuscript and recommendations were reviewed and approved by all authors. Subsequently, the manuscript and recommendations were reviewed by the NASPGHAN EHR SIG members through electronic communication and approved by the NASPGHAN Executive Council.

3 | BACKGROUND AND POTENTIAL

In 2009, the Health Information Technology for Economic and Clinical Health Act was enacted in the United States to accelerate EHR adoption, promote meaningful use and, ultimately, improve outcomes. Unfortunately, the subsequent rapid EHR adoption across clinics and health systems resulted in the implementation of a variety of EHRs creating data silos.⁸

Recent US regulations have attempted to remedy the difficulty of data sharing across established data silos. For example, government EHR certification programs require vendors to provide minimum data standards and EHR tools.⁹ In response, the market share has shifted to large EHR vendors,¹⁰ with most pediatric

hospitals utilizing Epic Systems Corporation (Madison, WI) or Oracle Cerner (Kansas City, MO).^{10,11} Data sharing and interoperability has also been motivated by the 21st Century Cures Act (21CCA) which mandates sharing of EHR data with patients and across health systems.¹²

Technologic EHR advances have attempted to reduce errors and standardize care. Computerized provider order entry (CPOE) has been shown to effectively reduce errors.¹³ Integration of clinical decision support (CDS) has assisted in decision-making and adherence to guidelines.^{14,15}

Ideally, improved data sharing and tools allow for the creation of a Learning Health System (LHS), where patient care data are systematically integrated with research evidence, enabling knowledge to be directly applied to inform clinical practice.¹⁶ Within an LHS, data collected during routine care can be used to not only enhance evidence-based decision-making at the bedside but also, in combination with data from other institutions, to update clinical guidelines, refine best practices, and generate new knowledge. This creates an iterative feedback loop, whereby research and QI findings improve patient care and insights from patient care inform research and quality improvement (QI) efforts, establishing a system capable of learning from its actions to continuously improve patient care. By investing in EHR tools and workflows for standardized data capture and reporting, data visualization, and identifying clinical pathways to inform CDS, the PGI community can move towards creating such an LHS.¹⁶ The potential exists to establish a LHS locally initially with spread across multiple institutions (Figure 1).

4 | CURRENT STATE

Due to the relative rarity of PGI health conditions, multi-institutional data are required to conduct research that is generalizable. Efforts have been made to create standardized data models across pediatric centers. Examples include the Pediatric Health Information System (PHIS), which collects data from over 50 children's hospitals and the PEDSnet multi-specialty, multi-hospital research-focused database.^{17,18} Collaborative networks specific to PGI include ImproveCareNow (ICN), a multicenter QI network established in 2007 to improve pediatric inflammatory bowel disease outcomes^{19,20} and the International Study Group of Pediatric Pancreatitis: In Search for a Cure (INSPPIRE) network developed for pediatric pancreatitis.^{18,21}

Despite the growing number of research and QI-focused networks, data collection often requires data transformation to enable data utility within the established data model which can introduce bias. Because EHRs offer advanced tools that are highly configurable,

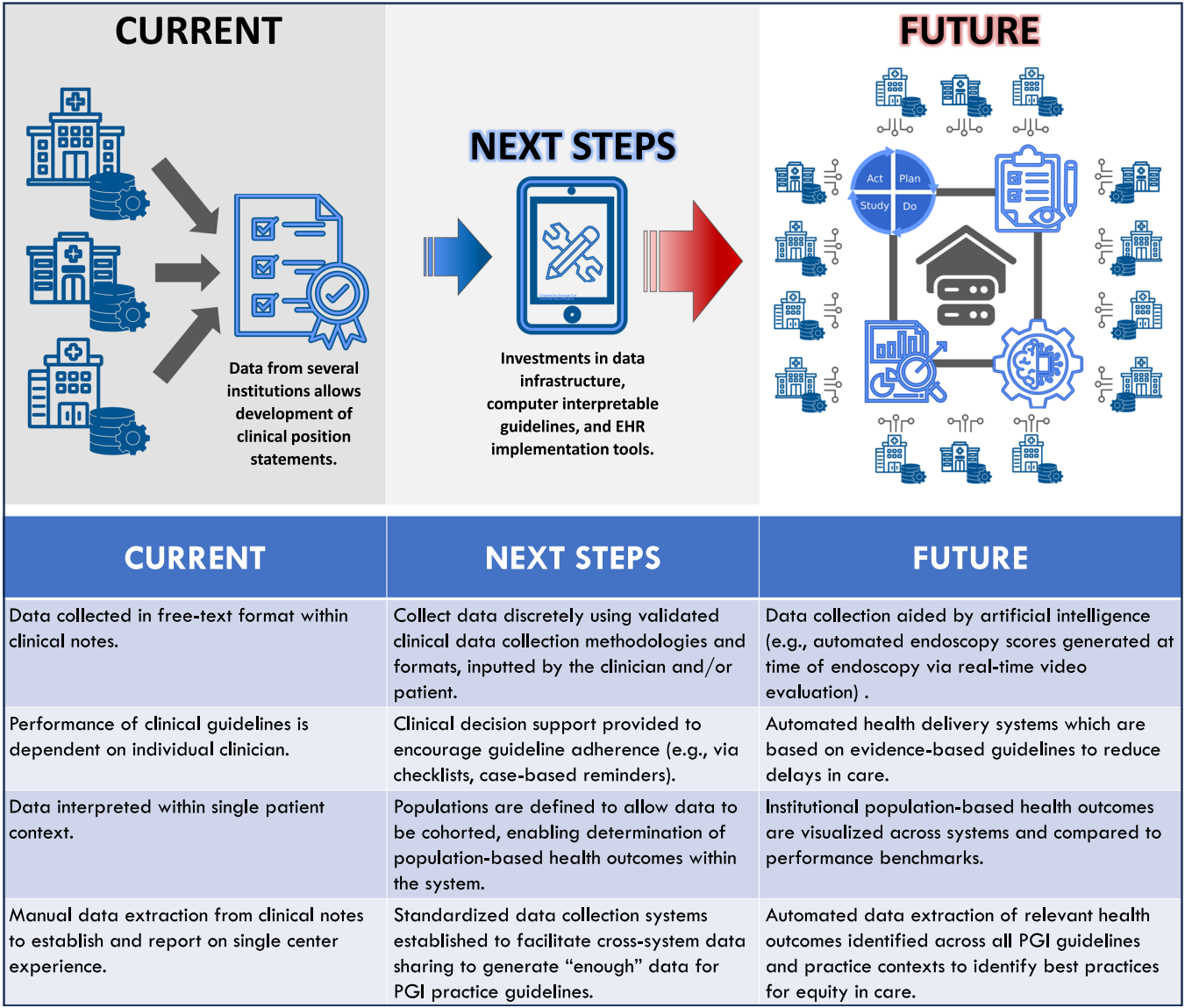


FIGURE 1 Learning health system. Creating standardized data dictionaries, computer interpretable guidelines, and tools for implementation leads to a future (moving from A to B) by which data can be collected and used to improve patient care within and across multiple health systems.

data can be collected during routine clinical care that do not require transformation before use. Standardized data collection tools can (and should) be designed to reduce bias in data entry and processing. Further work is needed to refine formation of guidelines to facilitate standard data capture and support decision-making.

5 | DATA CAPTURE

A foundational step for sharable data capture during clinical workflows is the creation of a data dictionary that identifies and defines relevant patient populations along with associated clinical and outcome variables being captured.²² Data dictionaries help ensure a clear understanding of each data element, its purpose, structure, and method of collection, and to promote

organization, understanding and efficient utilization of data within an EHR.^{23–25}

The literature is replete with research using highly variable populations and outcome definitions (e.g., definitions of clinical remission or response to disease therapies and data collection protocols²⁶). Despite attempts in meta-analyses to amalgamate data for comparison across studies, the quality and ability to compare disparate data frequently suffers, limiting application and generalizability of findings.^{27–29} Lack of standards and uniformity in data collection limits the capacity of the PGI community to consolidate data in adequate quantities necessary to inform the development of high-quality guidelines.

The issue of bias in healthcare data is paramount to this discussion. The main issue is whether data captured during healthcare delivery can adequately serve

other purposes including those related to research and monitoring health outcomes. Verheij et al. have identified nine possible sources of bias when using and re-using healthcare data for purposes other than healthcare delivery.³⁰ Whether these are actually significant sources of bias remains to be ascertained, but it is important to actively scrutinize EHR derived data for potential bias and purposefully set forth strategies to mitigate and reduce bias whenever possible.

Clear definition of outcome measures and metrics is crucial to simplify EHR implementation and promote seamless data sharing. Use of validated classification and coding systems with strong validity evidence (e.g., Endoscopic reference score (EREFS),³¹ Paris classification³²) is preferable. However, such standards frequently are not available in which case data variables must also be precisely defined.

There are already exemplars in the literature promoting and utilizing common data entry models. One well-established model is PEDSnet, a large national multispecialty network of children's hospital health systems that developed a longitudinal data resource dating back to 2009 to support observational research and clinical trials aimed at improving pediatric healthcare outcomes. Recent work relevant to this discussion includes the development and evaluation of an EHR-based computable phenotype to identify pediatric patients with Crohn disease.^{17,33} Additionally, the recent Pediatric Endoscopy Quality Improvement Network (PEnQuIN) guidelines, which outlined quality standards and indicators for pediatric endoscopy, meticulously defined each quality indicator to ensure standardized measurement.^{34,35} Further, to ensure that one is capturing identical data, data definitions must be universally understood (i.e., when using ratios, one needs to ensure the numerator and denominator are equivalent across sites).

Standardized data collection protocol recommendations should also be included to ensure data integrity and quality. Furthermore, such protocols can ensure data are optimized for development and maintenance of future AI algorithms. For example, weights should be performed without clothing or shoes. Lengths should be performed for children <2 years.³⁶ Race and ethnicity data should be self-reported and not based on data attributed to the patient by another.³⁷ Another important example includes precise definitions of time. For example, hospital length of stay is defined as time from admission to discharge. However, admission time may be attributed to many timepoints: check-in time to the emergency department, arrival time to an inpatient unit, or time of admission order, etc. Similarly, discharge time can be time of discharge order or when patient leaves the hospital. Clearly defining which timepoint to use reduces ambiguity in interpretation ensuring accurate comparisons and interpretation of findings.

5.1 | Data storage

To design data capture tools that can store data elements in a shareable format requires an understanding of data architecture, terminology, and interoperability. Data architecture refers to the predefined policies of an institution that determine how data flows and is managed from collection to transformation, distribution, and consumption. Data terminology, commonly called codes, refers to a structured data format that enables interoperability or transfer between EHR systems.³⁸ Data terminologies are broadly used, and have been created and maintained, at the international or national level. Table 1 reviews commonly used standard terminologies for sharing healthcare data that enable interoperability.

Together, the location within a data architecture and format of captured data is defined as a data element.³⁹ EHR vendors may have standard data elements for general use across sites or institutions may develop their own. When a data element is equivalent across sites, no processing is required for sharing between EHRs. However, if the location and/or formatting is different, transformation is required before comparison. A common problem of data location is data redundancy, where a single datapoint is captured in multiple locations within a data architecture (e.g., collecting contact information in different fields in the EHR instead of one centralized location), which leads to inconsistencies, data inaccuracies, and missed opportunities for data integration. An example data format issue is related to time stamps. For the time 8:30 pm, one institution may store the data in military time (i.e., 2030) and another in civilian time (i.e., 830) with a category list (AM/PM). Additionally, data can be stored in EHRs in many different formats which can complicate integration. Common EHR data formats include category lists (i.e., single or multi-selection from predefined options), numbers, (i.e., numerical value), Boolean (i.e., two possible categories), or strings (i.e., free-text).

A critical solution is the thoughtful creation of data elements, since once created, a single data element will collect and display data in multiple places within clinical workflows and the EHR. A single data element should be used for each narrowly defined data dictionary term. Other terms can be used for context. For example, endoscopy start time may be documented on a certain screen for a main operating room (OR) case but a different screen for a case in the endoscopy suite. Using the same data element (e.g., CaseStartTime) in both locations ensures that endoscopy start time will be collected in a uniform format. This allows for consistent display across contexts (schedule display, note, report, etc.) and facilitates data comparisons across sites. Another separate data element (i.e., CaseLocation) can provide context. Conversely, if the operating room start time and endoscopy start time are configured as different data elements (e.g., ORStartTime and

TABLE 1 Standard terminologies used when sharing healthcare data that enable interoperability.

Code terminology	Common use case	Limitations/comments
ICD (International Classification of Diseases) Codes	Patient cohort identification	May lack specificity
SNOMED CT (Systemized Nomenclature of Medicine – Clinical Terms)	Standardized, international, multilingual core set of clinical healthcare terminology	Does not work well as an interface terminology (i.e., for presentation to end users) or for administrative purposes (reimbursement or external reporting) because of its immense size, considerable granularity, complex hierarchies, and lack of reporting rules
NDC (National Drug Code)	Package-level information about specific drugs	Can also consider medication class
CPT (Current Procedural Terminology)	Patient cohort or procedure documentation	May lack specificity
LOINC® (Logical Observation Identifiers Names and Codes)	Clinical terminology used for laboratory test orders and results	Requires mapping to individual lab information systems.
RxNorm	Set of codes for clinical drugs, which are the combination of active ingredients, dose form, and strength of a drug	Reduces ambiguity when it comes to identical medications that have different names
DSM (Diagnostic and Statistical Manual of Mental Disorders)	Authoritative guide for diagnosing mental health disorders	Weaknesses in reliability, validity, cultural sensitivity, and medicalization of normal behaviors and emotions.

EndoStartTime), data will be stored in two separate locations, requiring combination into another data element for evaluation across site.

Data context (i.e., whether data are patient level or encounter level) is another important concept. Patient level metrics such as birth date and sex at birth are unlikely to change and do not require manual entry or validation at every visit. Conversely, encounter-level metrics require the clinician, staff, or the patient to enter or confirm data at each appointment (e.g., symptom data, allergies, and medication list).

5.2 | EHR data cohorting/consolidation

Pediatric gastroenterologists serve many patient populations that are often categorized into clinical cohorts by organ or disease. Accordingly, data must be evaluated from these contexts. One method to cohort data is to create groupings or registries so that data can be analyzed in clinical context. Similarly, consolidation of these data enables population health management or data visualization and analysis for clinical interpretation and utility.

Guidelines should provide clear definitions on what codes should be used to identify patient cohorts. Patient populations may be defined within the EHR by auto-cohorting groups of patients into registries by diagnoses or problem lists using established data terminologies (e.g., International Classification of Disease (ICD) or Systemized Nomenclature of Medicine (SNOMED) (see Table 1)), as has been previously performed in PED-SNet. While internationally recognized standards enable a common code set, medical record diagnoses or

problem lists are often inaccurate, and some rare conditions do not possess recognized diagnostic codes. Thus, further refined definitions (inclusion and exclusion criteria) of groupings or registries must be provided by experts to enable valid and appropriate cohorting of data. In general, registries should be more broadly defined to bring in data from all sub cohorts of a given population of interest. Finally, as is standard per the REporting of studies Conducted using Observational Routinely-collected Data (RECORD) guidelines (www.record-statement.org), before widespread usage of coding strategies, validation of extracted or cohorted data via manual chart review must be performed.⁴⁰

5.3 | EHR data collection tools

Clinical notes provide a rich source of data. However, most note data are not computer interpretable and have to be laboriously reformatted into discrete data for analysis.⁴¹ Integrating data elements into clinical note templates can standardize data collection and increase compliance with documentation⁴² but require providers to select from predefined categories.⁴¹ Common non-interpretable data recorded in notes is the clinical judgment of patient health status, often using personal definitions of “better” or “worse.” What is needed instead is a ClinicalDiseaseStatus data element allowing single selection of well-defined categories of quiescent, mild, moderate, and severe.²⁴

Another tool that can be utilized to collect data is the standardized questionnaire where patients enter discrete data using predetermined answer categories.⁴³ Additional benefits of these patient-reported outcome

measures (PROM) include the standardized collection method (same question, same wording, same answer categories) at each visit. Wherever possible, it is recommended to employ measures with strong validity evidence, particularly when the patient serves as the primary information source (e.g., PedsQL or IMPACT-III for quality of life^{44,45}). Further, patients often value incorporation of their perspective/answers in the note as it demonstrates their participation as a note coauthor.⁴⁶

5.4 | Operational considerations

Due to the personalized nature of clinical note creation among EHR users, adopting standardized note templates can pose challenges and be perceived as onerous. To mitigate these issues, user-centered design principles should be employed, involving clinical experts throughout the note template development process, and conducting usability testing to ensure ease of use.⁴² Note templates can automatically pull data from other sources such as standardized questionnaires, lab results, or problem lists to reduce documentation burden.⁴² Well-constructed note templates can promote adoption, enhance efficiency, and make data sharing within and across institutions a reality.^{42,47}

Use of applications connected to EHRs through application programming interfaces (APIs) can potentially enhance data capture using advanced tools such as artificial intelligence (AI). Examples include natural language processing (NLP) and generative AI tools (e.g., ChatGPT) that can automate documentation (e.g., patient-provider conversations, procedural encounters) or translate free-text data into discrete data categories (i.e., ascertaining diagnoses from free-text pathology reports or identifying disease states from free-text descriptions of symptoms).⁴⁸ However, recent literature reviews suggest further work is needed before full implementation and seamless clinical utility. While NLP holds promise to extract meaningful data from free-text notes,^{48,49} availability is currently not widespread within EHRs.

Generation of standardized data collection tools unfortunately does not ensure universal adoption or use.⁵⁰ Although these tools can be set up to mandate data entry, the necessity for such entry must be weighed against the associated burden. In cases where data entry is prioritized, both QI and implementation science methods may help to both improve data entry completion and maintain data quality and integrity. Baseline and continuous data entry monitoring should be performed to detect gaps that require improvement and assess the effects of related interventions. Additionally, process and workflow mapping should be performed to uncover opportunities for interventions and to identify alternate, potentially more reliable sources of information that could replace clinician documentation and reduce the burden of data entry.

6 | DATA VISUALIZATION

Standard data dictionaries enable development of standardized data reporting and visualization tools across organizations. Despite the demonstrated impact of using health-related data to improve care, providers often grapple with the intricacies of interpreting EHR data.^{51,52} Appropriate visualization of data is critical to convey important trends in a user-friendly manner to a wide range of users. EHR data are commonly extracted and visualized using external applications such as Microsoft Excel or Qlikview. However, tools to visualize data at both the patient and population levels are available in most EHRs. The benefit of utilizing an EHR data visualization tool is that, once configured, there is no need for routine data collection, as the data are dynamic and refresh to the most current state each time the report is opened.

Data visualization within the EHR can be at the patient level, organizational level, or multi-organizational level. Patient-level data visualization can simplify review for individualized care needs (i.e., pre-rounding). This can include checklist presentation of actionable items, such as scheduled screening performance reminders, as well as compiled presentations of multiple data elements using graphical or tabular formats over time to help clinicians understand disease trajectories. Organizational level data accessible within the EHR are helpful for both population health management as well as clinical performance monitoring and can be in the form of reports and dashboards. Such reports are often presented in a table format, displaying multiple metrics over time (called dashboards in some EHR systems). These pre-configured visualization tools allow for self-service data extraction. Organizational EHR dashboards can display real-time care-quality indicators, process metrics and outcomes metrics to identify opportunities for interventions and QI. More detailed self-service data reports can also be extracted to allow for patient-directed interventions. Quality dashboards can be a critical enabler in accelerating the uptake of quality indicators into practice, thereby improving healthcare performance, patient safety, and quality of care.^{53–55} There is also opportunity to compare quality indicators and outcomes in dashboards by racial, ethnic, and social determinants of health groupings to identify disparities in access to care, compare quality of care, and ensure care equity.⁵⁴

EHR vendors also use dashboards to display data across multiple centers (e.g., patient EHR portal activation rates). It is imperative to note that when sharing data among institutions, providers must adhere to Health Insurance Portability and Accountability Act (HIPAA) privacy rules apply and national standards to safeguard individuals' identifiable health information. With standardized data dictionaries and data elements, identical dashboards can be generated across multiple institutions which can be particularly helpful for patients with rare diseases. This facilitates the measurement

and consolidation of outcome variables across practices, allowing for re-evaluation of guidelines and expert recommendations, and ultimately helps determine practice or quality standards and benchmarks (i.e., a point of comparison against which measurements can be compared⁵⁶) based on real world evidence.

6.1 | A data visualization design and operational considerations

Design and implementation of EHR visualization tools should be carefully considered for optimal use. While dashboards can be developed for individual, esoteric needs, this approach limits cross-population or institution collaboration and data integration. For example, an organization may make separate dashboards for each disease state or process requiring users to change dashboards to find certain metrics across populations/processes. Alternatively, a single dashboard can be built using standard components that then enable cross-dashboard data comparisons (e.g., having a nutrition section addressing nutrition status and outcomes, i.e., displayed across all chronic disease dashboards). Of note, dashboards are only meaningful and representative after standard data entry/capture tools and workflows have been established. Since dashboards require more technical configuration than data capture tools, development may take additional time.

When designing QI-specific dashboards to satisfy the “Study” phase of Plan-Do-Study-Act cycles, outcomes measured at a specific regular intervals should be reported at the next highest consolidated schedule level (i.e., interventions expected to be performed hourly should be reported daily, interventions performed daily should be reported weekly, and interventions performed monthly should be reported annually). Additionally, systematic data visualization and quality indicators should be displayed alongside identified goals (Supporting Information: Figure S1B) in an ongoing fashion to facilitate interpretation. While useful locally, aggregated data becomes transformative when common metrics are evaluated and shared across multiple institutions, particularly for patients with rare diseases.

7 | CLINICAL DECISION SUPPORT (CDS)

Guidelines should be written in a computer interpretable and actionable way to facilitate design and implementation of CDS to standardize practice. Broadly defined, CDS involves presenting information in a way that assists in making informed decisions.⁵⁷ Ideally, CDS should provide the right information to the right person in the right format through the right channel and in the right time of a clinical workflow.⁵⁷ Within

EHRs, programmed CDS algorithms can, for example, identify specific clinical scenarios and suggest health-care tests to improve morbidity screening and/or medication orders to provide appropriate therapeutic interventions. Examples include CDS advisories to carry out missing health maintenance screenings for children with chronic illness or tailor biologic dosing based on drug level and disease activity. Methods by which and how guidelines should be translated into CDS have been published.⁵⁸ Similarly, subsequent evaluation of implemented CDS pathways across contexts and institutions must be an inherent part of the process to ensure effective and sustainable CDS integration that aligns with clinical workflows.⁵⁹

CDS alert mechanisms should be utilized wisely. Alerts can be interruptive (where providers cannot complete tasks without addressing the alert) or passive (where the alert provides situational awareness to the clinician without interrupting workflow). Interruptive alerts, often called “pop-up alerts,” block the screen and prevent users from proceeding until a decision is made and action performed. Benefits of interruptive alerts include their ability to incorporate metadata (i.e., data about other data but not the content of the data itself, such as how data are used) that provides information about how clinicians respond to such alerts, such as whether they were ignored, or the suggested behavior was performed. Passive alerts, in contrast, draw user attention but do not interrupt workflows and are less amenable to tracking clinician behavior. Examples include highlighting out of range laboratory investigations using color, providing guidance within an order set, or displaying reminders for completion of routine preventive care on a health maintenance report/checklist. Recommendations to use standardized order sets is another example of passive CDS that can ensure diagnostic testing, monitoring labs, and/or treatment plans are performed in line with current guidelines. It is important to note that individual organizations may have governance surrounding the implementation and use of CDS. Because alert fatigue has been associated with burnout,¹³ care should be used when utilizing interruptive alerts.

Advanced CDS can present clinical practice pathways to clinicians dynamically at the appropriate time for given clinical scenarios (i.e., hematemeses), ensuring timely adherence to established standards of care. Clinical practice pathways are algorithms derived from guideline recommendations that provide advice regarding next steps based on “If-then” scenarios using combinations of interruptive and passive CDS. When guidelines are written in a nonambiguous, computer interpretable way, clinical practice pathways can be more easily developed, implemented, and shared across organizations, eliminating the need for individual interpretation.

8 | DATA SHARING

The goal of adopting standardized EHR tools is to facilitate data sharing, working towards development of multi-organizational data sets that support clinical care, research, and QI endeavors in PGI. With the 21st Century Cures Act in the US, there is already mandated interoperability of many data elements across EHRs but many of these variables are not specific enough to inform development of evidence-informed guidelines. Appropriate data use agreements and ethical approvals should be in place before data sharing.

Automated EHR data sharing (i.e., interoperability) currently takes many forms, such as between two EHRs, between EHR and patient portals, and between EHRs and external sources. In general, automated data sharing requires a sending EHR data storage location, a receiving data storage location and code to transfer the data. Widely accepted standards for this data transfer code include Fast Healthcare Interoperability Resources (FHIR) and Health Level 7 (HL7) language. To enable a seamless sharing process, data elements must be designed with the necessary properties that facilitate this functionality. A full overview of interoperability is beyond the scope of this paper. Designed to facilitate interoperability between different platforms and systems, FHIR uses external web-based software programs that interact with EHRs through application programming interfaces (APIs).¹² FHIR can be used to integrate innovative applications to EHRs, including those capable of CDS, thereby facilitating increased adoption of guidelines.⁶⁰ Additionally, tools like FHIR offer opportunities to incorporate AI and machine learning algorithms, enabling the integration of predictive models or the operationalization of NLP algorithms.⁶¹

In research, data sharing typically begins with data queries and the extraction of local EHR data, followed by the combining multi-institution data. The use of standard common data elements facilitates data extraction at each individual site. Once programmed, data sharing across sites can be automated and scheduled, such as with ICN.

9 | SHARING TOOLS

Due to the time and expense involved in creating and sustaining tools for standard data capture, visualization, and CDS, EHR tools and templates should preferably be shared. Additionally, this would promote multi-center standardization of data capture. Like sharing data, sharing tools is done using fast healthcare interoperability resources Fast Healthcare Interoperability Resources (FHIR) or health level 7 (HL7). EHR tools using identical data terminology, a unified data dictionary and format, and within the same EHR vendor, should theoretically enable data sharing and common EHR tool implementation across sites. One example of shared tools is CDS. CDS has traditionally been developed and implemented at an

institutional level, but organizations are increasingly advocating for standardized implementation across sites. “Out-of-the-box” CDS tools can be more easily shared across organizations when standard data elements are used.

Unfortunately, sharing of tools is not straightforward and often a rather challenging process. Early adopters of EHR systems, particularly pediatric centers adopting an adult centered EHR, had to compensate for programmatic gaps with local, individually tailored solutions. As a result, there is notable data architecture and infrastructure variation across EHR systems such that tools originating from one institution require manual reconfiguration to work in the local EHR environment. Similarly, if an institution modifies or “personalizes” a multi-center tool for greater clinical utility, implementing the changes across different sites can be challenging and might not prove beneficial in all settings. EHR vendors are attempting to homogenize systems by promoting adoption of a system-wide build and via system-level updates.

10 | EDUCATION AND TRAINING

Across all medical specialties, there is a growing focus on clinical informatics efforts seeking to improve the implementation, functionalities, and utilization of EHRs in both clinical care and research. To stay current, the subspecialty of PGI requires a workforce equipped with expertise in data capture, data visualization, and CDS.

Medical schools and postgraduate training programs are increasingly including informatics education opportunities in their curricula to address this need.⁶² Accreditation Council for Graduate Medical Education (ACGME)-accredited 2-year clinical informatics fellowships are available with clinical informatics board certification available since 2011 via the American Board of Preventive Medicine (ABPM) and American Board of Pathology (ABPath). The ABPM practice (i.e., experience) pathway to certification is available until 2025, at which point a fellowship will be required for board eligibility. Furthermore, many organizations have their own infrastructure for training and experience and supplemental training can be sought through a variety of channels, including the American Medical Informatic Association (AMIA)⁶³ or EHR vendor sponsored courses.⁶⁴

11 | CURRENT PRACTICE GUIDELINE EXEMPLARS

Clear and precise guidelines are essential not only to facilitate implementation, but also for incorporation into EHR decision support tools (e.g., prompts in EHRs). To achieve this goal, the Institute of Medicine's clinical guideline development standards specify that guideline recommendations “should be articulated in a standardized form detailing precisely what the recommended

action is and under what circumstances it should be performed.¹⁷ While published guidelines have traditionally not outlined data elements or provided tools to facilitate integration within EHR, this information would greatly assist with implementation. Two notable examples of guideline-directed data infrastructure investment and implementation include the American Academy of Pediatrics' (AAP) Partnership for Policy Implementation and the recent joint North American and European Societies of Pediatric Gastroenterology, Hepatology and Nutrition PEnQuIN guidelines.^{34,35} Since 2005, the AAP has involved trained clinical informaticians in developing new clinical practice guidelines. This initiative aims to ensure that new guidelines are actionable, executable, and computable, facilitating their integration into EHR systems and reducing delays in adoption.⁶⁵ The Partnership for Policy Implementation includes informaticians who are AAP physician members and currently has PGI representation. The international PEnQuIN guidelines outlined endoscopy quality standards and indicators to inform QI efforts.^{34,35} An essential next step in implementing these guidelines involves the development of EHR protocols and data frameworks for active quality indicator monitoring and reporting to support continuous QI within and across pediatric endoscopy services. An example of how functionalities available in the EHR can be harnessed at a local level to facilitate real-time endoscopy data capture and visualization is further detailed in Supporting Information: Material S1.

12 | FUTURE STATE

Within the NASPGHAN community, there is the opportunity to lay the foundation for the required data infrastructure and supportive standardized tool sets needed to build a learning health system (LHS) for PGI (Supporting Information: Figure S1B). This process has already begun for pediatric endoscopy with PEnQuIN. New guidelines should be computer interpretable for ease of understanding and implementation into practice utilizing a similar format to the AAP's Partnership for Policy Implementation initiative. Clinical guidelines should aim to identify relevant key data metrics, with defined data elements and dictionaries, to standardize clinical, quality and research outcomes. The three steps to defining a data dictionary are as follows:

Step 1. Define the patient population using inclusion and exclusion criteria. Utilize standard terminologies like ICD 10 or SNOMED-CT

Step 2. Define patient data elements

- Patient demographics
- Clinical data (including PROMs)
- Lab and diagnostic tests

TABLE 2 Example data dictionary with metadatas.

Element name	Definition	Data type	Permissible values	Units of measure	Source of data	Frequency of collection	Coding standard
Patient Age	Age of the patient at time of encounter	Integer	0–120	Years	EHR	At each encounter	N/A
Sex	Biological sex of the patient	String	Male, female, other	N/A	EHR	At each encounter	N/A
Race	Self-reported racial category	String	White, Black, Asian, Other	N/A	Patient self-report	Once	N/A
Anti-TTG Level	Anti-tissue transglutaminase (TTG) antibody level, marker for celiac disease	Float	0–100 U/mL	Units/mL	Lab result	Every 3–6 months or as indicated	LOINC
Clinical outcome	Outcome status of celiac disease (e.g., improved, stable)	String	Remission, improved, stable, worsening	N/A	EHR	At each encounter	N/A
BMI	Body mass index (BMI), calculated from height and weight	Float	Calculated value	kg/m ²	Calculated from height and weight	Calculated	Calculated

Abbreviation: EHR, electronic health record.

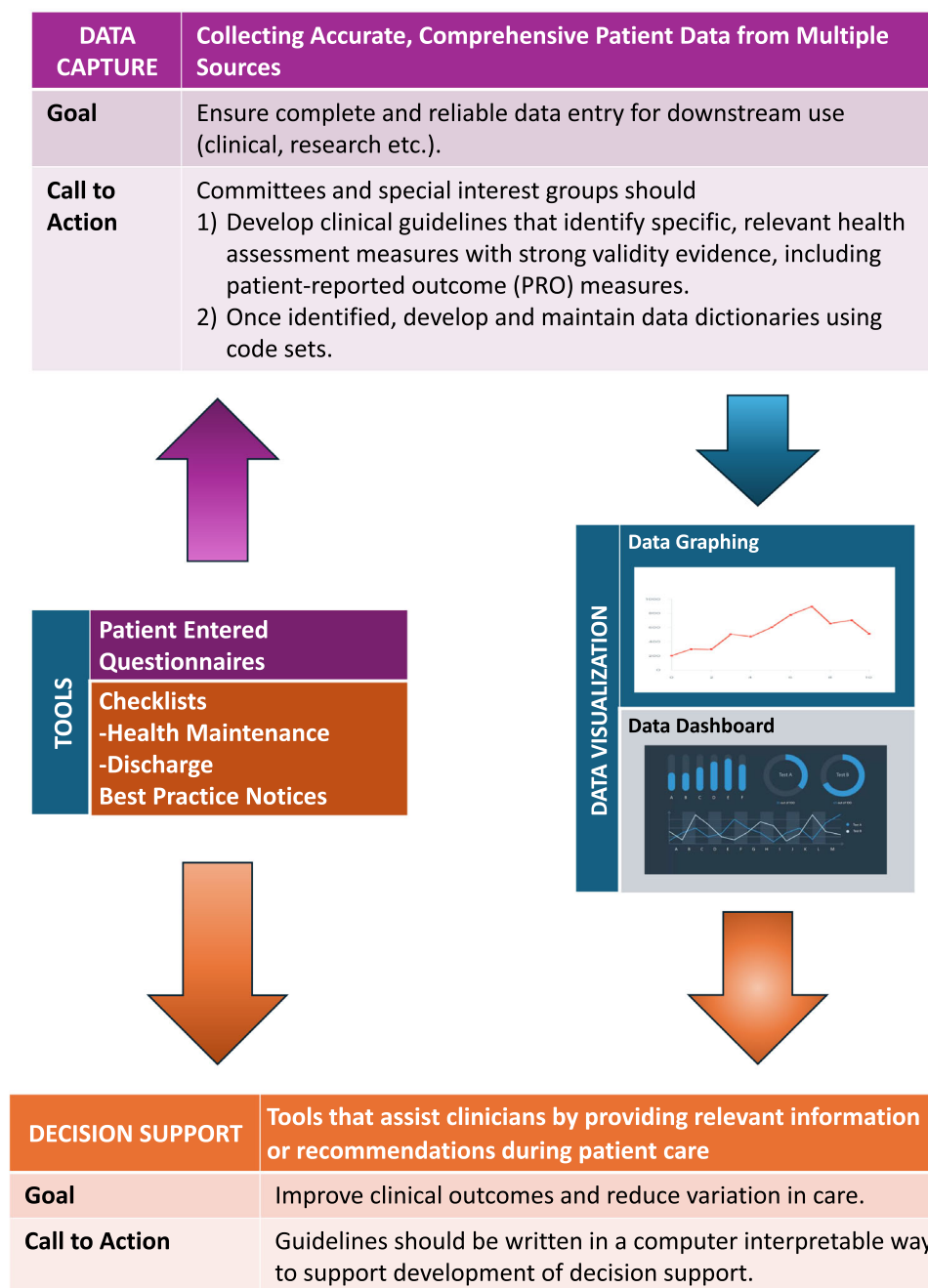


FIGURE 2 Call to action. This position paper calls for the standardized data capture and decision support to support development of high quality guidelines for North American Society for Pediatric Gastroenterology Hepatology and Nutrition (NASPGHAN) community.

- Medications and therapies
- Outcomes

Step 3. For each data element, provide a descriptive name, definition, data type, permissible values, units of measure, source of the data, frequency of collection, and coding standard if applicable

Table 2 provides an example of how to organize the metadata around data dictionary.

EHR vendor agnostic tool kits should be created with pre-determined methods to translate guidelines into practice. These investments are essential to reach the aspirational goal of global data sharing and integration required to: (1) generate high-quality validity evidence for guideline recommendations and inform development and updates; (2) identify best practices; (3) perform research; and ultimately,⁴ improve patient outcomes.

TABLE 3 Call to action recommendations.

NASPGHAN Members	NASPGHAN Committees	NASPGHAN EHR SIG
Stay informed about the latest published guidelines	Develop Clinical Guidelines that identify specific and relevant health assessment measures with strong validity evidence, including patient-reported outcome measures. Guidelines should also outline clinical pathways, incorporating clinical decision support algorithms to provide feedback to users, and order sets to ensure the right care to the right patient at the right time	Collaborate with EHR Vendors to operationalize guidelines for pediatric gastroenterology conditions and create national standards for disease-specific health assessment measures
Identify and cohort patient populations in EHR to enable recommended EHR tool utilization	Define patient populations using standard code sets (ICD 10 codes, etc.)	Collaborate with EHR Vendors to standardize code sets used to identify specific patient populations
Utilize disease-specific health assessment measures with strong validity evidence, including patient-reported outcome measures, in EHR documentation	Identify disease-specific health assessment measures with strong validity evidence, as well as areas where measures are still needed	Collaborate with EHR Vendors to develop and deploy EHR-agnostic health assessment measures with associated standard data elements, enabling standardized data acquisition and reporting across organizations to support clinical care, research, and quality improvement endeavors
Utilize NASPGHAN identified EHR data collection tools to implement guidelines in practice (e.g., Standard Utilization of Diagnostic Codes/Identifiers, Order sets, Note Templates, Patient Reported Outcome Tools/Questionnaires)	Offer guidance on the essential components of standard dashboards for population-based disease management	Work with EHR Vendors to operationalize and facilitate implementation of standard dashboards for population-based disease management

Abbreviations: EHR, electronic health record; NASPGHAN, North American Society for Pediatric Gastroenterology Hepatology and Nutrition; SIG, Special Interest Group.

13 | CONCLUSIONS

In the current digital healthcare environment, EHRs are an integral component of clinical practice, actively collecting and storing data essential for patient care and healthcare delivery. However, within PGI, there remains untapped potential in leveraging this wealth of data. Prioritizing investment in data infrastructure and architecture is crucial to enable widespread data sharing and aggregation across institutions, both nationally and globally. This is essential to lay the foundation for a learning health system (LHS), drive advancements in clinical practice guidelines, augment QI efforts, and propel research endeavors within the field. Figure 2 and Table 3 summarizes the call to action supported by this Position Paper.

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CONFLICT OF INTEREST STATEMENT

At the time of paper drafting, Dr. Miller was involved in limited consulting with Surescripts, LLC to contribute to the design of software solutions to facilitate prior authorization and address prescription writing errors for biologic and small molecule medications used in the treatment of inflammatory bowel disease. This limited engagement does not directly relate to the topic of this

position paper, which focuses on the realization of a learning healthcare system within pediatric GI through proactive incorporation of data standards in the writing of care guidelines. Data capture and outcomes tracking of diseases treated by pediatric gastroenterologists has a much broader impact including on research, clinical care redesign, reimbursement, etc. outside of the narrow project of design of software to facilitate prior authorization of biologic medications. No funding was provided for this manuscript.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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