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Running Head: District of Columbia pediatric asthma registry

Creation and validation of a citywide pediatric asthma registry for the District of Columbia

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ABSTRACT

Objective: To create and validate a citywide pediatric Asthma Registry to improve the care and outcomes of children and adolescents in Washington, DC through data-driven quality improvement (QI).

Methods: All available electronic health record data from inpatient and outpatient domains of Children's National Hospital were aggregated from an existing enterprise data warehouse. Inclusion criteria included asthma relevant ICD-10 codes over the prior 24 months. Available Asthma Registry measures include patient demographics, ambulatory visits, hospital admissions, persistent asthma diagnoses, and prescription of controller medications. Data capture was validated using US Census data and current asthma prevalence estimate of the Behavioral Risk Factor Surveillance System (BRFSS).

Results: The registry identified 15,991 DC children and adolescents with asthma aged 0-17 years, inclusive, at the end of 2020. This was 14.2% higher than the estimate of 14,001 children derived from BRFSS. Characteristics of those in the registry included: mean age of 9.5 (1.4) years, 57.9% male, 72.3% Black, and 66.7% publicly insured. Over the prior 24 months, 30.3% had ≥ 1 emergency department visit, and 10.5% had ≥ 1 hospital admission. Controller medications were prescribed for 59.6% of children with persistent asthma. Rates varied by sampled primary care practice sites.

Conclusions: A population-level pediatric asthma registry captures more children and adolescents with asthma in DC than a BRFSS-derived estimate, and provides city-wide measures of asthma-related utilization. The registry allows for stratification by primary care practice locations and asthma characteristics, supporting the design, implementation, and evaluation of QI projects at the practice, health system, and population levels.

Key Words: population health, disease registry, pediatric asthma, quality improvement

INTRODUCTION

Morbidity from pediatric asthma remains a significant public health challenge in the United States, with striking disparities in care and outcomes. Socio-economically disadvantaged, urban, and minority children and adolescents receive less guideline-based care and incur a disproportionate share of asthma-related morbidity.¹⁻⁴ Emergency Department (ED) visit rates, hospitalization rates, and death rates, for example, remain significantly higher among black youth than white youth.¹

These patients often depend heavily on EDs for care and face challenges in accessing ongoing longitudinal care.³

The District of Columbia (DC) provides a case study of these disparities, with cross-sectional lifetime asthma prevalence of DC youth nearly 40% higher than the national rate.⁵ Morbidity is also strikingly distributed across DC, with ED visits concentrated among disadvantaged and largely minority neighborhoods in the southeast corner of the city.⁶ Care remains largely episodic and ED-based, with less than 25% of patients seen in the ED for acute exacerbations of asthma returning to their source of primary care within 30 days.⁷ Despite more than a decade of evidence-based, targeted interventions,⁸⁻¹¹ Washington, DC has not met Healthy People 2020 targets for reducing asthma morbidity.¹²

Efforts to improve outcomes may be hindered by limited information sharing among the inpatient units, EDs, specialty and primary care providers, school nurses, case managers, and others involved in the continuum of care for youth with asthma. These ongoing challenges highlight the need for robust, adaptable, and sustainable systems for tracking entire populations of patients. Electronic health records (EHRs) that populate electronic data warehouses can support the identification of children with asthma, including those at risk ongoing for poor outcomes who are candidates for targeted interventions.¹³ Further, EHRs can generate quality measures to support quality improvement (QI) as well as health services research.¹⁴⁻¹⁶

Children's National Hospital (Children's National) is the only free-standing children's hospital and by far the largest provider of pediatric inpatient and outpatient care in DC.¹⁷ This presents a rare opportunity to aggregate city-wide asthma-related data to guide risk stratification and inform the development of targeted system-level interventions. We therefore aimed to develop and validate a clinically and administratively relevant pediatric asthma registry capturing a large majority of children and adolescents with asthma in Washington DC. By providing both patient-level data as well as practice-level metrics, the registry will support multiple efforts to improve citywide asthma care and outcomes.

METHODS

We created the Children's National Pediatric Asthma Registry (Asthma Registry) to include all pediatric patients diagnosed with asthma who interacted with any inpatient or outpatient resource of Children's National, including its affiliated and clinically integrated primary care practices. The multidisciplinary project team consisted of physicians from primary care, emergency medicine, hospitalist medicine, and pulmonary medicine, as well as managers and staff with expertise in informatics, quality improvement, and project management. This project was designed to inform longitudinal quality improvement (QI) initiatives at Children's National, and therefore does not constitute human subjects research. As such it was not under the oversight of the Institutional Review Board.

Study Population: The Asthma Registry incorporated clinical data, diagnoses, and billing codes. As shown in Table 1, children and adolescents were included in the Asthma Registry population if the patient was age 0-17 years, inclusive, received care within the Children's National health system in the prior 24 months, and had ≥ 1 International Classification of Diseases - 10 (ICD-10) diagnosis including the word 'asthma' during a clinical visit as a discharge diagnosis, clinical assessment, or problem list review by one of the EHRs. Patients were not included in the Asthma Registry if their only discharge diagnoses were for "reactive airway disease," "wheezing" and "bronchospasm." Other excluded diagnoses were of cystic fibrosis, sickle cell disease, or bronchiectasis. Patients with home ventilators and tracheostomies were also excluded. The Appendix includes additional detailed inclusion and exclusion criteria for the registry population. The Asthma Registry did not exclude children based on geographic location; however, for the

current analysis we included only children that live in Washington, DC in order to describe pediatric asthma morbidity among DC residents.

Data Sources: Documentation of clinical encounters at Children's National occurs within one of three different EHR systems: Cerner® is used by inpatient units, the ED, and outpatient specialty providers; eClinicalWorks® is used by primary care providers within Children's National as well as practices that participate in a health information exchange; and Greenway® is used by other primary care practices affiliated with but outside of Children's National. As shown in Figure 1, data from all clinical encounters are aggregated in the HealtheIntent® Enterprise Data Warehouse (EDW), including patient demographics, vital signs, medications, allergies, ICD-10 coded diagnoses, family history, social history, procedural history, encounter notes, laboratory results, and radiology results.

The HealtheIntent EDW is updated every 4-6 hours from Cerner, nightly from Greenway and weekly for eClinicalWorks. Data onboarding processes create a single Enterprise Master Person Index (EMPI) for each unique individual. During the data loading process, data is normalized and matched against an existing EMPI within the EDW. This process creates a longitudinal record for each patient, linking data for a unique person from all data sources to a single EMPI identity (ID). Algorithms can then be applied to create specific cohorts of patients and to assess their utilization of various services. For this study, we extracted data from December 31, 2020, after allowing all the relevant EHR records to update for that date.

We also utilized publicly available data to estimate the number of children age 0-17 years with asthma in DC. The United States Census provided the population estimate for Washington, DC, including the percent under 18 years of age.¹⁸ Current asthma prevalence estimates are available through the Center for Disease Control and Prevention's (CDC) Behavioral Risk Factor Surveillance System (BRFSS).⁵

Measures: Asthma-specific registry measures were selected based on asthma care guidelines from the National Institutes of Health (NIH),¹⁹ local practice and institutional QI priorities, and feasibility of capture from the available data. The project team then created definitions for each indicator (Table 1), including ED visits and hospitalizations for asthma, persistent asthma diagnosis, prescription of controller medication, and a high-morbidity asthma classification. Of note, the measure for persistent asthma was based on multiple criteria including history of ED visits, hospital admissions, prescription of controller medications, and ICD-10 diagnosis of persistent asthma. An indicator for high morbidity asthma was developed to identify the subset of patients at highest risk for poor outcomes, and was based on intensive care admission or high numbers of hospital admissions or ED visits. The definitions of persistent asthma and high morbidity asthma were developed specifically for the purpose of identifying children to target for QI interventions, and therefore reflected the priorities of local providers as well as the data available in the EHRs. Additional details of each criterion are included in the Appendix.

Demographic variables in the registry include a child's age; sex; insurance type classified as private, public, multiple payers, none, or unknown (based on payer data from each patient's most recent encounter); and race/ethnicity categorized as Black or African American, Hispanic, White, and Other/Unknown. Children with multiple values for race/ethnicity (at a single encounter or at different encounters) are classified as mixed race. Lastly, a variable was created to attribute each patient to a single primary care practice location. This was done through a two-step process which utilized the most recent visit to assign each patient to a specific practice group, and then within that practice group attributed the patient to the location at which the child had the most clinical encounters over a 24-month period.

Analyses and Reports: In order to assess the proportion of DC youth with asthma captured by the Asthma Registry, we first multiplied the 2019 US Census estimate of children age 0-17 years living in DC¹⁸ by the 2018 BRFSS current asthma prevalence⁵ to estimate the number of children age 0-17 years with asthma in DC. We then compared this estimate to the total of children in the Asthma Registry.

Each of the asthma indicators was assessed for the registry population in order to describe the cohort's asthma morbidity and utilization. Additionally, we summarized all measures for patients from Children's National primary care practice locations in DC in de-identified reports to facilitate QI activities. In addition to the de-identified reports, practices were able to access patient-specific data, including patients within their practices that met the criteria for each measure, as well as the number of times their patients interacted with the health system. Reports were available for all patients meeting criteria, not just for DC residents as presented in this analysis. The registry therefore served dual purposes of supporting QI and identifying specific patients in need of services. We created a map of ED visits made in 2020 by DC residents identified from the Asthma Registry by Zip code, yielding at-risk rates (visits per 1000 residents with asthma per year). Finally, we assessed trends in ED visits over time to identify temporal patterns.

RESULTS

The Asthma Registry included 15,991 unique children age 0-17 years with asthma that resided in the District of Columbia as of December 31, 2020. Table 2 presents their demographic and asthma-specific characteristics. The mean age of children in the registry is 9.5 (1.4) years (median = 9 years, range 0-17 years), and 57.9% are male. Most children were Black/African American (72.3%) or Hispanic (10.6%), and 66.7% had public insurance. A total of 4,843 children (30.3%) had ≥ 1 asthma-related ED visits, and 1,685 (10.5%) had ≥ 1 hospital admission for asthma in the prior 24 months. In addition, 31.2% met the definition for persistent asthma, and 2.8% met the definition of high morbidity asthma. Of patients meeting criteria for persistent asthma, 59.6% received one or more prescription for controller medications during the study period.

Table 3 presents asthma characteristics of patients receiving primary care site in fixed practice locations in DC affiliated with Children's National ($n = 11,061$, 69.2% of patients in the Asthma Registry). Within these practices, the proportion of attributed patients with asthma-related ED visits ranged from 31.3% to 55.8% (mean 43.3%), and the percent of attributed patients with asthma-related hospital admissions ranged from 7.4% to 22.1% (mean 15.6%). Children meeting criteria for persistent asthma ranged from 21.2% to 47.3% (mean 33.7%), and high-morbidity asthma ranged from 0.7% to 3.8% (mean 2.2%). Among patients with persistent asthma, prescription of a controller medication for asthma ranged from 44.8% to 70.3% (mean 58.9%).

According to the United States Census, the estimated population of Washington, DC as of July 1, 2019, was 705,749, with 18.2% or 128,446 children 0-17 years of age. The most recent estimate of current asthma prevalence, from the 2018 BRFSS, was 10.9% in DC for children 0-17 years of age. This yielded an external estimate of 14,001 DC children with asthma. This estimate is 12.4% lower than the cohort captured in the Asthma Registry.

The geographic distribution of at-risk rates for ED visits made by children in the Asthma Registry in 2020, shown in Figure 2, reflects known socioeconomic and racial disparities in DC.²⁰ Figure 3 shows temporal trends in ED visits over the 24-month period from July 2018 – June 2020, with monthly visits ranging from a low of 42 visits in June 2020 to a high of 605 visits in December 2019.

DISCUSSION

Our multidisciplinary team developed and externally validated a population-level citywide registry with near real-time reporting capabilities. This registry identified 15,991 DC children with asthma, which is greater than external estimate of 14,001 DC children with asthma based on population and prevalence estimates. While we had expected the registry to include most children with asthma in DC based on the prominence of Children's National Hospital within our city, we actually captured more children than estimated by other methods.

While it is possible that the registry over-counts children with asthma by capturing some children that do not have the disease or by including children that would not be captured through a self-report survey such as the BRFSS, it is more likely that the external citywide estimate of children with asthma may undercount DC children with asthma. The US Census is known to undercount young children, in particular minority children and those living in poverty.²¹ A recent analysis by the Population Reference Bureau estimated that the 2010 Census undercounted DC children by 16%.²² It is notable that the risk of undercounting is highest in the neighborhoods that account for high numbers of ED visits for asthma. Further, BRFSS asthma prevalence estimates for DC vary by year with wide confidence intervals.⁵ We therefore interpret the comparison of our registry cohort to the population estimate as confirming our expectation that a large majority of DC children with asthma are captured by the registry.

Unique circumstances made this high level of data capture and validation possible. Children's National provides a large majority of the inpatient and outpatient asthma care for DC youth.¹⁷ And the BRFSS treats DC as a state, providing an external estimate of asthma prevalence for the city. Therefore, while the methods used for the creation of this Asthma Registry are replicable in other contexts, the registry's capture will likely be different based on local care patterns. And other strategies may be needed in order to assess the degree to which the registry reflects the target population.

The registry enables us to consider "at risk" ED visit rates, rather than to report incidence based on ED and admission visit data. At-risk rates have been used at the national level to identify trends in disparities between black and white children with asthma, and differs from population-based rates in accounting for differences in prevalence rates between groups.¹ This data will support efforts to assess trends in morbidity among children with asthma, as well as the development of system-wide interventions and assessment of their effectiveness.

Children in the Asthma Registry demonstrate a high level of asthma morbidity, with nearly one third meeting criteria for persistent asthma and over 10% having one or more hospital admission for asthma in the prior two years. This indicates substantial opportunity for improvement. And while nearly two-thirds of children with persistent asthma have a controller medication prescribed, we note that the data reflect only prescriptions in the medical record, not prescription fills. While this may reflect a high level of the desired behavior at the provider level, we are unable to assess appropriateness of prescriptions or the level of uptake or adherence to the prescribed medication at the patient level.

The aggregate data from the registry are consistent with citywide demographic and utilization patterns. For example, the highest number of both cases and ED visits come from the comparatively socio-economically depressed and largely minority southeast portion of DC.^{17,20} This geographic distribution of risk reflects the city's disparities across a number of health and socioeconomic indicators, and reinforces efforts underway to locate services in high-need neighborhoods.^{17,20} In addition, as expected based on the well-documented seasonality of asthma exacerbations,²³ the fall and winter months had the highest numbers of both ED visits and hospital admissions. Further, the

major drop in ED visits for asthma from 2019 to 2020 reflects utilization patterns associated with the COVID-19 pandemic that have been described elsewhere.^{24–26}

The registry allows for a comparison of asthma quality measures across primary care practice locations within our health care system. The high variability likely reflects both different risk profiles of patients within each practice, and different asthma care pathways. The metrics allow for comparisons across practices and identification of care processes associated with positive outcomes that may be appropriate for adoption elsewhere. Further, the metrics support tracking of changes over time within a specific practice following QI initiatives.

In addition to allowing for practice-level comparisons, the registry produces practice location-specific lists of patients meeting different criteria, allowing for targeted interventions. For example, the registry identifies patients that meet our definition of persistent asthma based on diagnosis codes, prescription of controller medicines, and healthcare utilization. The registry also identifies the small number of patients meeting the definition of high morbidity asthma. This enables the stratification of patients into different risk levels, with tiered interventions based on asthma severity and utilization history. Primary care practices can use this information to design, implement and monitor QI activities aimed at improving outcomes among their attributed patients.

Within pediatric asthma, the use of population-level registries has been limited. Adult registries have focused on participants recruited for research studies²⁷ and patients with varying definitions of severe asthma.²⁸ One large practice association of pediatric primary care practices affiliated with Boston Children's Hospital used claims data to develop a definition of persistent asthma more inclusive than traditionally-used HEDIS measures, and are examining what patient characteristics predict risk for exacerbations.¹³ To our knowledge, no previous pediatric asthma registry has included a large majority of children with asthma within a given city.

This project had several potential limitations. First, the measures in the registry rely on the data integrity of the EHRs. Measures that were not collected in a standardized method within an EHR, or that were collected in incompatible ways across EHRs, were challenging to develop and therefore not included. For example, we were unable to include information about the completion of an Asthma Action Plan, which is a commonly used quality metric. Second, the external validation method that we used is based on estimates from the US Census and BRFSS, and any over or underestimation in those data sources may influence the capture rate of the Asthma Registry. In addition, we relied on the BRFSS estimate for *current* asthma prevalence for consistency with the registry's approach of describing children with active disease; however, we note that using the estimate for *lifetime* asthma prevalence would have increased the external estimate to which we compared the registry population. Third, we cannot exclude the possibility that we are missing children and adolescents cared for entirely within other smaller DC-based health care systems. We are working to address this limitation through data sharing agreements to integrate data from additional EHRs. Finally, the effort to attribute individual patients to specific primary care practice locations presented unique challenges. As patients often see different providers within a single practice, and the primary care provider identified by the family may differ from the provider assigned by their managed care source, we developed an algorithm to assign a single practice location to each patient. This approach supports our practice-based approach to quality improvement, but it does not allow for comparison across individual providers within each practice.

CONCLUSION/KEY FINDINGS

Our multidisciplinary team developed and validated a population-level pediatric Asthma Registry with broad capture of children in DC with asthma. The registry allows for stratification of patients into at-risk subgroups based on criteria such as ED visits, hospitalizations, and prescription

of controller medications, and for design of targeted interventions at the practice, health system, and population levels. Our methods can be replicated to create similar registries in other health systems and regions. Future work locally will use the registry to support the design, implementation, and evaluation of QI projects, as well as population-level initiatives to track the care and outcomes of DC residents longitudinally.

Declaration of interest: The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

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Table 1: Definitions used in development of the DC pediatric Asthma Registry

Indicators	Inclusion Criteria
Total Asthma Population	All patients who meet ALL the following criteria: • Age 0 – 17 years of age; and • ≥ 1 ICD-10 code diagnosis including the word ‘asthma’ during a clinical visit as a discharge diagnosis, clinical assessment, or problem list review captured by one of the electronic health record sources, • An outpatient visit or hospital admission captured by one of the electronic health record sources during the prior 24 months.
	Exclusion Criteria • An ICD-10 code diagnosis that includes the words “Reactive Airway”, “Wheezing” or “Bronchospasm” without the accompanying word “Asthma;” • Diagnosis of cystic fibrosis, sickle cell disease, or bronchiectasis at any time; • Presence of home ventilator use or tracheostomy at any time.
Asthma Population Metrics	Definition
Emergency Department Visits	All emergency department encounters made by patients within the registry population that meet the following criteria: • For patients age ≤ 365 days at the time of the clinical encounter, the ICD-10 code diagnosis in one of the top two positions* must include the words “Asthma”. • For patients age > 365 days at the time of the clinical encounter, the ICD-10 code diagnosis in one of the top two positions* may include the words “Asthma,” “Reactive Airway”, “Wheezing,” “Bronchospasm,” or other specific diagnoses codes included by the clinical project team.
Hospitalization Visits	All hospital admissions and “Observation in beds” encounters made by patients within the registry population that meet the following criteria: • For patients age ≤ 365 days at the time of the clinical encounter, the ICD-10 code diagnosis in one of the top two positions* must include the words “Asthma”. • For patients age > 365 days at the time of the clinical encounter, the ICD-10 code diagnosis in one of the top two positions* may include the words “Asthma,” “Reactive Airway,” “Wheezing,” “Bronchospasm” or other specific

	diagnoses codes included by the clinical project team.
Persistent Asthma	All patients within the registry population who, during the past 12 months, meet one or more of the following criteria: • ≥ 2 asthma-related emergency department visits (same criteria as ED visits), • ≥ 1 asthma-related hospitalizations (same criteria as hospitalizations), • Prescribed an asthma controller medication (same criteria as controller medication), • An ICD-10 code diagnosis that contains the words “persistent asthma”
Controller Medication Prescribed	All patients in the registry population who, during the last 12 months, were prescribed ≥ 1 asthma controller medication, including: • Inhaled Corticosteroids • Inhaled Corticosteroid/Long Acting Beta Agonist combination therapies • Inhaled Corticosteroid/Long Acting Beta Agonist/Long Acting Muscarinic Antagonist combination therapies • Leukotriene receptor antagonists • Nonselective phosphodiesterase inhibitors • Mast cell stabilizers • Biologic immunomodulators
High Morbidity Asthma	All patients in the registry population who, during the last 24 months, meet ANY of the following criteria: • ≥ 1 asthma-related PICU admissions • ≥ 3 asthma-related hospitalizations • ≥ 5 asthma-related ED visits

*ICD-10 code diagnoses for this measure are pulled from the primary and secondary positions **except** in the case in which there is not a hierarchy of diagnosis codes

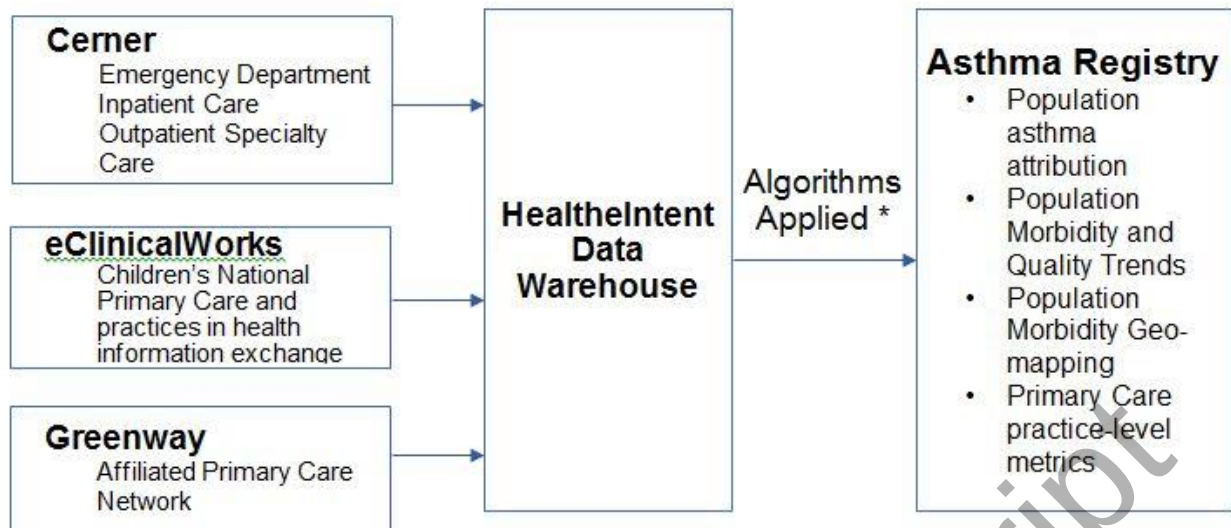
Table 2: Characteristics of 15,991 DC residents aged 0-17 years identified from the Asthma Registry on December 31, 2020

Characteristic	
Age in years (mean $\pm$ SD; median; range)	9.5 $\pm$ 1.4; 9; 0-17 years
Sex* n (%)	
Male	9,266 (57.9%)
Female	6,702 (41.9%)
Race/Ethnicity n (%)	
Black or African American	11,555 (72.3%)
Hispanic	1,694 (10.6%)
White	844 (5.3%)
Other/Unknown	1,898 (11.9%)
Insurance Type n (%)	
Public	10,670 (66.7%)
Private	2,381 (14.9%)
Multiple payers	1,911 (12.0%)
None	398 (2.5%)
Other/Unknown	631 (3.9%)
Asthma Characteristics n (%)	
≥ 1 ED visits over 24m	4,843 (30.3%)
≥ 1 hospital admission over 24m	1,685 (10.5%)
Persistent asthma	4,989 (31.2%)
High morbidity asthma	448 (2.8%)
Patients with persistent asthma prescribed controller medicines ≥ 1 time	2,973 (59.6%)
* 23 with unknown/missing gender	

Table 3: Characteristics of DC residents aged 0-17 years identified from the Asthma Registry stratified by selected pediatric primary care practice locations affiliated with Children's National Hospital

Primary Care Attribution	Unique Patients at each site	Patients with ≥ 1 ED visit over prior 24 months n (%)	Patients with ≥ 1 Hospitalization over prior 24 months n (%)	Patients with Persistent Asthma n (%)	Patients with High Morbidity Asthma n (%)	Patients with Persistent Asthma Prescribed Controller Medications n (%)
Mean (Range)	1229 (419-3110)	43.3% (31.3-55.8)	15.6% (7.4-22.1)	33.7% (21.2-47.3)	2.2% (0.7-3.8)	58.9% (44.8-70.3)
Location A	3110	1734 (55.8%)	686 (22.1%)	1165 (37.5%)	119 (3.8%)	800 (68.7%)
Location B	3105	1625 (52.3%)	521 (16.8%)	1090 (35.1%)	79 (2.5%)	591 (54.2%)
Location C	1074	336 (31.3%)	80 (7.4%)	330 (30.7%)	8 (0.7%)	232 (70.3%)
Location D	727	258 (35.5%)	102 (14.0%)	324 (44.6%)	15 (2.1%)	145 (44.8%)
Location E	725	352 (48.6%)	114 (15.7%)	154 (21.2%)	11 (1.5%)	99 (64.3%)
Location F	645	225 (34.9%)	87 (13.5%)	170 (26.4%)	13 (2.0%)	109 (64.1%)
Location G	637	349 (54.8%)	114 (17.9%)	213 (33.4%)	21 (3.3%)	114 (53.5%)
Location H	619	216 (34.9%)	111 (17.9%)	293 (47.3%)	10 (1.6%)	132 (45.1%)
Location I	419	174 (41.5%)	62 (14.8%)	114 (27.2%)	11 (2.6%)	74 (64.9%)

*Three Electronic Health
Record Systems within
Children's National*



* Algorithms specified in Table 1

Figure 1: Flow of data from electronic health records to the pediatric Asthma Registry

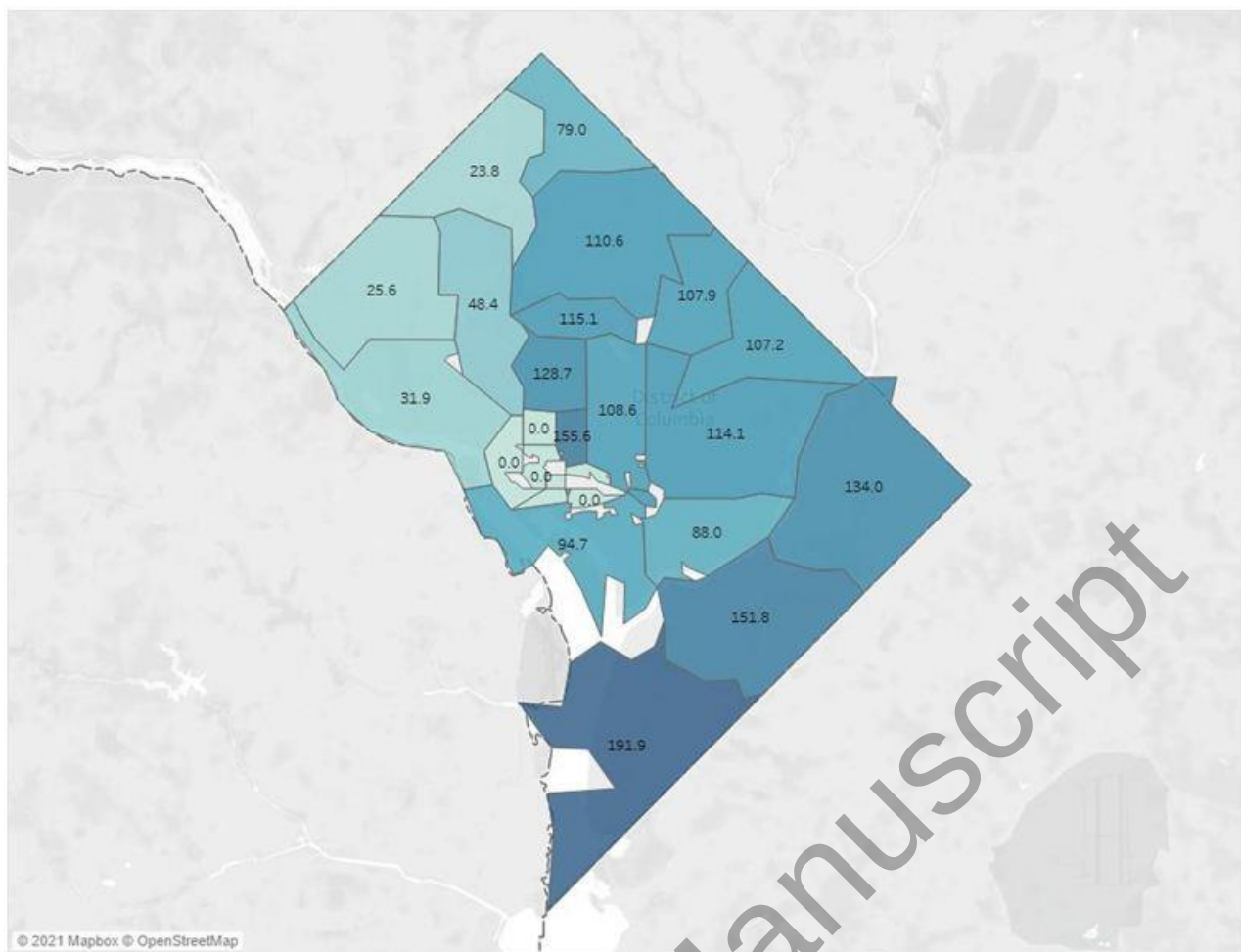


Figure 2: At-risk rates of emergency department visits in 2020 made by DC residents aged 0-17 years by Zip code (visits per 1000 residents with asthma)

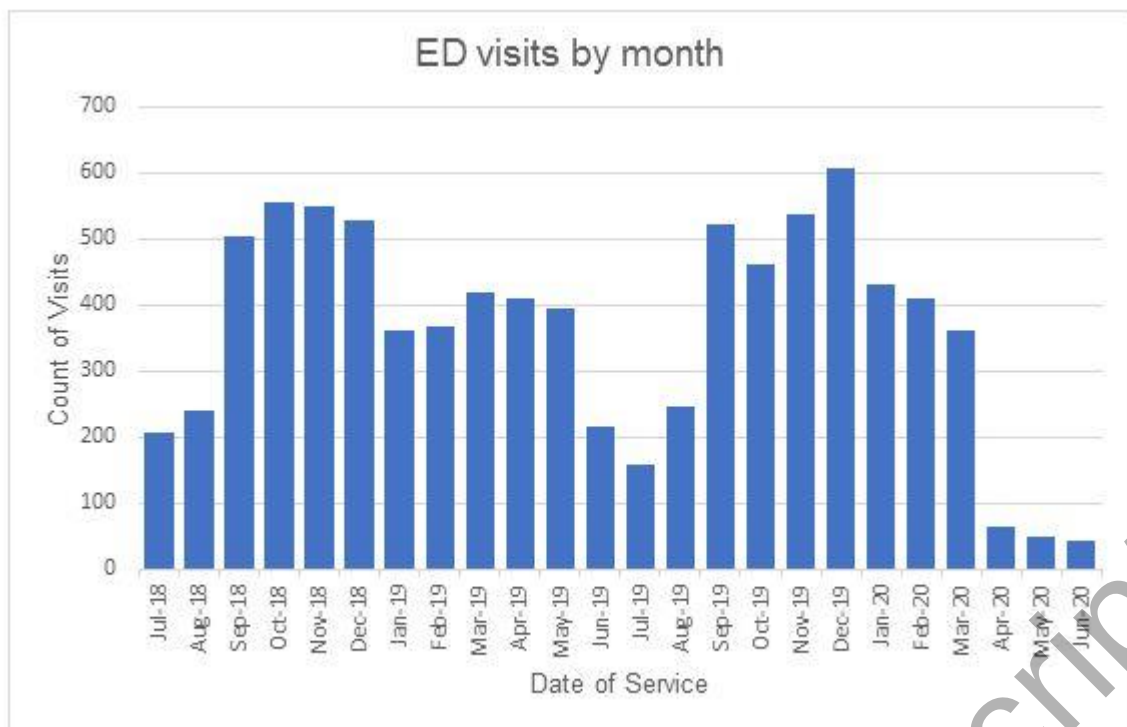


Figure 3: Emergency department visits for asthma made by DC residents aged 0-17 years, by month, July 2018 – June 2020