

6-9-2011

Addressing the Challenges of Reporting on Childhood Asthma in a Changing Health Care System: Building Better Evidence for High Performance

Meagan Lyon
George Washington University

Anne Rossier Markus
George Washington University

Maya Tuchman Gerstein
George Washington University

Sara J. Rosenbaum
George Washington University

Follow this and additional works at: https://hsrc.himmelfarb.gwu.edu/sphhs_policy_ggrchn

 Part of the [Community Health and Preventive Medicine Commons](#), [Health Information Technology Commons](#), [Health Policy Commons](#), [Health Services Research Commons](#), and the [Respiratory Tract Diseases Commons](#)

Recommended Citation

Lyon, Meagan; Markus, Anne Rossier; Gerstein, Maya Tuchman; and Rosenbaum, Sara J., "Addressing the Challenges of Reporting on Childhood Asthma in a Changing Health Care System: Building Better Evidence for High Performance" (2011). *Geiger Gibson/RCHN Community Health Foundation Research Collaborative*. Paper 51.
https://hsrc.himmelfarb.gwu.edu/sphhs_policy_ggrchn/51

This Report is brought to you for free and open access by the Health Policy and Management at Health Sciences Research Commons. It has been accepted for inclusion in Geiger Gibson/RCHN Community Health Foundation Research Collaborative by an authorized administrator of Health Sciences Research Commons. For more information, please contact hsrc@gwu.edu.



Addressing the Challenges of Reporting on Childhood Asthma in a Changing Health Care System:

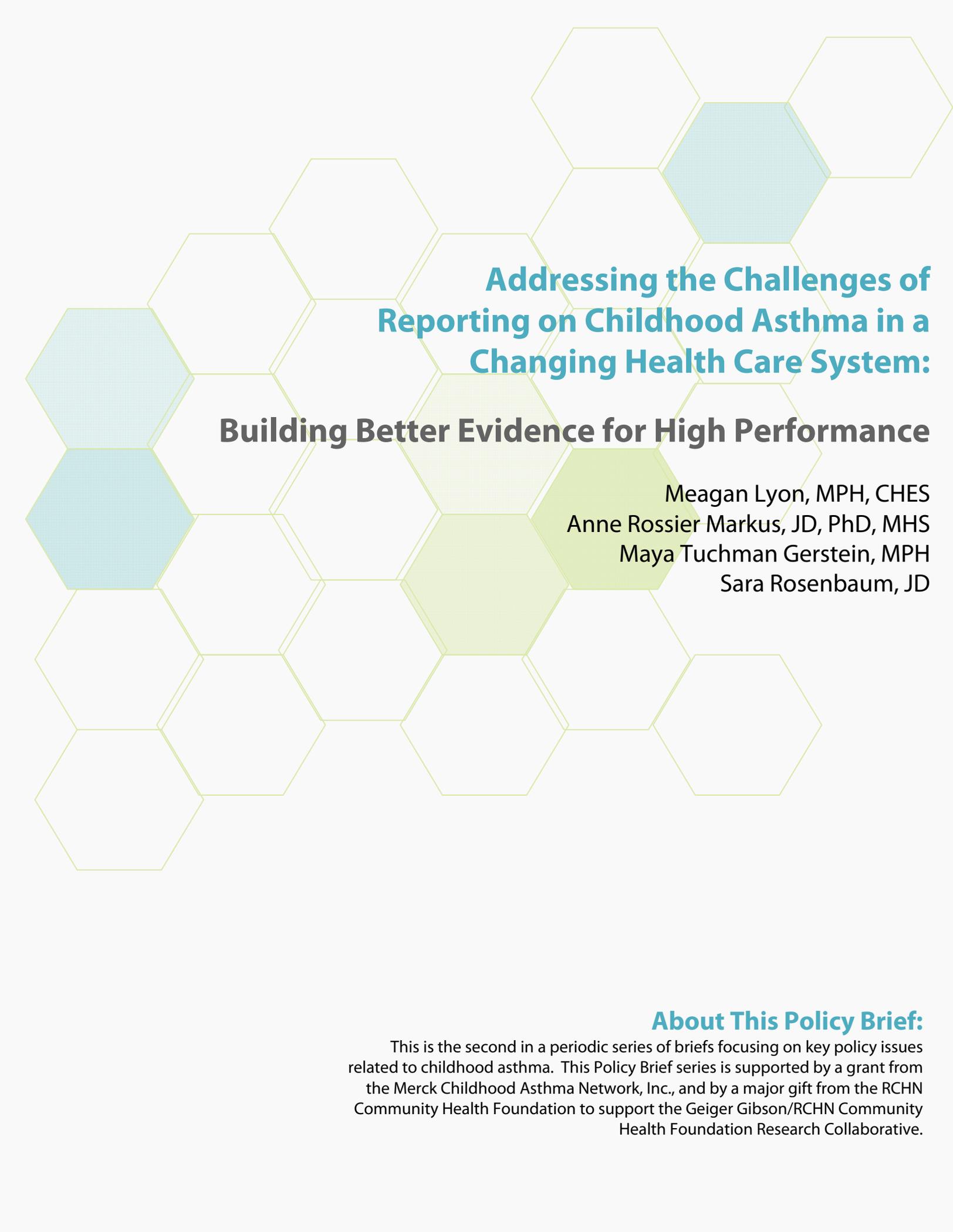
Building Better Evidence for High Performance



THE GEORGE WASHINGTON UNIVERSITY
SCHOOL OF PUBLIC HEALTH
AND HEALTH SERVICES

THE DEPARTMENT OF HEALTH POLICY





Addressing the Challenges of Reporting on Childhood Asthma in a Changing Health Care System:

Building Better Evidence for High Performance

Meagan Lyon, MPH, CHES

Anne Rossier Markus, JD, PhD, MHS

Maya Tuchman Gerstein, MPH

Sara Rosenbaum, JD

About This Policy Brief:

This is the second in a periodic series of briefs focusing on key policy issues related to childhood asthma. This Policy Brief series is supported by a grant from the Merck Childhood Asthma Network, Inc., and by a major gift from the RCHN Community Health Foundation to support the Geiger Gibson/RCHN Community Health Foundation Research Collaborative.

Executive Summary

Childhood asthma is a serious and costly chronic disease that burdens children and families as well as the health care systems that serve them. A key element to improving asthma outcomes is access to timely and useful data that can improve the quality of care and inform programs and policies to best serve those communities most burdened by asthma. This Policy Brief examines the nation's data collection framework for childhood asthma and considers steps that might be taken to strengthen it, including the development, collection and refinement of community-level data to inform local health care systems. Through a review of the public health surveillance system related to childhood asthma, including a specific look at existing asthma data, this brief lays out the challenges to the current system and identifies opportunities to develop responsive and timely data collection, monitoring and surveillance systems, harnessing health information technology (HIT) applications to address the many challenges of childhood asthma. This brief includes recommendations for improvements in public health reporting systems including standardization of measures and a focus on the development of real-time local surveillance and mapping technologies to best inform communities working to lessen their childhood asthma burden.

Introduction

This Policy Brief examines the challenges and opportunities that lie ahead in developing a community-level information system that is essential to meeting the health and health care challenges of childhood asthma. Complete, integrated information - about the community-level presence of asthma, its community impact, and the performance of local health care systems in alleviating the burden of illness – is essential in order to transform the health, social, and economic outcomes associated with serious and chronic illness.

No chronic condition better illustrates the importance of health information than childhood asthma. A widespread condition – and one that strikes certain communities particularly hard – asthma can be identified, treated, and well managed under evidence-informed guidelines and with strong parental involvement, even as broader public health efforts are undertaken to prevent it. Where asthma is poorly managed, its adverse impact is felt community-wide, in increased health costs, lost school days and work time, and most importantly, needless childhood illness and at times, death. In 2007 alone, asthma cost the United States an estimated \$56 billion (2009 dollars) in direct expenditures, with productivity losses due to mortality and morbidity costs accounting for nearly \$4.5 billion.¹ Among all conditions for which children are hospitalized, asthma is considered the most avoidable. In 2008 alone, the Medicaid program experienced an estimated \$582 million in costs related to hospital discharges for children with asthma.² The Centers for Medicare and Medicaid Services (CMS) recently identified more comprehensive asthma management as a major opportunity for reducing Medicaid program costs³.

Experts consistently point to information about community incidence, patient access, and health care quality and outcomes as fundamental to any meaningful effort to improve the quality of care, promote population health, and control the growth of health care costs. ⁴ In its 2011 Report to Congress on a National Strategy for Quality

¹ Barnett, SBL, Nurmagambetov TA. Costs of Asthma in the United States: 2002-2007. *J Allergy Clin Immunol.* 2011; 127:145-52.

² GW analysis of 2008 HCUP data

³ Letter from HHS Secretary Sebelius to State Governors. February 3, 2011.

<http://www.hhs.gov/news/press/2011pres/01/20110203c.html>. Accessed April 20, 2011

⁴ 76 Fed. Reg. 19528 (April 7, 2011). These three aims were most recently discussed in the Administration's proposed rules governing accountable care organizations. ; Kenney GM, Ruhter J, Selden TM. Containing Costs and Improving Care for Children in Medicaid and CHI. *Health Affairs.* 2009; 1025-36.; Wagner, EH, Glasgow RE, Davis C, et al. Quality Improvement in Chronic Illness Care: A Collaborative Approach. *Journal of Quality Improvement.* 2001; 27(2): 63-80; Mangione-Smith R, DeCristofaro AH, Setodji CM et al. The Quality of Ambulatory Care Delivered to Children in the United States. *N Eng J Med.* 2007; 357(15):1515-23 ; Hoppin P. et al. Investing in Best Practices for Asthma: A Business Case. August 2010 Update. Asthma Regional Council, 2010; Kattan M, Stears SC, Crain EF, et al. Cost-Effectiveness of a Home-Based Environmental Intervention for Inner-City Children with Asthma. *J Asthma and Clin Immunol.* 2005; 116:1058-63; Krieger, J, Takaro TK, Song L, Beaudet N, Edwards K. A Randomized Controlled Trial of Asthma Self-Management Support Comparing Clinic-Based Nurses and

Improvement in Health Care,⁵ the Administration highlighted this link between evidence on the one hand and health care and population health improvement on the other, emphasizing that a central aim of the Strategy was to “improve the health of the U.S. population by supporting proven interventions to address behavioral, social, and environmental determinants of health in addition to delivering higher-quality care.”⁶

This Policy Brief examines the nation’s data collection framework for childhood asthma and considers steps that might be taken to strengthen it, with the objective of improving health care outcomes and providing a model for the effective community based and data-informed management of asthma and other chronic conditions.

Asthma: A Key Test of the Power and Capabilities of Health Information

There is no stronger example than childhood asthma of a costly and disabling health condition that strikes individual children and disproportionately burdens certain populations, especially children at elevated risk for disparities in health and health care. While asthma is not an infectious disease like measles, in some ways it might as well be. Childhood asthma is more than a patient-specific health problem; as underscored by local area studies, asthma can impact entire rural and urban communities in which elevated poverty, economic and social stressors, and housing and environmental risks make life less safe for children⁷. National estimates and specialized studies indicate that asthma strikes nearly one in every 10 children and one in 7 low income children⁸. Children who are members of certain racial and ethnic minority groups experience the greatest impact. Asthma affects approximately one in

In-Home Community Health Workers. *Arch Pediatr Adolesc Med.* 2009; 163(2): 141-149; Krieger JW, Takaro TK, Song L, Weaver M. The Seattle-King County Healthy Homes project: A Randomized, Controlled Trial of a Community Health Worker Intervention to Decrease Exposure to Indoor Asthma Triggers. *Am J Public Health.* 2005; 95(4): 652-659.

⁵ <http://www.healthcare.gov/center/reports/quality03212011a.html>

⁶ National Strategy to for Quality Improvement in Health Care, <http://www.healthcare.gov/center/reports/quality03212011a.html#na> (Accessed April 20, 2011)

⁷ Sandel M, Wright RJ. When home is where the stress is: expanding the dimensions of housing that influence asthma morbidity. *Arch Dis Child.* 2006; 91:942-948; Williams DR, Sternthal M, Wright R. Social Determinants: Taking the Social Context of Asthma Seriously. *Pediatrics.* 2009;123: S174-S184; Rauh VA, Chew GR. Deteriorated housing contributes to high cockroach allergen levels in inner-city households. *Environ Health Perspect.* 2002; 110 (suppl 2):323-7; Wright RJ, Mitchell H, Visness CM et al. Community violence and asthma morbidity: the Inner-City Asthma Study. *Am J Public Health.* 2004; 94:625-32; Lapnear BP, Aligne CA, Auinger P, Weitzman M, Byrd RS. Residential Exposures Associated with Asthma in US Children. *Pediatrics.* 2001; 107: 505-511;

⁸ Vital Signs: Asthma Prevalence, Disease Characteristics, and Self-Management Education- United States, 2001-2009/. CDC MMWR Early Release May 3, 2011.; Akinbami LJ, Moorman JE, Liu X. Asthma Prevalence, Health Care Use, and Mortality” United States, 2005-2009. National Health Statistics Reports. No. 32. January 2011.; Bloom B, Cohen RA, Freeman G. Summary health statistics for U.S. children: National Health Interview Survey, 2009. National Center for Health Statistics. Vital Health Stat 10(247). 2010.

6 non-Hispanic black children and one in 5 children of Puerto Rican heritage.⁹ Community-based health care safety net providers such as community health centers report childhood asthma prevalence at double the national norm.

In short, asthma is both an individual condition and a broader indicator of community health. Real-time information about how asthma affects both patients and populations is thus extremely valuable. All pediatric health care providers should be knowledgeable about and supported to undertake high quality childhood asthma management, but certain providers need to be particularly well equipped and integrated into broader public health efforts that aim to attack asthma's root causes. It is essential to understand in which communities or neighborhoods – both urban and rural – asthma levels are particularly elevated. Payers and public health authorities need ongoing information to measure the quality of health system performance and identify communities in which efforts either are succeeding or need to be modified or intensified. Producing and using information about childhood asthma thus becomes a bellwether for the nation's health information system more broadly.

This challenge – to produce integrated, real-time, community-level information about community and patient health and health care - requires linking disease incidence and prevalence measures from numerous sources with clinical information. Together this information allows public health experts and payers to map the condition's impact, support health care providers, report on clinical and programmatic outcomes and target resources. It is this ability to analyze and use patient- and community-level information in real time that will stand as the real breakthrough in the nation's health system.

One important element of health information is the nation's public health surveillance system. Public health experts define surveillance as the systematic collection, analysis, and evaluation of data. These data, in turn, are used to inform public health programs and policies aimed at reducing morbidity and mortality.¹⁰ Good surveillance depends on the collection of certain types of information. One type is information about specific demographic characteristics of individuals affected by a health condition. Another is information about which patients are receiving treatment, the types of treatment they are receiving in relation to evidence-informed standards of care, and the health outcomes of effective treatment as measured by indicators of health such as reductions in the need for hospital care and in lost school and work days. Compiling such information about childhood asthma requires the ability to collect and analyze evidence from many sources such as schools, hospitals, pharmacies, clinics and private physician practices, and parent surveys. Some information, such as health care utilization data, might be collected continuously. Other information, such as

⁹ Vital Signs: Asthma Prevalence, Disease Characteristics, and Self-Management Education- United States, 2001-2009/. CDC MMWR Early Release May 3, 2011.;Akinbami L, Moorman JE, Garbe PL, et al. Status of Childhood Asthma in the United States, 1980-2007. *Pediatrics*. 2009; Vol 123, Supplement 3, S131.

¹⁰ CDC.Updated Guidelines for Evaluating Public Health Surveillance Systems. MMWR. 2001, 50(1-35).

surveys of parents, might be collected periodically. All data need to be collected over time so that researchers can measure trends, target policies, programs and services as conditions change, evaluate the longer-term effectiveness of health and health care interventions, and formulate broader public health policies aimed at reducing the incidence and prevalence of illness.

The Current State of Childhood Asthma Information and Surveillance

Valid population-specific data about the diseases that affect children and families helps stakeholders to understand the needs of a community and how to appropriately direct resources and interventions to address those needs.¹¹ Under the Centers for Disease Control and Prevention (CDC) guidelines, states have broad latitude to define which conditions they monitor and the evidence that monitoring systems rely on. Furthermore, federal funding to help support surveillance activities is limited. In 2010, only twelve states treated asthma of any type, including occupational asthma, as a reportable condition.¹² Because of the limits of Congressional funding, CDC funding for states is insufficient to finance asthma monitoring in all states. Currently, CDC grant conditions establish only minimal standards for childhood asthma information collection and reporting at the community level, focused on the characteristics of the communities and populations affected, the rate of health care utilization services that are indicative of uncontrolled asthma (such as hospitalization and emergency department use), the impact of asthma on communities of different population size, and the proportion of children receiving evidence-based asthma management known to be effective. While other sources support data collection – in particular the federal investment in electronic health records (EHRs) – most of these applications have not yet been fully implemented, and policies related to the exchange of health information among public health systems, social service and education agencies, hospitals, physicians, and pharmacies, are just beginning to be formulated.

Several discrete data collection efforts provide valuable information about childhood asthma at the national level. Through its National Center for Health Statistics, CDC conducts a variety of national surveys (see Appendix I) that function as surveillance tools for monitoring health, including questions related to asthma. The Health Resources and Services Administration (HRSA), which oversees the community health centers program, has since 1996 required health centers to report asthma outcomes among their patients, with additional asthma measures that include pediatric patients as part of the HRSA Disparities Collaborative in 2005-2006.¹³ These data are available

¹¹ Brown CM, Anderson HA, Etzel RA. Asthma: The states' challenge. *Public Health Reports*. 1997; 112(3):198-205. ; Levy BS. Toward a holistic approach to public health surveillance. *American Journal of Public Health*. 1996; 86:624-625.; Boss PL, Kreutzer RA, Luttinger D et al. The Public Health Surveillance of Asthma. *Journal of Asthma*. 2001; 38(1):83-89.

¹² Council of State and Territorial Epidemiologists. State Reportable Conditions Query. <http://www.cste.org/izenda/ReportViewer.aspx?rn=Condition+All&p1value=2010&p2value=Asthma>

¹³ Personal communication with HRSA. November 16, 2010. ; There is a proposed asthma measure, for adults and children about pharmacologic therapy for CY 2011 UDS reporting. Proposed measure:

from all federally funded health centers and offer one of the best ongoing sources of information about community-level asthma through the lens of more than 1,200 health centers operating in over 8,000 sites.

Medicaid and the Children's Health Insurance Program (CHIP), two Federal programs which together provide coverage for one in three U.S. children, could be a rich source of data on pediatric asthma. However, while the CMS oversees the performance of both programs, utilization and claims data are not centrally maintained or analyzed. State Medicaid programs are not expected to compile and report such information for states and communities. The Title V Maternal and Child Health Block Grant program, which is administered by HRSA, similarly provides no ongoing information about community and state-level prevalence of childhood asthma or the proportion of children receiving treatment. Under HRSA requirements, Title V programs must report certain state-level child health indicators (see Appendix I), but asthma is not included.

In addition to the federally supported data collection and reporting systems described above are the data systems developed- in part through federal investments- for public and private payers. Childhood asthma has become a focus of quality measurement and improvement in the payer community; along the way, much information has been collected that, in turn, could be harnessed for broader clinical and systems improvement. For example, twenty-seven state Medicaid and CHIP programs use asthma measures to monitor the quality of managed care plans.¹⁴ CHIPRA also has a core measure set that includes one asthma health care utilization measure,¹⁵ although it is voluntary for state Medicaid and CHIP programs.¹⁶ CMS has begun compiling reports of state data from External Quality Review Organization (EQRO) efforts that include asthma as part of their quality improvement work. Among private payers, performance on childhood asthma measures is also a common focus of quality clinical monitoring.

In the U.S. public health system, it is generally the responsibility of states, working under broad federal guidelines, to collect and analyze public health information, including disease surveillance data, as key components of population health monitoring and promotion. Certain conditions, particularly infectious diseases such as sexually transmitted diseases, HIV, and influenza, are considered reportable conditions by virtually all states and their reporting is incentivized by financial and technical support from the CDC. By contrast, federal and state data collection and reporting

Asthma – Pharmacological therapy: Percentage of patients age 5 to 40 years with a diagnosis of persistent asthma (either mild, moderate, or severe) who were prescribed either the preferred long term control medication (inhaled corticosteroid) or an acceptable alternative pharmacological therapy (leukotrene modifiers, cromolyn sodium, nedocromil sodium, or sustained released methylxanthines) during the current year.

¹⁴ Medicaid Managed Care Quality Benchmarking Project. National Committee for Quality Assurance. Prepared for Centers for Medicare and Medicaid Services. August 23, 2010.

<https://www.cms.gov/MedicaidCHIPQualPrac/Downloads/NCQAMBench.pdf>

¹⁵ CHIPRA measure: Annual number of asthma patients (≥1 year old) with ≥1 asthma related ER visit (S/AL Medicaid Program)

¹⁶ AHRQ. CHIPRA Health Care Quality Measurement and Improvement Activities. <http://www.ahrq.gov/chipra/>

policies are less active and uniform for other conditions such as childhood asthma, despite their high prevalence and costs to health and health care. Consequently, though conforming to current federal guidance, state-level surveillance and reporting is not standardized for asthma.

As part of the public health information system, the CDC has identified six basic elements of an effective disease surveillance system for any health condition (Figure 1).

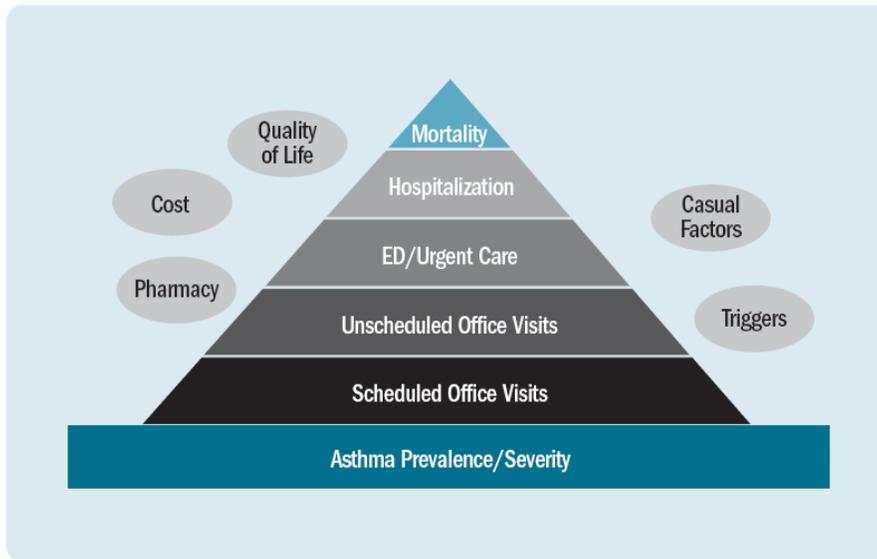
FIGURE 1. CDC's Six Basic Elements of an Effective Disease Surveillance System

- 1) Prevalence
- 2) Use of scheduled office visits to treat the condition*
- 3) Use of unscheduled office visits to treat the condition *
- 4) Emergency department (ED) visits*
- 5) Hospital admissions*
- 6) Deaths*

* These elements are also used as indirect indicators of quality of care furnished to children with asthma, with high ED use and inpatient admissions suggestive of care that is of poorer quality and does not effectively manage the condition in a lower cost and less burdened ambulatory care setting.

Through its National Asthma Control Program (described below), the CDC has also identified 6 key elements in high quality asthma surveillance, displayed in Figure 2.

FIGURE 2. The Asthma Surveillance Pyramid



Source: Centers for Disease Control and Prevention. "A Public Health Reponse to Asthma," PHTN Satellite Broadcast, Course Materials 2001.

Despite the recognized policy importance of a robust, disease-specific surveillance system, an evaluation of current practice reveals fragmentation that has real implications for the nation's health.

What Childhood Asthma Monitoring Might Look Like

Obtaining more robust and useful information about childhood asthma involves updating traditional ideas about surveillance to include focused, strategic efforts to locate, target, and assist the most significantly burdened communities. Certain emerging health information technologies hold major promise to supplement the availability of data currently available through public health surveillance and information culled from provider activities and claims. Asthmapolis, an asthma inhaler tracking program, is a prime example of innovative surveillance technology- put to work for the public health system (Figure 3). Applications like these can be employed to gather, analyze, and present information about childhood asthma, and are central to a modern health care system. Innovative surveillance tools, including geomapping using real-time data, can be used to collect a range of data including hospital and ED utilization data, the number and location of children under treatment, and measures of treatment in relation to evidence-informed standards published by the National Institutes of Health (NIH).¹⁷ These data can help identify the presence of asthma, the effectiveness of appropriate treatment, and the highest-risk and costliest patients who

¹⁷ National Heart, Lung, and Blood Institute. *National Asthma Education and Prevention Program Expert Panel Report 3: Guideline for the Diagnosis and Management of Asthma*. Bethesda, MD: National Institutes of Health; 2007

need the most intensive intervention to help them manage and control their asthma.¹⁸

FIGURE 3. Asthmapolis

Asthmapolis is an asthma tracking system that aims to improve the management of asthma through the use of GPS enabled inhalers. Medication sensors determine the time and location when an inhaler is used and send that information to a server where anonymous and voluntarily shared data is aggregated for scientists and public health workers.

Asthmapolis is also available in a mobile application program that allows individuals to map and track their asthma symptoms, triggers and medication use, monitor their trends over time, and identify locations that exacerbate their asthma symptoms.

More information is available at: <http://asthmapolis.com/>

Tools applied to assess the presence of other health conditions and the effectiveness of treatment hold promise for childhood asthma. One example is focused geo-mapping such as the "ResistanceMap,"¹⁹ an application that tracks the presence of antibiotic-resistant superbugs over time. "ResistanceMap," which includes community-level tracking capabilities, allows users to pinpoint states and locales where specific superbugs are most prevalent and identify changes over time. By providing geographic information system (GIS) functionality, "ResistanceMap" can help communities plan and carry out quality improvement efforts, public education and awareness campaigns, while enabling public health officials to work with targeted health care providers to strengthen treatment and management regimens.

"ResistanceMap" is designed to track infectious diseases, but there are examples of similar GIS tools being used to address serious public health conditions such as obesity. For example, the United States Department of Agriculture (USDA) maintains a Food Environment Atlas that creates state-level maps highlighting key indicators of obesity, including, among other measures, food access in restaurants and grocery stores, food assistance and food taxes, and physical activity levels.²⁰ This information allows families to understand their risks of exposure to a public health threat while

¹⁸ Ibid.

¹⁹ ResistanceMap. <http://www.cddep.org/resistancemap>. *Extending the Cure*, project of the RWJF's Pioneer Portfolio.

²⁰ USDA Food Environment Atlas. <http://www.ers.usda.gov/foodatlas/>

empowering better practice and policymaking decisions at community levels. The software also allows users to identify threats at a county level, thereby providing a more precise lens through which to view the risks associated with obesity. Given what is known and documented about the seasonality of asthma attacks and hospitalizations, tracking seasonality and environmental pollutants or measures could be done in real time and mapped to local jurisdictions to identify risks in those communities. A comprehensive asthma mapping tool could literally provide a picture of what environmental risks look like in different communities during peak asthma periods, and help focus abatement efforts.

What Current State-Level Data Produced Through CDC's National Asthma Control Program Tell Us About Childhood Asthma

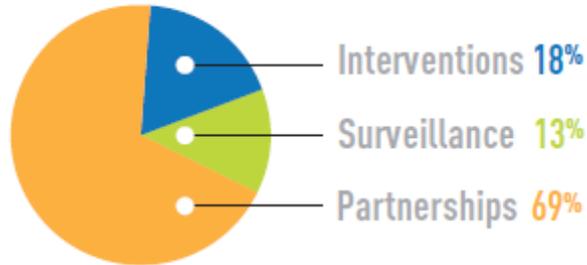
In 1999, the CDC launched the National Asthma Control Program as a means of responding to a significant increase in asthma prevalence at the national level during the 1980s and 1990s. The purpose of the program is to systematically understand the asthma burden and to allow public health officials and policymakers to get answers to key questions, including the total number of people with asthma, the number of cases that occur over time, the distribution of the disease burden among subgroups of the population, the level of case control, and the cost of asthma.²¹

The National Asthma Control Program funds states, cities, and school programs. CDC funding is used to assist in local control efforts and improve state and local surveillance activities. Surveillance expenditures account for 13% of funded activities, while 18% goes for health interventions, and 69%, to CDC "partnership" collaborations among the CDC, state health departments, the Environmental Protection Agency (EPA), and private organizations focusing on asthma prevention and control (Figure 4, below).²²

²¹ CDC, *Breathing Easier*, 2009

²² CDC, *Breathing Easier*, 2009

FIGURE 4. CDC's National Asthma Control Program Components and Share of the Budget

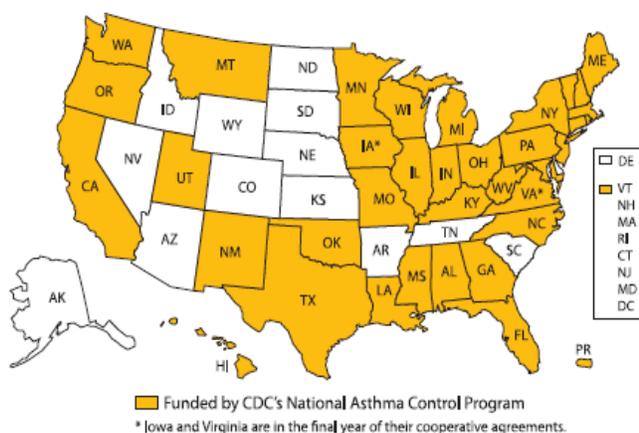


Source: CDC, Breathing Easier, 2009.

The National Asthma Control Program has grown from a total expenditure of \$800,000 in 1999 to \$13.3 million in 2007. That year, awards were made to 34 states, the District of Columbia and Puerto Rico, meaning that not all states receive support for asthma-related information development activities.²³ As of 2010, CDC funds were sufficient to support grants to only 36 jurisdictions. (See Figure 5 for jurisdictions receiving funding as of 2010)

²³ CDC, Breathing Easier, 2009

FIGURE 5. Thirty-Four States, Washington, DC and Puerto Rico Have CDC-Funded Asthma Control Programs.



Source: CDC, Breathing Easier, 2010

The Program's aim is to track the burden of asthma as well as efforts to target and reduce that burden.²⁴ As part of this program, jurisdictions receiving funding are expected to periodically release an asthma burden report detailing the impact of asthma in their area. CDC guidelines allow considerable variation in the reportable measures and data collection approach that informs these burden reports, including the survey instruments used to conduct measurement, the specificity of information reported, the techniques used to gather and assess the information, and the time periods over which measurement occurs.

In order to build a more complete picture of what is known about childhood asthma, the research team at George Washington University's Department of Health Policy undertook an effort to analyze all state asthma burden reports available as of November 2010 on each state's website. A total of 36 state reports were available as of that date. The research team examined the content of the burden reports, the types of measures reported and the comparability of the information across the states. To better understand both the variation in reported information as well as the commonly reported elements, we reviewed the reports using CDC's six-dimensional approach to surveillance: (1) prevalence and severity; (2) scheduled office visits; (3) unscheduled office visits; (4) emergency room visits; (5) hospital admissions; and (6) deaths. To streamline the results, we categorized these elements into five domains: (1) prevalence; (2) health care utilization; (3) morbidity, (4) disease management, and (5) cost and coverage. (See Appendix II – List of variables collected at the state level)

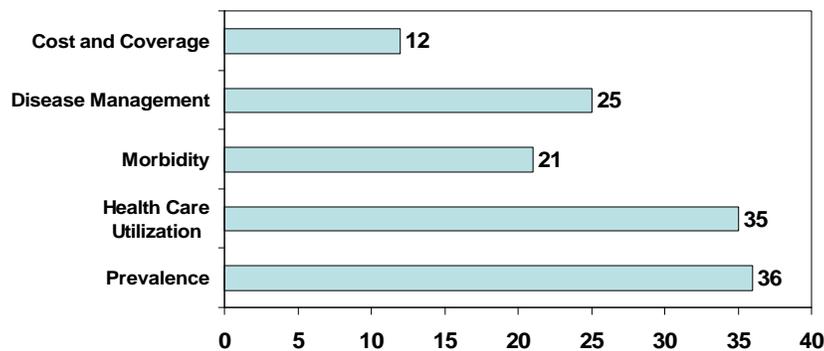
²⁴ CDC National Asthma Control Program. *Guide for State Agencies in the Development of Asthma Programs*. December 2003. <http://www.cdc.gov/asthma/nacp.htm>

Findings

Overall status of state asthma surveillance

All 36 states reported asthma prevalence measures. However, only one-third reported on asthma costs or the extent of health insurance coverage among children with asthma, and only slightly more than half reported on measures of morbidity such as activity limitation and missed school (Figure 6).

FIGURE 6. Number of States/Jurisdictions Reporting Data on Asthma, by Measure Sub-Category, 2010

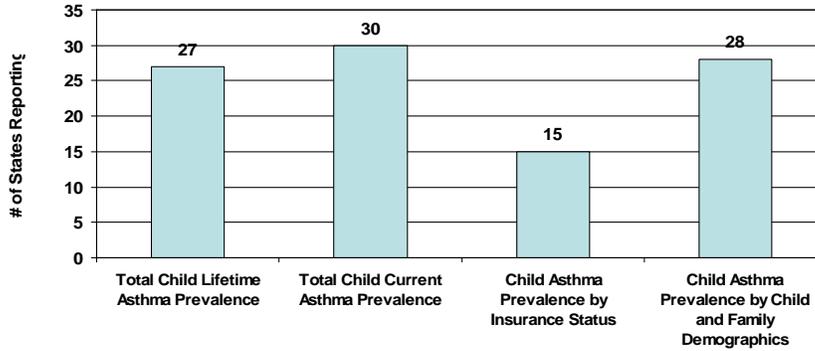


Source: GW SPHHS Analysis of 36 State Asthma Burden Reports Available as of November 2010

Prevalence (n=36; 100%)

Accurate measures of the prevalence of asthma, both lifetime and current, are the cornerstone of understanding disease burden as well as trends in the population. All 36 states reported on prevalence, using a total of 23 different measures. Thirty states reported on measures of current asthma prevalence in children, 28 states reported on measures of prevalence by family or child demographics, and 27 states reported on measures of lifetime asthma prevalence in children. Fifteen states reported on prevalence measures by insurance status; of those, eight reported this for Medicaid and CHIP covered children by age group (Figure 7).

FIGURE 7. Specific Prevalence Measures Among 36 State Asthma Burden Reports, 2010

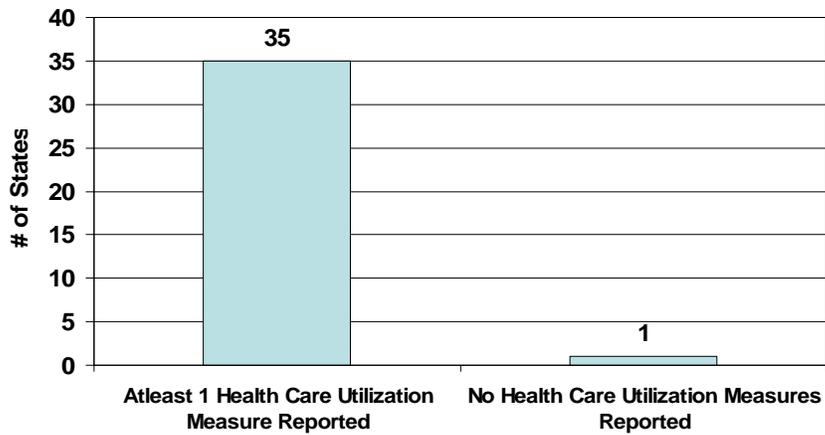


Source: GW SPHHS Analysis of 36 State Asthma Burden Reports Available as of November 2010

Health Care Utilization (n=35)

Health care utilization measures, which are available through hospital discharge records and national surveys, are key indicators of disease severity, management, and control as well as access to different types of service in a community (e.g., ambulatory care, ED care). Thirty-five states reported on at least one health care utilization measure and a total of 21 different measures of health care utilization were reported. Notably, the measurement system included only one measure on routine office/outpatient visits (Figure 8).

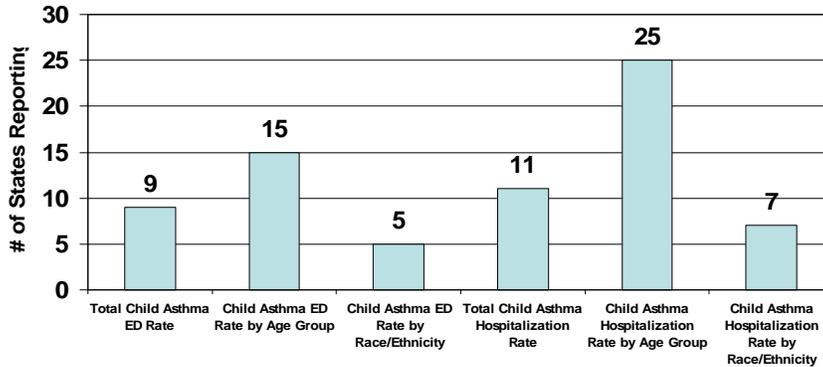
FIGURE 8. Health Care Utilization Reporting Among 36 State Asthma Burden Reports, 2010



Source: GW SPHHS Analysis of 36 State Asthma Burden Reports Available as of November 2010

Typical utilization measures include hospitalization and ED encounter rates. These rates can indicate a number of trends, such as poorly controlled asthma as well as inadequate access to primary and ambulatory care, reflecting a dearth of providers or lack of access to those providers by community members. Nine states reported on total ED utilization rates among children with asthma, while 11 states reported on total hospitalization rates among children with asthma. Fifteen states reported on ED measures by age group among children with asthma, while 25 states reported on hospitalization measures stratified by age group of children with asthma (Figure 9).

FIGURE 9. Specific Health Care Utilization Measures Among 35 State Asthma Burden Reports, 2010



Source: GW SPHHS Analysis of 36 State Asthma Burden Reports Available as of November 2010

Morbidity (n=21)

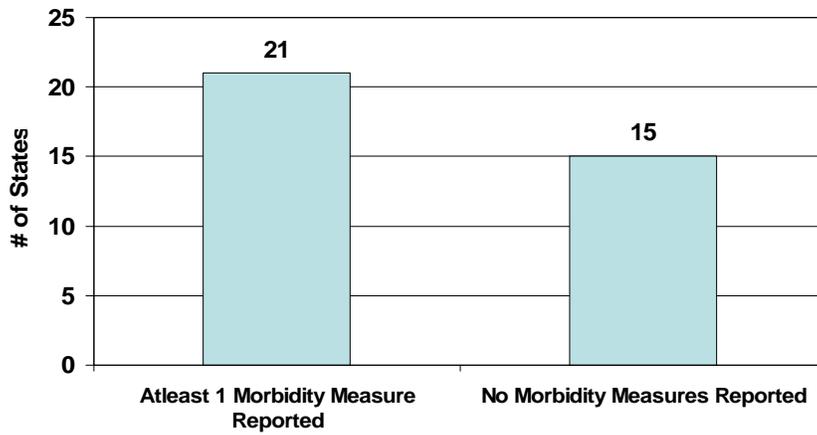
Morbidity measures, including asthma symptoms, activity limitations, missed school, and the presence of asthma attacks represent important measures of symptom severity and control. These indicators can also provide insight into the asthma burden experienced by children, families, and schools²⁵ and help inform more effective patient-focused education efforts, which have been shown to help reduce asthma morbidity.²⁶

Twenty-one states reported on at least one morbidity measure, while a total of 29 different morbidity measures were reported across all states. These included 13 measures related to symptoms, seven related to activity limitations, and five related to attacks (Figure 10).

²⁵ Diette GB, Markson LM, Skinner EA, Nguyen TTH, Algatt-Bergstrom P, Wu AW. Nocturnal Asthma in Children Affects School Attendance, School Performance, and Parents' Work Attendance. *Archives of Pediatric and Adolescent Medicine*. 2000;154:923-928.; Glazebrook C, McPherson AC, Macdonald IA, Swift JA, Ramsay C, Newbould R, Smyth A. Asthma as a Barrier to Children's Physical Activity: Implications for Body Mass Index and Mental Health. *Pediatrics*. 2006;118(6); Goodwin RD, Pine DS, Hoven CW. Asthma and Panic Attacks Among Youth in the Community. *Journal of Asthma*. 2003;40(2):139-145.

²⁶ Coffman JM, Cabana MD, Halpin HA, Yelin EH. Effects of Asthma Education on Children's Use of Acute Care Services: A Meta-Analysis. *Pediatrics*. 2008; 121:575-596. ; Guevara JP, Wolf FM, Grum CM, Clark NM. Effects of Educational Interventions for Self-Management of Asthma in Children and Adolescents: Systematic Review and Meta-Analysis. *BMJ*. 2003; 326:1308-1309.; Martinez FD. Managing Childhood Asthma: Challenge of Preventing Exacerbations. *Pediatrics*. 2009;123: S146-S150.

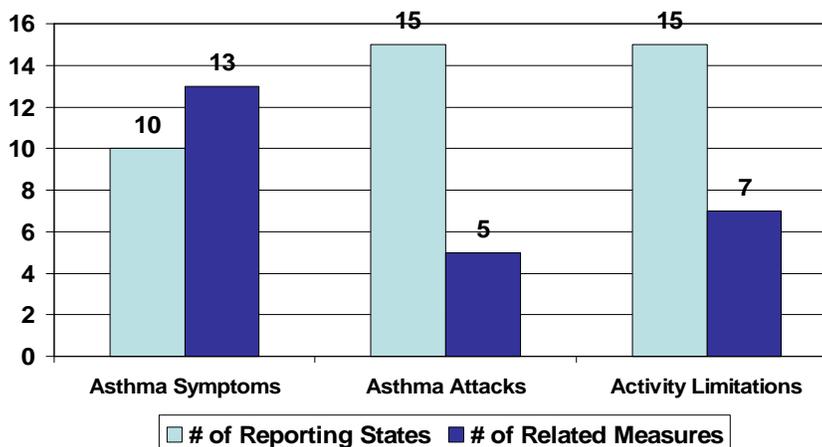
FIGURE 10. Morbidity Measures Reporting Among 36 State Asthma Burden Reports, 2010



Source: GW SPHHS Analysis of 36 State Asthma Burden Reports Available as of November 2010

Morbidity reporting showed great variation, with 13 different measures in use. Asthma attacks showed the least variability, perhaps because they represent the most severe measure. Fifteen states reported on seven different activity limitation measures, with the most frequently reported measure about children with current asthma being school days missed within the past 12 months (Figure 11).

FIGURE 11. Specific Morbidity Measures Among 21 State Asthma Burden Reports, 2010.



Source: GW SPHHS Analysis of 36 State Asthma Burden Reports Available as of November 2010

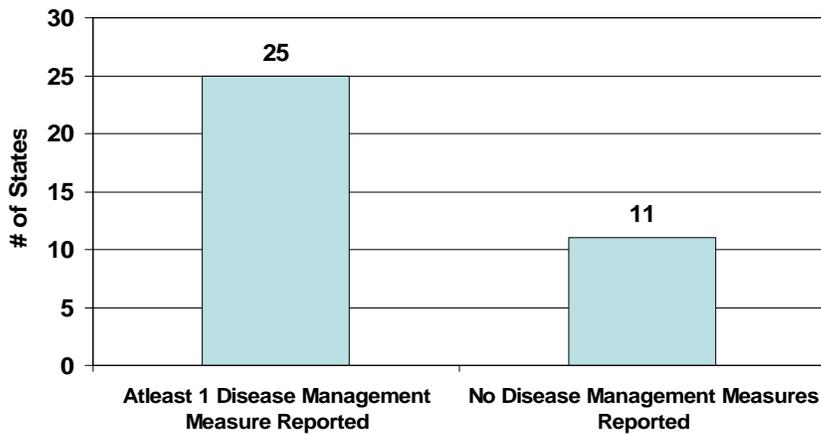
Disease Management (n=25)

For children with asthma, comprehensive disease management consists of several core elements as identified in evidence-informed guidelines; each involves family and other support systems, and each is critical to the success of an effective treatment and control regimen. For example, medication use, self-management education, and environmental exposure remediation are all central to disease management.

Twenty-five states reported disease management measures that incorporated the above-referenced aspects of disease management, including patient-level and environmental measures (Figure 12). Of these twenty-five states, thirteen have reported on at least one of 39 separate measures that together provide a picture of how well asthma is being managed at the patient level. (See Appendix II for list of disease management measures). The burden reports also captured information on environmental exposures and trigger remediation, which evidence shows are correlated with asthma symptoms and attacks.²⁷ Twelve of these states reported on environmental exposures using eight related measures, focusing on both first and second-hand smoke exposure to tobacco among children with asthma. This type of exposure has a known causal link to increased asthma prevalence, frequency of symptoms, and disease severity.

²⁷ Lapnear BP, Aligne CA, Auinger P, Weitzman M, Byrd RS. Residential Exposures Associated with Asthma in US Children. *Pediatrics*. 2001; 107: 505-511; Wu F, Takaro TK. Childhood Asthma and Environmental Interventions. *Environ Health Perspect*. 2007;115:971-975.; Rosenstreich DL, Eggleston P, Kattan M, et al. The role of cockroach allergy and exposure to cockroach allergen in causing morbidity among inner-city children with asthma. *New England Journal of Medicine*. 1997;336:1356-63; Gent JF, Belanger K, Triche EW, Bracken MB, Beckett WS, Leaderer. Association of pediatric asthma severity with exposure to common household dust allergens. *Environmental Research*. 2009.

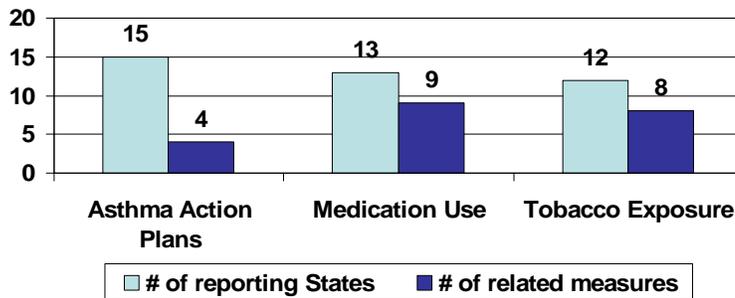
FIGURE 12. Disease Management Reporting Among 36 State Asthma Burden Reports, 2010



Source: GW SPHHS Analysis of 36 State Asthma Burden Reports Available as of November 2010

Of the 39 patient-level disease management measures, four relate directly to the provision of asthma action plans. Fifteen states reported on one of these four measures, the most common of which was the percent of children with asthma who had received an asthma action plan from their clinical provider (Figure 13).

FIGURE 13. Specific Disease Management Measures Among 25 State Asthma Burden Reports, 2010.

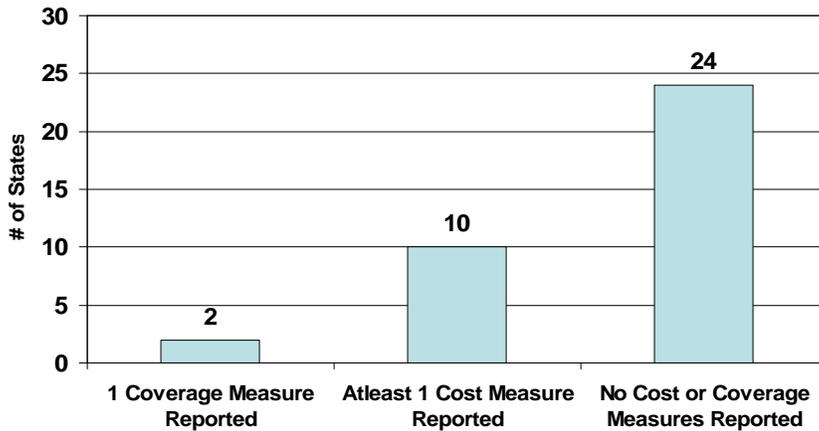


Source: GW SPHHS Analysis of 36 State Asthma Burden Reports Available as of November 2010

Cost and Coverage (n=12)

Ten states reported on the cost of childhood asthma services, using nine measures. The most frequently used measure, average charges per asthma hospitalization by age, was used by six states. Despite the importance of insurance in assuring access to high quality asthma care, only two states reported on the proportion of children diagnosed with asthma who had health insurance coverage (Figure 14).

FIGURE 14. Cost and Coverage Reporting Among 36 State Asthma Burden Reports, 2010.



Source: GW SPHHS Analysis of 36 State Asthma Burden Reports Available as of November 2010

Overall reporting

Beyond differences in the frequency of reporting on any particular measure, there is significant variability in how and what states report. While the available data provide valuable information on asthma trends within individual states, data are not reported for a common year, limiting comparability across states. Some categories of data were more widely collected and reported, such as prevalence and health care utilization, whereas data about cost and coverage and certain aspects of disease management, such as environmental assessments or remediation, were less frequently collected and reported.

Even where common measures were reported, there was no uniform set of variables collected across the funded states. For example, many states collected data about asthma action plans but collected slightly different information about the plans or asked about them with sufficient variation that they were, in fact, asking different questions. Additionally, the states used different measurement ranges, including different age ranges and categories for race and ethnicity, as well as years of school among middle or high school children and the definition of students in school level data. Many states reported school data but some states only reported on certain

grades (e.g., sixth, eighth, and tenth grades), thus only representing a small portion of all children in that state. Sources of school data were also only for public schools and omitted a portion of the child population who are not enrolled or attending a public school or are not currently in school.

Several states report data variables that are particularly useful when considering asthma from a holistic perspective, such as asthma prevalence by body mass index (BMI) (one state) and asthma management (i.e. asking about training on different inhalers, medications, and management strategies) (seven states).

Finally, the state asthma reports contain very little sub-state level data, despite the known utility of community- and neighborhood-specific data in measuring community variation and targeting resources.

Conclusions and Recommendations

This analysis underscores the importance of comprehensive and consistent information in effective management of childhood asthma, one of the most widespread and costly health conditions faced by children and their families. Health information allows communities, states, and the nation to understand the impact of a condition, the populations and communities most affected, and progress in treatment, management, and health outcomes. Our analysis of CDC-supported state asthma reporting systems reveals both the absence of comprehensive reporting in all jurisdictions as well as a lack of uniformity regarding what measures are reported, how key terms are defined for collection and reporting systems, the time period over which information is collected, and how information is presented.

There are important reasons to bring particular focus to asthma, as well as reason to do so at this particular time. First, basic reporting is in place through important periodic national surveys, grants to states for asthma control programs, information available through the community health centers program, and the identification of childhood asthma management as a reportable measure for many payers under the National Committee for Quality Assurance (NCQA) and other quality measurement systems. This provides a baseline for expanded data collection on the one hand, and condition-specific focus on the other. Further, this is an opportune time to address collection of public health information. A commitment to prevention and public health is embodied in the Affordable Care Act, and the tools for technology-enabled collection of data at the practice level are in place as a result of the national investment in HIT under the American Reinvestment and Recovery Act (ARRA). These investments position the nation, over time, to enhance its ability to monitor population health and measure the effectiveness of health care.

Extending existing data collection capabilities requires a targeted national asthma information initiative, as part of a national focus on effective collection and analysis of

health information that takes into account what is known today, the direction in which knowledge must move, and what steps are needed to get there. This effort might encompass multiple federal health agencies, state and local public health agencies, health care providers now in the HIT adoption stage, and consumers and families.

As part of a targeted national effort, certain types of health information might be collected less frequently than today (e.g., every 2-3 years) but with more focus on state- and community-level information that can help identify health patterns to inform and health care interventions. While measuring year-to-year changes is ideal, the cost of this approach in relation to the expectation of changes over time might argue for somewhat less frequent but more robust information. Rather than annual, limited, and highly variable reports from a portion of states, more valuable might be bi-annual information from all states that captures information at the county level, using harmonized collection and reporting periods, common and clearly defined reporting measures, and common measurement and reporting methods that track the CDC surveillance framework. Following the establishment of a baseline reporting system that contains sufficient information and harmonization to provide a comprehensive picture, reporting might be updated periodically.

To create better health information about childhood asthma, the definition of what elements are essential to improved outcomes should be reconsidered. Many existing clinical performance measurement systems focus narrowly on prescriptions and hospitalizations, thereby missing the opportunity to capture data on asthma management, including asthma education, case management, and environmental remediation efforts or comorbid conditions, such as obesity and depression. In a national effort to upgrade information on child health asthma management, it is important to consider whether measures of quality need to conform better to evidence-informed quality guidelines so that progress toward meeting such standards actually can be measured. A more comprehensive set of measures that are more clearly articulated and defined could be endorsed by CMS, and as quality of care data become available, this information could be added to the state information base maintained through the CDC investment. While Medicaid and CHIP represent a national starting point, the National Quality Strategy's emphasis on all-payer information means that over time, public health agencies could receive information on key measures from all payers. Potential expanded measures include:

- The percentage of patients evaluated during at least one office visit for frequency of daytime and night-time asthma symptoms. (Quality measure from National Quality Forum or NQF);
- The percentage of pediatric patients with persistent (mild, moderate, or severe), not well controlled, or very poorly controlled asthma who were prescribed either the preferred long-term control medication (inhaled

corticosteroid) or an acceptable alternative treatment. (Quality measure from National Quality Forum or NQF);

- The percentage of children with asthma who have been appropriately evaluated for exposure to significant environmental triggers, such as environmental tobacco smoke, dust mites, cats, dogs, molds/fungi, or cockroaches, either by history of exposure and/or by allergy testing. (Quality measure from the HRSA Disparities Collaborative).

As HIT adoption moves forward, it will be increasingly important for states to provide more robust information to public health agencies. Information on childhood asthma represents a valuable place to begin such an undertaking, since the basic CDC framework for collecting and analyzing such information through the asthma control program is in place. The Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule contains an express public health exception that allows public health agencies to acquire, aggregate, and de-identify such data in order to create information that can inform localities about the proportion of children with asthma who receive effective treatment. Health care utilization data on hospital admissions and emergency department also would provide insight into utilization patterns of and changes over time. Of particular importance is the enhancement of state to capture and report local-area data. Specifications for local reporting and mapping at the zip code, neighborhood, or community level would greatly enrich the utility of the reported information.

Potential sources of data include the federal investment in state asthma control systems with data collection and reporting capabilities, claims data from federal health care programs, comparable data collected by private payers that elect to do so, and data from other federal initiatives such as the community health centers program and grants to states to support maternal and child health activities. These data can be supplemented by periodic national surveys, revised and updated to consider new information.

Essential to strengthening the public health information system is the use of new tools to better capture asthma data that can, in turn, be used by local communities to identify and decrease their asthma burden. Existing gaps between clinical systems and public health systems need to be bridged; a comprehensive public health information network could serve as the connector between clinical and environmental and public health data. Applications such as geomapping can be used to track the burden of asthma and guide appropriate and timely resource deployment. Existing initiatives like the federal Public Health Information Network could be expanded beyond communicable disease surveillance to incorporate the exchange of data on asthma and other chronic and debilitating conditions. Interoperable solutions are essential and merit support – as are further interagency collaborations.

Curtailling health care costs while improving the quality of care and the health of populations are a "triple aim" for the nation. Because health care costs and health status are driven by myriad conditions, a health information infrastructure is needed that can serve the needs of the entire population.

At the same time, all journeys begin with the first step. With resources already invested in child asthma reporting, a sensible step is to marshal the resources that are available, in order to develop a framework that can serve as a model and platform for other diseases and conditions that merit comparable attention because of the potential impact of health information to respond to and address the "triple aim" of the nation – to cut costs, improve quality of care and health outcomes.

APPENDICES (available online at www.mcanonline.org and www.rchnfoundation.org)

APPENDIX I- SURVEILLANCE BACKGROUND AND CONTEXT

APPENDIX II – LIST OF VARIABLES COLLECTED AT THE STATE LEVEL

APPENDIX III – TABLE OF STATES