ASTHMA IN CHICAGO

DISPARITIES, PERSPECTIVES AND INTERVENTIONS

2011 REPORT

Featuring contributions from local researchers, community members, and health professionals

COMPILED BY

RESPIRATORY HEALTH ASSOCIATION®
of Metropolitan Chicago

This report was compiled by Respiratory Health Association of Metropolitan Chicago in cooperation with various partners whose efforts are represented herein. The views of the contributors are their own and do not necessarily reflect the views of Respiratory Health Association of Metropolitan Chicago. Although experts may reach differing conclusions about certain challenges or interventions, we wish to acknowledge and appreciate the work of the many individuals and institutions – including those not specifically named in this report – who are working to address asthma in Chicago.

Edited by Audrey Eisenberg and Julie O'Brien

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Foreword

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According to recent data released by the Centers for Disease Control and Prevention (CDC), asthma now affects one in 10 children in the United States, a 12 percent increase over the last decade.[1]

Although this rise in prevalence is astounding, it does not reflect the disproportionate nature by which asthma affects communities of color. From 2001 to 2009, asthma increased by nearly 50 percent among black children, meaning nearly one in six black children is now living with asthma.[1]

Not surprisingly, children in certain Chicago neighborhoods face a heavier burden of asthma-related deaths and emergency room visits. Factors such as dilapidated housing stock, poor air quality and limited access to care often compound the issue.

On behalf of Respiratory Health Association of Metropolitan Chicago and other local asthma stakeholders, we are pleased to present this compilation report. We are thankful to the contributing researchers, community members, health professionals and elected officials whose perspectives demonstrate our city's unique challenges and opportunities for implementing effective interventions to reverse the upward trends in asthma prevalence.

I am particularly proud of the work of Respiratory Health Association of Metropolitan Chicago to address asthma through community-focused and school-based interventions, such as the Healthy Lungs Initiative with Cook County Health and Hospitals System and our Fight Asthma Now® youth program described herein.

Helping children manage their asthma must play a fundamental role in any local community health programming, particularly in the face of huge federal cuts in funding for asthma initiatives.

We cannot allow asthma to take a backseat to other health equity issues facing Chicago's communities. Our approach to this epidemic must be built upon collaborative efforts that seek to improve health systems and impact individual health behaviors by addressing gaps in knowledge and increasing access to asthma care.

Epidemiology

Neighborhood disparities

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Per a recently released CDC report, the prevalence of pediatric asthma continues to increase nationally, with black and poor children being most burdened.[1] Since 2000, the Sinai Urban Health Institute (SUHI) has been documenting and working to eliminate asthma disparities in Chicago's most vulnerable communities.

Between 2002 and 2003, SUHI completed a comprehensive health survey in six racially/ethnically and economically diverse Chicago community areas. The findings reveal that children in disadvantaged, minority Chicago communities are particularly burdened by asthma, both in terms of prevalence and severity. Specifically, a greater proportion of black (16 percent) and Puerto Rican (21 percent) children had been diagnosed with asthma when compared to Mexican (9 percent) or white (12 percent) children. When potentially undiagnosed asthma was considered, the prevalence of asthma reached 25 percent among black and 34 percent among Puerto Rican children.[2]

A greater proportion of black (16 percent) and Puerto Rican (21 percent) children had been diagnosed with asthma when compared to Mexican (9 percent) or white (12 percent) children.[2]

This local-level data has been invaluable in soliciting an appropriate response to this unacceptable situation. SUHI has focused a series of four comprehensive interventions on impacting asthma disparities locally. Community Health Workers (CHW) making home visits are at the heart of SUHI's initiatives. Completed interventions have been associated with significant decreases in asthma related morbidity (e.g., 50 to 75 percent reductions in emergency department visits) and improved quality of life; significant cost-savings ranging from $4 to $13 saved per dollar spent have been realized.[3] In short, the lives of more than 1,000 families have been improved via these initiatives.

Next steps include taking the home-based CHW model to Chicago Housing Authority properties and efforts to utilize evaluation in impacting policy toward reimbursement for CHW models. These issues and many others are discussed in our book, *Urban Health: Combating Disparities with Local Data.*

Community influences on asthma

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Youth in urban settings suffer from disproportionately high rates of asthma, which are not solely attributable to individual risk factors. A 2010 study piloted an intervention to consider community environmental factors impacting youth asthma.

The goal of the StudenT Asthma Research Teams (S.T.A.R.T.) project was for students to identify personally relevant community factors affecting their asthma, raise community awareness, and improve asthma outcomes through improved self-efficacy.

The project consisted of a 10-week afterschool program piloted at a Chicago Public School in Uptown. Students with asthma used journaling and photography to document community factors impacting their asthma. With help from film experts, they then used their most important findings to generate two Public Service Announcements (PSAs). These PSAs were premiered to community members and distributed to popular community venues. Efficacy of the PSAs was measured through a pre- and post-knowledge and attitudes survey.

Participating students' (n=15) average peak expiratory flow improved by 28 L/min. 53.2 percent of documented factors were negative. 12.2 percent were due to bad influences in the neighborhood such as alcohol and drugs, lack of family support, and community violence. Average score on the pre- and post-PSA survey improved significantly regarding asthma definition, prevalence, negative implications and community factors impacting asthma.

Once refined, this curriculum can be used in Chicago-area schools to improve asthma outcomes and understanding of neighborhood factors impacting asthma.

Epidemiology

Asthma in Chicago

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Asthma prevalence in Chicago and throughout the United States is high. The National Health Interview Survey reported that in 2008 and in 2009, 13.8 percent of children under 18 years of age in the United States had been diagnosed with asthma.[4] Similarly, the Behavior Risk Factor Surveillance Survey reported that in 2008, 14.9 percent of children ages 5 to 9 years and 16.2 percent of children ages 10 to 14 years in the United States had previously been diagnosed with asthma.[5] In Illinois, 14.8 percent of children ages 5 to 9 and 15.6 percent of children ages 10 to 14 had previously been diagnosed with the disease.[5]

Asthma prevalence in Chicago is also high, but generally not higher than overall in the country. Surveys among a stratified cluster random sample of seventh and eighth graders in the mid-1990s found prevalence of previously diagnosed disease of 16 percent, with rates somewhat higher in low-income neighborhoods and predominantly African-American schools.[6] More recently, a survey of elementary school students found that 13 percent had been diagnosed with asthma, with higher rates in low-income and high crime neighborhoods.[7,8]

Differences in morbidity and mortality are far greater than differences in prevalence ... suggesting that there are potentially modifiable social factors contributing to disease outcomes.

Differences in morbidity and mortality are far greater than differences in prevalence. Earlier studies noted five times higher deaths rates in African-Americans[9,10] and strong and inverse associations between asthma hospitalizations and deaths with community income level.[9,11] Deaths have decreased recently in the United States and in Chicago, although racial disparities in deaths increased, with blacks in Chicago in 2003 being eight times more likely to die from asthma than non-Hispanic whites.[12]

Racial and economic disparities in asthma morbidity and mortality, in light of fairly modest differences in prevalence, suggest that there are potentially modifiable social factors contributing to disease outcomes. Effective intervention strategies in Chicago have varied and involved a variety of institutions that serve children with the disease, involve community partners and collaborate to address myriad factors contributing to asthma prevalence, morbidity and mortality rates.[13]

Englewood

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The Addressing Asthma in Englewood Project (AAEP) is a community-based asthma intervention utilizing a community health educator model to reduce asthma morbidity among children residing in the Englewood and West Englewood communities and the surrounding neighborhoods on the South Side of Chicago. Phase I of the program included screening for asthma within schools, linking families with asthma with appropriate services, educating providers and community members, and conducting home visit education. During Phase I, AAEP accomplished more than a 50 percent reduction in measures of asthma morbidity and emergency health care utilization among families receiving the home visit program. In 2011, AAEP began Phase II, which will define more specifically effective components of the intervention and refine a coordinated care model that can be replicated in future programs.

Goals of Phase II of the program are:

1. To reduce asthma morbidity and improve quality of life among children and their families with asthma in and within 10 blocks of the Englewood and West Englewood communities
2. To refine our understanding of the key components of the intervention
3. To identify costs and benefits of the program components
4. To develop sustainable infrastructures within the community that will support long term care coordination

Specific program activities will include:

1. Identification of children with asthma
2. Continuation of home visit program by community health educators with families of children with asthma
3. Integration of the intervention with local health care service providers
4. Ongoing education of health care providers and community members
5. Development of linkages among institutions and persons serving children with asthma
6. Development of policy and organizational changes within individual institutions and public agencies that foster coordination of care

This project is supported by Merck Childhood Asthma Network, Inc.,
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Local Perspectives

Humboldt Park

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The Sinai Improving Health Community Survey in 2004 reported that in Humboldt Park, 17 percent of children were diagnosed with asthma and an additional 11 percent were positively screened, meaning potential asthma rates were at 28 percent.[14] Non-Hispanic black children were diagnosed at a rate of 16 percent with a positive screening rate at 16 percent, meaning a potential of 25 percent asthma prevalence.[14] Puerto Rican children had a 21 percent diagnosis rate with an additional 13 percent positive screening rate, meaning a staggering 34 percent prevalence rate.[14]

These rates were significantly higher than the national rate, and the report set off a series of events leading to the formation of the Greater Humboldt Park Community of Wellness (GHPCW), a grassroots, community-based health coalition serving the Chicago community areas of Humboldt Park and West Town.

The GHPCW wants to ensure that all research conducted in greater Humboldt Park is addressing the community's priorities, does not harm community residents, will offer job opportunities to residents, supports the local economy and ensures proportional distribution of resources. The Asthma Task Force of the GHPCW took on the charge of initiating and coordinating asthma research in the community. Multiple projects resulted, all of which compliment each other and help build a better understanding of asthma in the community.

In Humboldt Park, the rate of potential asthma among Puerto Rican children is 34 percent.[14]

The investigators now benefit from their own work and the work of the others, and the community receives high quality, useful information, services and opportunities from a wide variety of sources. Future work is being planned to conduct more asthma interventions aimed at comorbid asthma and obesity, asthma and violence prevention and asthma genetics.

A parent speaks up

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While Pam Jenkins was breastfeeding her 5-day-old son, Darrien, she watched as he turned blue and purple in her arms.

"It was a nightmare," Pam said. "He was my first child and I was on my own. I didn't know what to do."

Over the next several years, Darrien would wheeze during the day and wake up coughing during the night, but it wasn't until he was 5 years old that he was finally diagnosed with asthma.

Even then, Pam was given little information on managing asthma, reducing triggers and removing allergens from her home. Darrien was in the emergency room on a regular basis, and he missed school so often that he had to repeat second grade.

"It's amazing how a lot of people don't think of asthma as a serious disease, but it is when it's not controlled."

Frustrated with a lack of information and support, Pam did her own research and found new doctors to treat her son. As she learned more, she was inspired to leave her nursing program to become a respiratory therapist instead. She has made it her personal and professional mission to help people living with asthma.

"For a long time I thought my son was alone in having asthma," Pam said. "Once I got in contact with Respiratory Health Association and developed my career, it was comforting to know that my son wasn't singled out. And it made me want to get educated and get out to voice what I'm learning and what I know."

Now Darrien is 14 years old and about to enter eighth grade, and thanks to his mom's efforts, his asthma is well controlled.

"I'm just so proud of where he's come from and what he has been able to do," Pam said.

Pam lives in Chicago's Chatham neighborhood, where she is an advocate for asthma awareness and education. She serves as a resource for fellow parents of children with asthma, in addition to working as a respiratory therapist for the last three years.

"It's a personal issue of mine that I broadcast into my community," Pam said.

Local Perspectives

Unifying asthma stakeholders

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The *Annals of Allergy, Asthma & Immunology* recently reported that although 70 percent of healthcare providers surveyed were aware that asthma guidelines exist, only 39 percent had actually read them, and only 46 percent of those who had read them were using them to manage their patients with asthma.[15]

There is a community of asthma stakeholders – doctors and nurses from the top hospitals, allied health professionals from every corner of the city, community-based organizations, and concerned parents – working arm-in-arm to reduce the impact of asthma on our communities, and they form the Chicago Asthma Consortium (CAC).

The CAC educates practitioners on the latest innovations in asthma care and research; shares a broad range of asthma information across the world through its website, www.chicagoasthma.org; fosters the collaboration of Chicago's asthma stakeholders through task forces, which conduct projects that maximize the collective wisdom of the community; and reaches out to neighborhoods to identify barriers to the delivery of good healthcare to those who need it most.

The results of this effort are amazing. Researchers from competing medical schools are collaborating to apply for and win national grants, more practitioners are properly implementing asthma guidelines, community-friendly materials are being produced and distributed, schools and childcare facilities are healthier, and the barriers to good healthcare are being reduced in a manner which respects the residents of Chicago's many unique neighborhoods.

Asthma action plans

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The Chicago Asthma Consortium recently reviewed surveys done in Chicago schools that have reported between 11 and 44 percent of students as having asthma,[7] despite CPS student data showing only 4 percent of students on record as having the disease. This is a call to action for better asthma management and better asthma care in our schools.

A simple way to ensure better care for students with asthma is to increase the use of asthma action plans. The 2007 National Asthma Education and Prevention Program (NAEPP) guidelines recommend that every person with asthma learn how to manage the disease based on a written asthma action plan developed in partnership with their healthcare provider, but the Centers for Disease Control and Prevention reports that only 34.2 percent of persons with asthma have a written asthma action plan.[16]

An asthma action plan is a roadmap of how and when to make changes in an individual's asthma care and includes treatment goals, a list of daily medications and peak flow measurement, symptoms, use of quick relief medications, quality of life and activity levels. This allows the patient to learn to manage asthma, react to signs of asthma, and respond properly in an emergency. It eliminates guesswork and, by enhancing communication among a child's caregivers, provides guidance to make adjustment of medicines at home, work or school in response to asthma symptoms and peak flow measurements.

Centers for Disease Control and Prevention reports that only 34.2 percent of persons with asthma have a written asthma action plan.[16]

Healthcare providers must follow the NAEPP asthma guidelines to provide asthma action plans for children. In doing so, parents will be best equipped to handle asthma emergencies and communicate their child's needs to school staff. By ensuring that caretakers in a child's life are properly trained on managing asthma, we can reduce the number of asthma emergencies and hospitalizations.

Community Asthma Interventions

Bringing care to underserved kids

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In some Chicago neighborhoods, asthma prevalence exceeds the national average by as much as 25 percent. After learning of the tragic reports of asthma-related deaths in Chicago, four Chicagoland physicians — Dr. Philip Sheridan, Sr., Dr. Philip Sheridan, Jr., Dr. Paul Detjen, and Dr. Eric H. Gluck — were inspired to form Mobile C.A.R.E. Foundation in 1998.

Mobile C.A.R.E. Foundation's mission is to provide free and comprehensive asthma care and education to children in Chicago's underserved communities via mobile medical units, the asthma vans.

An innovative mechanism for diagnosing, treating and educating underserved students, Mobile C.A.R.E. Foundation converts Winnebago vans into fully functional doctors' offices on wheels to bring the doctor to the patient, often while he or she is in school. By delivering care in this setting, Mobile C.A.R.E. overcomes the barriers to access faced in hard-to-reach communities while maximizing cost-effectiveness and accessibility.

Mobile C.A.R.E.'s core program delivers high quality asthma care coupled with personalized education at dozens of public and parochial schools and Head Start sites. Mobile C.A.R.E. partnered with Chicago Public Schools to enroll and treat students on Chicago's west, south and now north sides, all of which are hotbeds of alarming rates of asthma incidence and asthma-related morbidity and mortality among Hispanic and African-American children.

Children receiving medical care and health education on the asthma vans experience markedly fewer emergency room visits, hospitalizations and missed school days. Through improved control over their asthma, children are healthier and happier and their families' quality of life is improved.

Healthy Lungs Initiative

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Cook County Health and Hospital Systems is pleased to partner with Respiratory Health Association of Metropolitan Chicago on the Healthy Lungs Initiative. This initiative uses health educators to provide education on COPD, asthma and smoking cessation. Educators are deployed throughout the Cook County health system – our in-patient units, clinics and urgent care settings – and in other safety net clinics to help patients quit smoking, learn about asthma and COPD, use inhaled medications more appropriately, and reduce their environmental exposure to smoking and asthma triggers.

From late September 2008 through the end of April 2011, we have had 17,637 patient contacts for smoking and 9,307 contacts for asthma/COPD education.

Patients are benefiting and responding to these valuable state-of-the-art services. Our doctors notice the heightened skill and confidence that people with asthma have to manage their condition as a result of this attention to patient education. We are excited that in our asthma clinic, nearly one in five people who smoke (17 percent) report quitting smoking as a result of this intervention.

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More than 12 million people in the United States had an asthma attack in the past year,[1] and exposure to tobacco smoke is a leading cause of asthma attacks. Therefore, reducing smoking among patients with asthma and their family members is an important step in reducing asthma attacks and healthcare costs. Across the Cook County Health System, this program has documented a smoking cessation rate of 15 percent, well above what would be expected by usual medical care. Furthermore, since the Healthy Lungs Initiative began, the percentage of patients saying their homes are smoke-free has risen from 28 to 38 percent.

Using health educators has been shown to greatly reduce costs in healthcare and provide a positive impact on patient and provider interactions. The Healthy Lungs Initiative is a prime example of a model that could be implemented in other institutions.

Legislative efforts

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Asthma can take a drastic toll on our communities. When asthma is properly managed, we see better health outcomes, fewer emergency room visits and obvious healthcare savings.

Until 2001, students' quick-relief inhalers were locked up in the school nurse's office. The law was changed to protect students' rights to carry their asthma inhaler in school, which gives children the ability to avoid asthma emergencies. Unfortunately, there is little compliance with this law because few students obtain physician consent to carry their inhaler.

As an example of how few students are in compliance, of eight schools in the predominantly black community of Englewood with enrollment of 3,330 children, only 38 children had forms to self carry. Assuming an asthma prevalence of 19 percent among black children in Chicago,[7] approximately 627 children should be carrying inhalers. That means that 589 children are either unprotected or carrying hidden inhalers.

To remove a barrier to wide use of the self-carry inhaler law, I helped pass legislation in 2010 to allow parents to provide consent for their children. There are safeguards in place for this permission to be granted, including a prescription as proof that the inhaler belongs to that student and written consent from the parent that the student can properly use his or her inhaler. We are the first state in the country to improve the inhaler consent law this way.

Thought leaders, public health experts and medical professionals need to continue to look at creative and innovative ways to help our communities address asthma.

Asthma education

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Education is a key component in addressing asthma in our communities. For our part, Respiratory Health Association of Metropolitan Chicago has developed tailored asthma education programs for three main audiences: people living with asthma; caregivers, teachers and community members; and healthcare professionals.

Our programs are developed to meet the specific needs of Chicago's diverse, urban population and have been recognized for their innovation and effectiveness on both a local and national scale.

Fight Asthma Now® (FAN) empowers children living with asthma with the knowledge and skills to properly manage their asthma. Our educators visit Chicago Public Schools and teach students how to identify and avoid triggers, manage asthma episodes and control asthma on a long-term basis. This free program offers a separate curriculum for youth and for teens, with the teen portion including specific skills and activities related to living on one's own after high school. The program is validated and demonstrates positive gains in asthma knowledge among participants, showing that they are able to better manage the disease. Since 2007, nearly 5,000 children have participated in the FAN program at their local schools.

Among children ages 5 to 17, asthma is the leading cause of school absences due to a chronic illness. It accounts for an annual loss of 10.5 million school days per year.[1]

For caretakers, we developed the Asthma Management program, which covers the basics of caring for a person with asthma, including early warning signs, common triggers, proper medication use and how to handle asthma emergencies. We offer this free, 1-hour program for parents, school staff, childcare providers and community groups to ensure that each adult in a child's life can properly care for asthma and manage emergencies.

In addition, our online library features "What You Need to Know" information sheets, which provide brief guidance on a variety of topics ranging from proper inhaler technique to trigger avoidance. These free materials can be downloaded at www.lungchicago.org/library.

Finally, we equip healthcare professionals by hosting an annual preparatory workshop for the certified asthma educator exam and featuring asthma experts in conferences such as our Catch Your Breath® Women & Lung Health event, lectures of the Chicago Respiratory Society, and grand rounds presentations at local hospitals.

Recommendations for a community response

Continue raising awareness about asthma disparities affecting certain Chicago neighborhoods. Once hailed with the unfortunate distinction as the "epicenter of the nation's asthma epidemic," Chicago exemplifies disturbing national trends in asthma. In particular, rising asthma prevalence and morbidity rates are disproportionately affecting communities of color. Local researchers, community members, health professionals and public health leaders must work together to keep this issue at the forefront of discussions about our city's health priorities.

Improve identification of students with asthma to enable more targeted school-based education for students and their caregivers. School health records and data systems should indicate whether a child has asthma, and this information should be analyzed to improve coordination of resources for children with asthma. Moreover, students identified as having asthma should have asthma action plans and should be informed of their right to carry and use their inhalers at school. In conjunction with these efforts, school policies should be updated to reflect compliance with Illinois self-carry inhaler laws. Finally, educators and school personnel should participate in regular training to learn how to care for children with asthma and prevent asthma emergencies.

Support local research efforts. Chicago's academic institutions are at the forefront of improving our understanding of genetic and environmental risk factors, asthma comorbidities, and studies that seek to discover new treatments for asthma. Linkages between research institutions, local schools and community organizations must be strengthened to pave the way for fresh insights and opportunities to pilot groundbreaking interventions for asthma care.

Address other socioeconomic and environmental issues that exacerbate asthma. Healthcare professionals and others should take care to disseminate culturally appropriate asthma education materials. Furthermore, local organizations and elected officials must integrate a multi-pronged policy approach to improve indoor and outdoor air quality and reduce exposure to secondhand smoke and particulate matter (including diesel exhaust and soot).

Improve quality of care and promote effective models of coordinated care. Health systems and hospitals should support local efforts in their surrounding communities to address asthma through education, improvements in quality of care and other services. Integrating asthma care across health and other neighborhood settings – including use of community health educators – can improve asthma care and self-management of the disease, thereby reducing expensive emergency room visits and overall healthcare costs.

RESPIRATORY HEALTH ASSOCIATION®
of Metropolitan Chicago

Asthma by the Numbers

Population

- As of 2009, an estimated 8.2% of the U.S. population (24.6 million people) live with asthma. This is a 12.3% increase in prevalence compared to 2001.[1]
- Each day, 11 Americans die from asthma. There are more than 4,000 deaths due to asthma each year, many of which are avoidable with proper treatment and care. In addition, asthma is indicated as "contributing factor" for nearly 7,000 other deaths each year.[2]
- The proportion of the population with at least one asthma attack in the previous year was 4.2%. That is, 12.8 million people (8.7 million adults and 4.0 million children aged 0–17), or 52% of those with current asthma.[1]

Children

- Over 10 million U.S. children aged 17 and under (14%) have ever been diagnosed with asthma; 7.1 million children still have asthma (10%). [3]
- Among children ages 5 to 17, asthma is the leading cause of school absences due to a chronic illness. It accounts for an annual loss of 10.5 million school days per year.[1]
- In some areas of Chicago, as many as 59% of children (age 0 to 12) diagnosed with asthma live with a smoker despite secondhand smoke being a major asthma trigger.[5]
- In Chicago, Puerto Rican children have the highest asthma prevalence rate (34%), compared to the national average of 10%.[5]
- More than half (58%) of all children with asthma in Chicago had a severe asthma attack in the past year, and nearly one-third (31%) had an asthma attack so severe that they thought their life was in danger.[6]

Living with asthma

- In 2008, it was reported that nearly one in seven persons with asthma had an asthma attack requiring urgent outpatient care.[4]
- Only 34.2% of persons with asthma have an asthma action plan and only 12.2% have taken a class to learn how to manage their asthma.[4]
- In a Chicago survey, 28% of people with asthma reported being awakened by breathing problems at least once a week.[6]

The cost of asthma

- Children in poor families were more likely to have ever been diagnosed with asthma (18%) or to still have asthma (14%) than children in families that were not poor (13% and 8%).[3]
- In 2007, the estimated societal cost of asthma was $56 billion ($50.1 billion due to medical expenses, $3.8 billion due to lost productivity, $2.1 billion due to premature death).[4]
- Nearly 4 times the number of uninsured individuals with asthma were unable to buy prescription medication (40.3%) compared to insured individuals (11.5%).[4]

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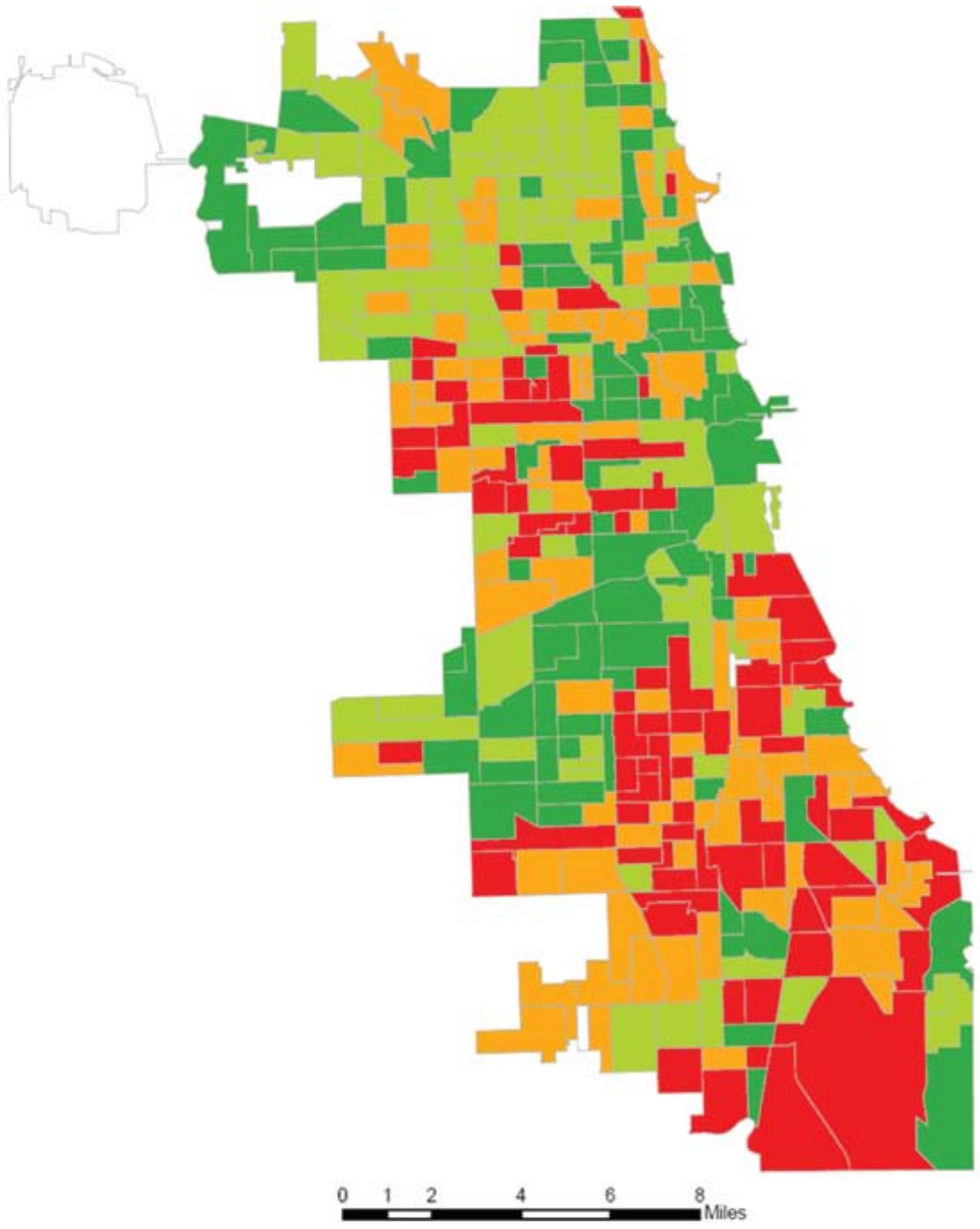
Childhood asthma prevalence in Chicago



Arranged in quartile groups by neighborhood average asthma prevalence:

Group 1	Group 2	Group 3	Group 4
8%	12%	17%	25%

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