

# WORKING SESSION 1C: ASTHMA: CHRONIC DISEASE AMONG CHILDREN

---

## REORGANIZING HEALTH SYSTEMS TO PROMOTE BEST PRACTICE MEDICAL CARE, PATIENT SELF-MANAGEMENT, AND FAMILY-CENTERED CARE FOR CHILDHOOD ASTHMA

Daniel Hyman, MD

### INTRODUCTION

The following presentation discusses strategies for improving care for children and families who have been diagnosed with, or are suffering from recurring symptoms of asthma. The approaches discussed are equally applicable to any chronic condition in childhood, but this article focuses on asthma.

The purpose of this presentation is to: 1) identify the gap that exists between care as it is and as it ought to be for children with asthma; 2) describe a model for care of children with chronic conditions; 3) introduce an approach to improving your office system's design, and to enhancing family and patient self management for children with chronic conditions; and 4) describe an approach to changing one's clinical practice.

### BACKGROUND: THE NATIONAL INITIATIVE FOR CHILDREN'S HEALTHCARE QUALITY (NICHQ)

First, to set the stage and to provide background about an initiative that promotes children's healthcare, the National Initiative for Children's Healthcare Quality is:

- An education and research organization dedicated to improvement in the quality of children's healthcare.
- An organization whose mission is "to eliminate the gap between what is and what could be in healthcare for all children."

- A non-profit organization, founded in 1999.
- Located in Boston, with other offices in Vermont, Washington, and North Carolina.

### DEFINING THE GAP

Recognizing that there is a gap between optimal and typical care of asthma is the first step to take in attempting to improve primary care practices, hospitals, and emergency rooms.

In 1997, when it issued its *Expert Panel Report*, the National Lung Heart and Blood Institute (NHLBI) stated that, with proper treatment, asthma symptoms should almost always be controlled. Despite this statement, annual CDC reports on the morbidity of asthma regularly show that among children birth to 18 years of age, there are:

- 14 million doctor visits
- 10 million lost school days
- 500,000 emergency room visits
- 160,000 hospitalizations

There is a great deal of data that also consistently demonstrate that physicians are not following NHLBI guidelines for asthma management, especially as they relate to severity categorization, use of anti-inflammatory therapy, and use of written asthma management plans. The reasons for these sustained, and in fact worsening, morbidity data and management gaps, have nothing to do with physicians and other providers not working hard enough, being smart enough, or caring enough. We were not trained how to coordinate chronic care.

(*Ethn Dis.* 2003;13[suppl3]:S3-94-S3-98)

**Key Words:** Asthma, Patient Self-Management, Health Systems

---

From the National Initiative for Children's Healthcare Quality.

---

*There is a great deal of data that also consistently demonstrate that physicians are not following NHLBI guidelines for asthma management, especially as they relate to severity categorization, use of anti-inflammatory therapy, and use of written asthma management plans.*

---

It is clear that we do a better job managing acute conditions that require little coordination (eg, strep throat) than we do with chronic conditions that require coordination, follow up, and consistency.

### NHANES Data

Although prevalence data for asthma by race are fairly comparable, with about 4% of people in each group carrying a diagnosis, there are dramatic differences in the rates of emergency department care, inpatient hospitalization, and mortality between racial groups. One can hypothesize many reasons for this, but our job at this point, is to begin to identify strategies to reduce or eliminate these disparities.

There have been a series of studies published in the past few years that have consistently demonstrated shortfalls in the key process measures for management of children with asthma, especially in groups of children insured through Medicaid. In Connecticut, the Medicaid MCOs reviewed charts of children with asthma identified as "high utilizers." Fewer than half of the children were on inhaled corticosteroids, fewer than 40% had written treatment plans, and, in

---

*This model includes 6 components, which can, if incorporated into care systems in an organized way, improve outcomes both functionally and clinically, by creating partners between motivated patients/families and prepared proactive practice teams.*

---

only half of the cases, did the chart reflect any review of environmental tobacco smoke exposure. It would be impossible to control asthma symptoms in the absence of reliable provision of these key components of asthma care.

### A CARE MODEL FOR CHILD HEALTH

Ed Wagner, MD, an internist in Seattle, has written extensively on improving care for people with chronic conditions. His *Improving Chronic Illness Care* model has been adapted by NICHQ into a Care Model for Child Health (CMCH). This model includes 6 components, which can, if incorporated into care systems in an organized way, improve outcomes both functionally and clinically, by creating partners between motivated patients/families and prepared proactive practice teams.

The 6 components are:

1. Decision Support: incorporating principles of evidence-based care into the care process;
2. Delivery System Design: rethinking who does what in the office, and how to make it reliable as a process;
3. Clinical Information Systems:

- use of electronic (or other types of) databases can improve population-based care;
4. Family and Self-Management Support: this component refers not only to providing patient education, but also about forming a partnership in which the patient understands his/her condition, how to use medications, how to prevent symptoms, and how to recognize and react to the early onset of symptoms;
5. Community Resources: linkages with community-based support services can improve overall care management for patients with chronic conditions.
6. Health Care Organizations: policies of payers and employers can create incentives or disincentives for chronic illness management. Providers need to work in an organized way to move the payment and regulatory system in a direction that facilitates optimal care.

Two of these components (Delivery System Design and Family and Self-Management Support) will be discussed comprehensively in the following report; a summary of the remaining 4 elements is first provided.

### Decision Support

As a primary care practice, the initial step that must be taken to improve care for asthma is to reach agreement about using the guidelines for asthma care published by the NHLBI in 1997, and updated in summer 2002. These guidelines specifically link treatment choices to disease severity, and provide symptom-based criteria for classifying asthma disease severity into either intermittent or persistent categories. Patients with persistent asthma are further grouped into mild, moderate, or severe groups. The choice and dose of daily controller medication(s) for these persistent patients is determined by their disease severity. Teams must also agree to provide

written asthma management plans to patients, especially those requiring daily controller therapy, to guide prevention and home treatment of early symptoms. The existing gap between current care processes and recommended care processes demonstrates that practices must incorporate these evidence-based treatment approaches into their care systems in order to provide optimal care.

### Clinical Information System

To reliably provide coordinated care for patients with chronic illnesses, providers need to know more about this special population. We need to think about care needs of patients not only when we are together in the exam room but also at regular planned intervals dependent upon disease status. A “registry” facilitates this type of planned population-based care. Registries can be electronic databases or simple paper logs, but the primary purpose of a registry is to assist in identifying patients in need of services, even those who do not seek services.

### Community Resources

A primary care practices can help families by creating linkages to resources outside their offices, including school nurses, visiting nurse agencies, patient education, and support services, etc. Some organizations make home visits to do assessments, provide teaching, and/or promote remediation in public housing. These efforts are critical to optimal care.

### Healthcare Organization

Policies of health systems can either encourage or discourage comprehensive care for chronic conditions. Whether, for example, spacer devices are covered by a health plan has an impact on care decisions and treatment effectiveness. Fair reimbursement for follow-up care for patients is an important indicator of this kind of support. Advocacy by providers to the payers may be necessary to improve the regulations within which a provider works.

### Delivery System Design

Don Berwick, director of the Institute for Healthcare Improvement, has often said, “Each system is perfectly designed to achieve the results it gets.” Reflecting on this statement, look at this example. If only 72% of my 2-year-old patients are completely immunized, it is because my system is not able to accomplish better results than that. This is the kind of result my current system gets. If only half of children with asthma have a written treatment plan, again, it is because that is what our system is set up to achieve—it is not a conscious choice, it is simply a reality.

The corollary to this system rule is: changing care requires changing the office system. Changing office systems requires that a practice team consider a few key questions—who, what, where, when, and how?

Practices participating in improvement projects almost always need to make changes to their office systems to accomplish their goals. These changes include choosing or developing, and making accessible to the providers, a single written asthma management plan (AMP). Many practices place a poster in each exam room that summarizes symptom-based asthma classification guidelines and the choices for appropriate treatment based upon this classification. Also, many practices begin to use a “Living with Asthma” (LWA) patient survey. This tool allows patients to report their symptoms and current treatments to their provider by filling out a form instead of solely through oral history taking. Samples of a written AMP, NICHQ Medication/Severity Poster and LWA survey can be downloaded from [www.nichq.org](http://www.nichq.org).

Finally, practices need to rethink who is responsible for each of the steps in the new care process, from distributing surveys to completing and reviewing management plans, to enrolling patients in a registry and then using the registry to prompt the scheduling of planned follow-up visits.

A few key points regarding the design of the office system include:

- Defined roles and delegated tasks—front office staff, nurses, medical office assistants are all teammates to physicians and nurse practitioners who are trying to better coordinate chronic condition care. All the work can not be done, and is not best done, by the provider in the exam room.

- Care provided in planned visits for optimal asthma care can not be provided at the time of acute visits for management of wheezing. Well child-care visits do not occur frequently enough, and are generally focused on a broader set of issues, not just asthma. Visits need to be arranged and thoughtfully organized to accomplish core aspects of asthma care: severity assessment, agreement on and review of a written treatment plan, review of asthma triggers and avoidance, early recognition of symptoms and initiation of therapy, etc.

- An effective office system creates and trains a team to work together in a prepared and proactive way. Do not underestimate how motivating it can be for office staff to be included in a meaningful project that meaningfully improves care for patients, especially if the staff person or one of their family members has asthma.

- Who, what, where, when, how. One needs to ask and answer very specific questions regarding how work will be divided and how each aspect of care will be delivered.

### Family/Self Management Support

Care planning should be done by focusing on ways in which asthma symptoms interfere with life, school, work, etc, and by identifying effective strategies for adherence to prescribed treatment plans. Although some practices have well-organized patient education plans with people trained specifically to provide this education, this, by itself, does not create true partnerships. The following section is reprinted with per-

mission from a NICHQ training manual.

*What is Family and Self-Management Support?*

Family and self-management support is a counseling technique based on the idea of creating a partnership between the provider and the patient, or in the case of very young children, the patient's family. One of the primary tenets of family and self-management support is that the family and patient need to be actively involved in managing the disease. Family and self-management strategies strive to help patients and families understand the disease, make informed decisions, participate in the management of care, and adapt to life with chronic illness. The ultimate goal is to enable patients to live as normal and full a life as possible.

The following outline describes steps and several sample scripts that could be used with patients.

*Steps to Using the Self-Management Support Approach*

**Establish a Focus.** Establishing a focus for the session is an important first step to ensuring good self-management. This is an opportunity for you to learn from the patient and family about their chief issues and concerns about the disease. Learn about patient and family concerns and perceptions by asking open-ended questions, such as:

- What about having asthma is difficult for you as a family?
- What about having asthma is difficult for your child?
- What do you find most challenging about your child's asthma?
- What are some changes you'd like to experience with regard to managing your child's asthma?

**Share Information.** You also need to share information about the disease with the family and patient, emphasizing your particular concerns around the disease. This will assist them in making an

informed decision about where to focus their efforts. Share this information in a non-judgmental manner, reinforcing important issues that may have been raised during your initial discussion. For example, use a statement such as, "Asthma is a chronic illness—that doesn't mean you can't manage it and have a normal life."

**Develop a Shared Goal.** Shared goal-setting is a collaborative process that incorporates both the provider's and the family's perspective. With a few open-ended questions, providers can identify not only important patient perceptions about asthma but also the most significant barriers a patient may face. Be certain to describe how to breakdown a goal into smaller, achievable steps. For example, if someone says they want to see their child run without wheezing, you can break that down into sticking to a medication regime, being aware of asthma triggers, and so on. The following questions can be posed to your patients' family members: "With regard to managing your child's asthma, what are some things you would like to change?" "What are the aspects of your child's asthma that are most troubling to you?" "In terms of dealing with your child's asthma, what would be an ideal day for you?"

**Develop an Action Plan.** After setting a shared goal, it is important to create an action plan with the family and patient. The action plan includes a discussion of how, what, when, where, and the frequency of the new behavior. It also includes a discussion of likely barriers to success and some strategizing about how to overcome these barriers. An important step in family and self-management support action planning is rating the family or patient's confidence in the plan. Use a statement such as, "On a scale of 1 to 10, with 1 meaning you are certain you couldn't accomplish your plan and 10 being certain you could accomplish your plan, how would you rate your confidence in your plan?"

The goal is for the confidence level

to be between 6 and 9. If it is a 10, the chosen plan may be too easy. If it is less than 6, review the plan and see if there are ways to boost the patient's confidence.

**Use Problem-Solving Techniques.** Often during the action planning part of a counseling discussion, problems are identified. These problems often act as barriers to new behaviors. One problem-solving method is outlined below.

- Identify the problem
- Brainstorm possible solutions
- Pick one solution
- Suggest that family/patient try the solution for 2 weeks.
- If that solution doesn't work, try another for 2 weeks.
- If that doesn't work, find a resource for other ideas (solutions).
- If that doesn't work, accept that the problem may not be solvable now. This doesn't mean that the problem may not be solvable in the future.

**Follow-up.** A key step in self-management support is agreeing on a follow-up plan. The plan does not need to be elaborate. It usually can be as simple as setting a specific date to check in. The important point is that the patient knows you will follow-up and that he or she will be expected to report on progress toward goal.

**MODEL FOR IMPROVEMENT**

The Model for Improvement is a simple, 3 question approach to beginning the process of office-based improvements in care. The 3 key questions are:

- Aim: What are we trying to accomplish?
- Measures: How will we know that changes are resulting in improvements?
- Ideas: What changes can we make that will result in improvement?

The approach taught at NICHQ to

## ASTHMA: CHRONIC DISEASE AMONG CHILDREN - Hyman

practices participating in QI work is a small cycle change approach frequently referred to as the PDSA model, or Plan-Do-Study-Act.

The American Academy of Pediatrics has recently launched a CME, distance learning, practitioner tool for physicians wanting to improve their practices. The Educating Physicians on Quality Improvement in Pediatric Practice (EQIPP) uses PDSA cycles applied to improving asthma care and has 4 units:

Unit 1: Measure practice outcomes to identify opportunities for improvement

Unit 2: Evidence based care with link to tools

Unit 3: Implement changes with small tests

Unit 4: Learn from small tests: did the tools and strategies improve the process of care? Measure again.

## CONCLUSION

Making changes and improvements in your practice requires starting small and taking a series of steps that improve care, improve outcomes, and reinvigorate you and your partners and teammates in practice. Start by rethinking your system and how it is working. Focus on strategies for improving your partnerships with your patients. It is easy to make small changes that touch people's lives in meaningful ways.