

Asthma and COPD Coalitions

The wide-focus characterization of a disease is epidemiologic—where the disease occurs, in what populations it occurs, its prevalence, its identifiable association with precipitating and etiologic factors. The narrow-focus characterization of a disease is its manifestation in an individual—its symptoms, its effects on quality of life and life span, its response to treatment, and whether it can be prevented.

It is beneficial to society in the broadest sense, and to the individual, to (1) prevent a disease when possible, and (2) to treat a disease effectively when it occurs. Achievement of these goals requires effective combination of broad-focus and narrow-focus approaches at both societal and individual levels. The basic component required to achieve these goals is information from the broadest to narrowest focus that can be used to increase societal and individual awareness, provide guidance for public policy development and change, and to create long-term activities to reduce the burden of disease.

Asthma has increasingly been the target of efforts that use streams of information from multiple levels and sources to create sustainable activities that have the goal of reducing asthma prevalence at the societal level and asthma burden on the individual.

These efforts are conducted by coalitions—the bringing together of people, organizations and institutions that share a goal of reducing asthma prevalence and burden. A common approach of the asthma coalitions is to influence public policy at the community level, encourage development or improvement of medical resources for asthma treatment, and create heightened community awareness of asthma as a preventable and treatable disease.

Coalitions can tap into and/or promulgate networks of organizations, institutions and people with similar interests in preventing asthma and reducing asthma burden. Members of networks may include (1) city, county, state and federal agencies, (2) schools, school districts and school boards, (3) non-profit professional medical and health-care societies, (4) community-based organizations and community leaders, (5) consumer advocates, (6) children's advocates, (7) for-profit organizations that may support

and/or help to fund coalitions activities, and (8) communications media that can create and disseminate information and educational products from the coalition.

Success of asthma coalitions has motivated efforts to develop similar coalitions for prevention and effective treatment of chronic obstructive pulmonary disease (COPD). The differing etiologies of asthma and COPD influence differing approaches to public policy and public information. Asthma is a disease in which underlying genetic factors render an individual susceptible to precipitating environmental factors that the individual may be able to mitigate but may not be able to eliminate. COPD is in large part a self-inflicted disease caused by tobacco smoking in the majority of individuals in whom it occurs. Different approaches to public policy and individual awareness are mandated by the differing etiologies of asthma and COPD.

Development of an asthma or COPD coalition requires funding, guiding vision, achievable specific goals, action plans for achieving goals, well-defined targets for coalition activities, accountability, and sustainability over a defined period of time.

A common characteristic of an asthma coalition is concentration of its effort in an urban area defined by (1) geographic boundaries, (2) low income, (3) poor-quality residential housing, (4) high prevalence of asthma in children and adults, and (5) limited access to medical care. Also a common characteristic of asthma coalitions is their identity as demonstration projects rather than as research projects. Although information is gathered in the course of coalition activities, the purpose of the coalition is to produce results that contribute to improved prevention and treatment of asthma in the target community.

Sponsorship, funding and purpose of an asthma coalition is characteristically provided by a sponsoring/funding organization or institution. A number of coalitions may be associated with such a body. Reporting on activities at Chest 2008, annual meeting of the American College of Chest Physicians, were coalitions associated with:

- Environmental Protection Agency—Communities in Action for Asthma Friendly Environments;

- Center for Disease Control—Controlling Asthma in America Action Project, an 8-year project with coalitions in Oakland, California; Minneapolis-St. Paul, Minnesota; and, St. Louis, Missouri;
- Merck Childhood Asthma Network, Inc.—coalitions in Englewood (Chicago) Illinois; Northern Manhattan (New York City), New York; San Juan, Puerto Rico; Philadelphia, Pennsylvania; and, Los Angeles, California;
- American College of Chest Physician—Chicago, Illinois;
- American Legacy Foundation—Lehigh Valley, Pennsylvania, Latino Outreach Program; and,
- Ad Council, Environmental Protection Agency—Goldfish public awareness media project.

The activities undertaken by a coalition derive from vision and goals established at the outset. Working from vision and goals, the focus of a coalition's activities may be examples such as:

- Working with schools to influence school district awareness of asthma as a problem, to use schools as a means of reaching children and parents with asthma awareness and training;
- Working with medical resources to enhance access to diagnosis and treatment;
- Working with community-wide organizations and municipal, county or state agencies to reduce or eliminate sources of environmental pollution and asthma triggers;
- Packaging asthma awareness information in communications formats accessible to, and usable by residents in the target community;
- Using public relations effectively to make communications media and policy makers aware of the coalition's activities;
- Where necessary, offering appropriate training to key gate-keepers at target organizations such as schools and clinics;
- Where necessary, developing bilingual versions of information and training;
- If need is indicated, developing resources to offer community-wide screening for asthma in children and concomitant asthma education for children and parents;
- Assuring financial viability of coalition activities;
- Developing networks for exchange of information and mutual support activities; and,
- Assuring that the coalition's leadership is supportive, creative and productive.

Lessons learned by asthma coalitions may be useful in the development of COPD coalitions. Some fundamental issues differentiate asthma from COPD as a disease to be addressed by coalition activities. One such issue is the proper focus of coalition activities—e.g., the focus of an asthma coalition is to change the community care environment for asthma prevention and treatment, whereas COPD is not a “community” disease but rather a disease of individual responsibility for smoking cessation. Asthma is a disease actively sought to diagnose in its early phase in emergency rooms and physician offices. Mild to moderate COPD is less actively sought as a diagnosis and is often missed altogether when spirometry and/or smoking history is omitted from physical examination. Omission of spirometry from physical examination is an example of an issue that a COPD coalition can address by education regarding spirometry technique and proper procedure coding for physician reimbursement.

Case-finding and patient education regarding smoking cessation may require recruitment of family physicians and general internists to identify individuals with mild to moderate COPD. Case-finding versus screening for COPD, including radiography, is an issue a coalition may discuss on the basis of factors such as (1) case-finding versus screening, and (2) cost of screening on a cost-benefit basis.

Experience with asthma coalitions has demonstrated that coalition activities can unite a disparate community to achieve a well-understood goal. Successful coalitions are able to develop the organizational and financial resources to sustain the activities.

Standards of Practice

Asthma coalitions are formed to bring together people and organizations that share an interest in reducing prevalence and improving treatment of a disease that can be effectively addressed by community action. The ground chosen for coalition activity is commonly an urban, inner-city, low-income community that often has poor-quality residential housing. While asthma occurs in all populations at all income and education levels, the greatest prevalence and most limited access to treatment is found in inner-city areas.

An asthma coalition is typically non-profit, operated and guided by a combination of dedicated volunteers and paid staff. Funding is commonly provided by a grant or grants from non-profit bodies and/or government agencies dedicated to health-care issues.

Essential to asthma coalition success are factors that include:

- A guiding vision derived from evidence-based data regarding the disease, the target community and target populations;
 - Achievable goals with target schedules and deadlines;
 - Selection of defined target populations and how to best reach them—e.g., through schools, emergency departments, asthma clinics, electronic and print media;
 - Assurance of financial viability and sustainability;
 - Accountability for goals and finances; and,
 - Data collection to track coalition activities and indicate any need for changes in tactics or strategy.
- An asthma coalition may have a self-limited lifetime as a demonstration project, or may seek resources to become a sustainable, on-going program.