

COMMUNITY ASTHMA

Community Asthma Initiative PROGRAM REPLICATION MANUAL



Boston Children's Hospital Community Asthma Initiative Replication Manual: Needs Assessment, Implementation and Evaluation

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Introduction

About This Manual

This manual has been developed for individuals or groups considering the creation of a community asthma home visiting and case management program to address the high rates of poorly controlled asthma in their communities, especially among low-income racial and ethnic minority populations. This manual seeks to assist programs with program development, implementation, maintenance and evaluation.

Boston Children's Hospital (Boston Children's) is a tertiary care hospital, but it is also the largest provider of pediatric primary care in Massachusetts. As a non-profit institution, it is required to perform a community needs assessment every three years. In the 2003 needs assessments, asthma was identified by the community as one of four major pediatric health concerns, along with mental health, obesity and injury prevention. In addition, asthma was noted to be the top single admitting diagnosis. African American and Latino children living in Boston were admitted at three to five times the rate of white children, indicating an important health disparity.

In order to address these disparities, Boston Children's Office of Community Health(OCH) (community benefits) initiated the Community Asthma Initiative (CAI) in 2005 to provide enhanced asthma services to children receiving emergency asthma care at the hospital, starting with a pilot intervention in four ZIP codes that encompassed neighborhoods with some of the highest asthma rates among African American and Latino residents. Applying the NHLBI National Asthma Education and Prevention Program guidelines, the CAI intervention has worked to reduce the burden of asthma on children and families through a combination of:

- Tailored asthma education, case management and home visiting that includes environmental assessments and a moderate amount of remediation for families of children who have been hospitalized, seen in the Emergency Department (ED) or referred by primary care providers (PCP's) or subspecialists due to poorly controlled asthma;
- 2. Advocacy for broad-based changes in health care delivery for people with asthma.

Based on an understanding of the many barriers to good asthma control, the project supports the entire family with respect to culture, language and beliefs through interventions in the home, school and community.

CAI and OCH continue to build on vital partnerships with community-based organizations, health care providers, parent groups, and public health administration and advocacy groups to address the Social Determinants of Health that have led to these health disparities, such as substandard housing and limited access to comprehensive asthma care, including case management and home visiting.

For children needing asthma ED care or hospital admissions, CAI has demonstrated consistent remarkable reductions in subsequent ED visits (54.6%) and admissions (81.9 percent). CAI's cost-effective services have demonstrated a return on investment (ROI) of 1.46, i.e., for every dollar spent on CAI, there is a savings of \$1.46 to society. CAI's success can serve as a replicable model of a population-based intervention.

> "For every dollar spent ...there is a savings of \$1.46 to society."

Theoretical Framework

Health equity framework, addressing social determinants of health

Health equity is defined by Healthy People 2030 as "the attainment of the highest level of health for all people. Achieving health equity requires valuing everyone equally with focused and ongoing societal efforts to address avoidable inequalities, historical and contemporary injustices, and the elimination of health and health care disparities."



Figure 1: Reference: Institute of Medicine. (2003). The Future of the Public's Health in the 21st Century. Washington, D.C.: National Academies Press. Original source: Dahlgren G, Whitehead M. 1991. Policies and Strategies to Promote Social Equity in Health. Stockholm, Sweden: Institute for Future Studies The social determinants of health (SDOH)-defined by the World Health Organization as the social conditions in which people are born, live and work¹-underlying these health disparities include poverty, racism, poor indoor air quality due to cockroaches and rodents, mold and other environmental exposures typical of substandard housing¹, low health literacy, including low expectations of asthma control, distrust of the medical system and the medications being prescribed, inadequate insurance coverage, and social conditions, such as community violence. Smith et al. reported that low parental expectations for asthma control and competing family priorities (e.g., housing, home/neighborhood safety, job, personal/family relationships, income, or parents' or other family members' health) were associated with suboptimal asthma control and under-use of controller medications (medications prescribed for people with "persistent" asthma and administered daily on a preventive basis). In addition, under-use of controller medication was associated with parental overestimation of the child's asthma control, no established time to administer medications, and parental concerns about the safety of asthma controller medications.

Social-ecological model

The program uses a social-ecological framework, as envisioned by the Institute of Medicine (2003). From addressing the individual child, the program moves to the family, the home environment, the community, including schools and primary care providers, and then moves to the broader health context through advocacy and efforts to impact health policy. Boston Children's intentionally built all three levels into the program model. We believe this framework provides a more sustainable model of prevention and treatment as it reaches beyond individual children to their circles of contact and to the policies that impact them.

Getting Started

Needs assessment

The Office of Community Health (OCH) contains the community benefits effort for Boston Children's. OCH performed a Community Health Needs Assessment (CHNA) (2003) that identified asthma as one of the top issues for the community. OCH has a community advisory board and strong partnerships in the community with neighborhood health centers and community-based organizations that represent and serve different populations within Boston, and parents who bring their children to the hospital for care. OCH conducts its needs assessments through both a formal and informal process. The formal assessment is performed every three years to meet regulatory requirements (IRS and state attorney general).

OCH has used an outside consulting group to assist with this process. Consultants are responsible for gathering data, best practices, environmental scans, talking with stakeholders and conducting focus groups. They also pull all the information together in a final report that is user-friendly and is shared with all the stakeholders. The 2019 CHNA was conducted in collaboration with the Boston Public Health Commission and multiple stakeholders in the city, including community organizations, community development corporations, health centers and other hospitals. The Boston Children's 2019 needs assessment can be found here, <u>https://www.mass.gov/doc/chna-final-report-thechildrens-medical-center-corporation-health-care-conservation-project-bostonchildrens-hospital/download</u> and the City of Boston CHNA, <u>http://www.bostonchna.org/wp-content/uploads/2020/12/BostonCHNA-FINAL-091319.pdf</u>

During the planning for CAI, the hospital also worked with its Information Services Department to review hospital admissions (and ED visits) with asthma as a primary diagnosis in the prior five years in the proposed ZIP codes to assess for asthma prevalence. This showed that 70% of patients admitted for asthma were from neighborhoods near Boston Children's.

Planning your needs assessment

Many resources exist to guide organizations on how to conduct a community needs assessment. A good resource for planning is: https://www.chausa.org/communitybenefit/assessing-and-addressingcommunity-health-needs

GIS Mapping

State and city public health department reports with statistical data of numbers and percentage of local hospital admissions attributable to a primary asthma diagnosis, and admission rates by age, race, ethnicity, income, neighborhood and schools were also helpful to further demonstrate the health inequities that we were seeing among our hospital's population. Poverty, race and ethnicity and asthma rates can be mapped together to identify disparities, as geographic areas with high asthma incidence. Mapping can be performed in advance for planning or after the fact to demonstrate where children with poorly controlled asthma live.



69.3% of CAI patients lived in an area where ≥20% of families live below the poverty level Federal Poverty Level (considered "poverty areas")

Identifying model programs

Evidence from national randomized clinical trials,^{5,6,7,8} previous models of culturally sensitive care,^{8,9,10,11} and National Asthma Education and Prevention Program 2007 guidelines,¹² indicated that comprehensive community-based approaches are most effective in reducing environmental allergens, missed school days and emergency department (ED) visits, and in increasing symptom-free days. Previous literature also showed that quality improvement (QI) evaluation approaches can monitor multifactorial interventions to improve outcomes such as ED visits and hospitalizations for asthma.¹³ Multilevel interventions to reduce health disparities can be derived from the socio-ecological model.¹⁴.

The planning team conducted a thorough literature review to identify existing research and model programs. In addition, the team was able to make a site visit to the Harlem Children's Zone's asthma home visiting program prior to program initiation for technical assistance on program design and implementation. Our program also received a great deal of guidance from local partners, in particular the Boston Public Health Commission and their partners conducting Healthy Homes research regarding home environmental interventions and Integrated Pest Management.

Over the years, we have been able to provide technical assistance to other hospitals and group practices in Massachusetts and nationally that are starting their own programs.

Initial planning group

At Boston Children's, the planning group consisted of:

- » Internal Steering Committee: met monthly
- » Office of Community Health (Community Benefits) medical director, OCH grant writer
- » Program director
- » Hospital Information Services Department

During the needs assessment process, the hospital's Information Services provided summary reports of patients seen in the ED or admitted, stratified age, race/ethnicity, insurance and ZIP code. A system of generating daily re- ports of admissions and ED visits was developed. Patients are identified weekly and monthly according to asthma diagnostic codes and the ZIP code of their residence.

- » Primary care representative
- » Nursing: Asthma clinical nurse specialist and community asthma educator
- » Allergy and/or pulmonary subspecialist
- » Evaluator
- » Government Relations
- » A community-based organization already receiving community benefits funds to conduct limited asthma home visits

External partners consulted during planning:

- » New England Asthma Regional Council
- » Boston Public Health Commission Asthma Control program director
- » Boston Medical Center pediatrician/asthma researcher

Mission statement

To provide asthma education, case management, home visiting to those from low-income communities with poorly controlled asthma and systemic change to address asthma social determinants of health and support a sustainable model of care.

» Boston Public Schools Student Health Services

Ongoing community input and feedback

CAI has one Community-Family Advisory Board:

A. Community-Family Advisory Board (meets 2-4x/year)

Comprised of parents and guardians (86.7% Black and 20% Hispanic) who have been served by our program, as well as other community members, such as a school nurse, a clinic nurse and a youth swim program director. This group has been invaluable in providing a real-life perspective for the program. Active and committed parents can be great ambassadors for the program with other parents whose children have asthma, as well as the larger community and policymakers.

Parents and community members have provided important feedback about asthma education, concerns about pest management, expense of co-pays for asthma medication, and the desire to do more community education and asthma-specific activities.

Clinical Partners

CHPCC (Children's Hospital Primary Care Center), MEHC (Martha Eliot Health Center), CHCs (Community Health Centers)

Policy System Collaborators

- BAHVC (Boston Asthma Home Visit Collaborative
- MAAP (Massachusetts Asthma Action Partnership)
- BPHC (Boston Public Health Commission)
- DPH (Department of Public Health)

Asthma Coalition

Community Connections

Schools
 Parent Advisory Board

• Steering Committee

B. Ongoing Community Partnerships:

- » Boston Public Health Commission
- » Boston Asthma Home Visit Collaborative
- » Breathe Easy at Home (BEAH)-participants include City of Boston Inspectional Services Department, Boston Housing Authority)
- » New England Asthma Innovations Collaborative (NEAIC)/ Asthma Regional Council of New England
- » Neighborhood Health Centers
- » Boston Public Schools
- » Head Start

Roles/Job Descriptions/Staffing

The Community Asthma Initiative team is multidisciplinary and includes both funded and in-kind staff. We will describe the members of our team as a way to identify the various roles that may be important to your program's success and mission, while appreciating that funding, patient population, cultural and linguistic competency and other factors will determine your staffing configuration.

Our overall structure is a nurse-supervised (or other clinical role, such as respiratory therapist) Community Health Worker model. Our structure has evolved over the years.

Staff mix of clinical staff (may be MD, RNs, social workers, respiratory therapists, etc.) and CHWs; mix will depend on multiple factors, e.g., funding, language needs, etc. In our experience, it is best to have all staff under one roof for supervision and team work.

The CAI Program Director/Principal Investigator (PI) 0.4 FTE (0.2 Basic Program, 0.2 Grant Related), is a pediatrician with an MPH and experience directing community health programs for medically underserved youth, as well as expertise in Quality Improvement initiatives throughout the hospital. She oversees all aspects of the program including program development, implementation, grant-writing and reporting, budgetary management and contracts, dissemination of information and development of program products, and program evaluation.

The Clinical Director/ Nurse Case Manager 1.0 FTE, in our program is a nurse practitioner, but may also be a nurse, respiratory therapist or other clinician who has clinical asthma experience, experience with community or public health projects and the ability to supervise the clinical staff. She/he provides case management and asthma education for families and supervises the Community Health Workers. This person is the main point of contact for referrals, whether through the inpatient unit, ED or referrals from primary care or specialty providers and evaluates the patient for eligibility. In our program, this person also does the majority of intakes, both to become familiar with all the patients and families in the program, followed by a review of the patient's clinical and social history. This also is an opportunity to convey to the family that the nurse case manager is part of the team who will be coordinating their care. Then, the history can be summarized and provided to the CHWs, who will in most cases do the actual home visits. The nurse case manager works closely with the CHWs around any medical or social issues that come up during the visits, including continued poor asthma control and any barriers to improved control, including lack of understanding of or access to medications, home environmental triggers, other financial stressors, etc. The nurse and CHWs have weekly supervision meetings to discuss cases and share resources. The clinical director, along with other team members, also meets on a regular basis with the asthma team in the hospital's primary care clinic in order to review shared cases and discuss new referrals.

The Community Health Worker/Health Educator/Home Visitor, 2.0 FTEs, works closely with the clinical director and other team members to provide home-based services to pediatric asthma patients and their families through tailored asthma education on asthma anatomy and physiology, medications, home environmental triggers and other related topics. They will perform home environmental assessments and provide education on environmental remediation as needed. She/he will reinforce instruction provided by health care providers, including the primary care provider, specialists and the clinical director. They will assess client/family needs and will develop intervention plans in conjunction with the family and other involved persons. They will provide case management and serve as a liaison, case manager and advocate for clients in interactions with health, government, and social service agencies. They will contribute to future growth and development of the program and provide training around case management to other staff both internal to the organization and to CHWs at other agencies. She/he will serve as part of the health care team.

As part of providing asthma education, community health workers will explain medications prescribed by health care providers and will teach patients how to take them. The CHW will assess the patient's asthma control, using specific data collection tools that will both guide the visit and document the findings. Questions about whether or not they should be on a medication, or whether the dosage should be changed will be referred to the health care providers as well as the clinical supervisor.

The Program Coordinator provides support to the program, facilitates program communication, performs administrative duties and assists with the evaluation of the program. She/he will order supplies, track expenditures, arrange meetings and provide needed administrative support to the program, PI and staff. She/he coordinates the Community-Family Advisory Board (C-FAB) meetings including scheduling room, ordering food, contacting members, mailing flyers and preparing minutes. She/he assists in writing reports, disseminating information and producing products for the program. She/he works with the evaluator to set up data management systems, enter data and help track patients and products for the program.

The Evaluator 0.2 FTE (0.1 FTE in Basic Program, plus varying amounts for analysis and grant tasks) is an employee of the Office of Child Advocacy and evaluates all OCA's community programs. She/he assists with evaluation design, questionnaires and data management systems (see Evaluation).

Information Services Department: Close relationships are developed to produce regular reports of patients seen for care, and access to hospital databases.

Responsibilities of all Asthma Team members

- » Work with team to identify barriers to asthma management and to create solutions and prioritize needs.
- » Participate in weekly or biweekly team meetings to discuss feedback from C-FAB meetings, discuss funding strategies, opportunities for expansion and/or improvement, data collection, data management, evaluation and the status of structural change initiatives.
 - Weekly supervision meeting by clinical director and/or nurse case manager to review cases with CHWs.

Program Model

The Child and Family

The program identifies individual children through in-patient admission and emergency department (ED) visit records as well as by specialty and primary care provider referrals. Providers identify children at highest risk and in greatest need for asthma intervention services. In the case of CAI, a primary aim of the program was to improve the asthma control of children, the majority of whom are low-income black and/or Latino, who have been hospitalized, as well as children who have been seen in the ED for asthma. Families are offered the opportunity to participate in the program, and the provider explains the program's benefits to the family and develops a personalized asthma management plan.

Recruitment/enrollment

» Define enrollment criteria

- Identify your geographic area: we initially identified four ZIP code areas in a pilot, based on some of the zip codes with highest rates of asthma in the city, plus a zip code that included a satellite clinic of Boston Children's.
- Risk criteria (see referral form in appendix)

Recruitment approach may depend on your setting, as well as cultural norms for the groups you're working with.

- » Establish the relationship with the family
 - culturally and linguistically competent staff
 - non-judgmental approach

For some cultural groups, an introduction from a trusted health care provider or other community member, or a face-to-face meeting in the clinic or hospital may precede the acceptance of a home visit.

» Hospital-based or clinics affiliated with hospitals—work with information services to access real-time hospital census lists and ED logs, as well as retrospective lists of patients recently admitted/in the ED in the past week —we receive an updated list weekly. As a hospital-based program, we attempt to meet as many families as possible face-to-face during their stay, since face-to-face meetings, whether in the clinic, ED or inpatient unit, with parents provide for a more personal encounter and these families are more likely to accept a home visit after discharge. This also eliminates the need to wait for provider referrals, and –on the other hand, you do want to make both hospitalists and community primary care providers aware of your program, so they understand the collaborative nature and don't feel like you are taking over their patient's care. In addition, hospitalizations and ED visits provide "teachable moments," inwhich parents are often eager to participate in CAI in the hope of avoiding a future moderate to severe exacerbations. Parents also are open to receiving help around home environmental triggers, such as pests or mold, that have often been longstanding. CAI may assist in facilitating the follow-up visit with the child's medical home. We accept referrals from primary care providers and sub-specialists that match the general enrollment criteria of poor asthma control.

Other settings where an asthma home visiting program may be located are

- Community-based organizations, including public health departments
- Medical homes
- Asthma team with Community Health Worker (CHW)/Patient Navigator integrated into the clinic, supervised by nurse or other clinical provider
- Payment reform models, such as Accountable Care Organizations (ACO), global and bundled payments, may make this a more financially feasible and costeffective team approach for comprehensive asthma care through the medical home.
- » Insurers can identify patients with poorly controlled asthma that need additional services and contract with a home visiting organization

The Role of Community Health Workers

Employing community health workers (CHW) as members of the underserved racial and ethnic communities in which they work is one evidence-based strategy for providing culturally competent care. CHWs have been endorsed for their cultural and linguistic competence, their ability to form trusting relationships with clients and families and mediate between health care providers and their clients, acting as coaches for individuals and families.

Case management

Each child whose family agrees to participate in the program is assigned to a Community Health Worker. The CHW is matched to the family according to linguistic or cultural appropriateness whenever possible. The CHW coordinates services with the primary care provider and assesses what the child

and family need to successfully manage the child's asthma. Depending on the results of the assessment, children are either referred to or provided with the necessary services, including home visits tailored to meet their individual needs. Rather than a "one size fits all" approach, this method is tailored to the individuals, ensuring each family has an intervention that will work with their particular circumstances, culture, language and home environment. Services provided may include:

- » Facilitate appointments with primary care providers, urgent care, asthma specialists
- » Care coordination between providers and community resources
- » Reminders and referrals for influenza shots
- » An Asthma Action Plan to be shared with the family, school nurse and primary care provide

- » A home visit for individualized asthma education and environmental assessment to identify and reduce asthma triggers in the home
- » Advocacy assistance with landlords, housing authorities and others
- » Assistance with enrollment in health insurance or assistance around co-pays
- » Connection to resources for educational, support and physical activity programs in the family's neighborhood.

Also, patients and their families receive follow-up to review asthma management techniques and answer questions; assess adherence to the Asthma Action Plan; identify progress on overcoming barriers; assess new barriers; and receive referral to other services if needed.

It is important to note that while the individual child referred to the program is the target of the intervention, other family members benefit through increased knowledge about their own asthma management and environmental changes. Very often more than one family member, including parents and caregivers, has asthma and is in need of education, asthma supplies and referral for services. On average, two family members have asthma in this population. This increases the reach and the impact of the program on this population.

The Home Visit¹⁵

Asthma education in the home is an interactive process and tailored to the child's and family's needs.

Things to consider:

- » Parental low expectations of asthma control, e.g., parents may believe it is normal for a child with asthma not to be able play sports or to end up in the ED multiple times a year
- » Fears about inhaled steroids, due to myths and misconceptions, that lead to non-adherence

Assessment of control and risk:

Asthma Control Test (ACT) or other asthma control tool: This is a great way to introduce the concept of asthma control. This tool does need some explanation initially, in particular to correct the misconception that the child's asthma is under control if he needs frequent Albuterol use or if keeping the child quiet is necessary to keep him/her out of the ED. The ACT is an excellent teaching tool that allows patient/family, home visitor and provider to track control over time. The ACT asks about symptoms and asthma control over the previous four weeks. Documentation of daytime and nighttime symptoms is also becoming a common quality measure tracked by payers.

Other programs find it more useful to use a two-week recall, since people are more likely to accurately remember the previous two weeks, rather than four.

Other asthma control tools available online are:

- » The Asthma Therapy Assessment Questionnaire (ATAQ)
- » Test for Respiratory and Asthma Control in Kids (TRACK), which is an alternative for younger children, sinceit is designed for children under 5, whereas the ACT is only validated for children over 4.

In addition, we ask specifically about:

- » Missed school and workdays by patient or parent
- » Limitations in physical activity
- » Courses of oral steroids
- » Number of hospitalizations and ED visits

This is also an opportunity for the client and family to identify their own specific goals for asthma control, e.g., the child wants to participate in sports.

Assess family's knowledge of asthma basics, role of medications

- » Step 1: "Tell me what you know about what asthma is." Generally, this will lead to a basic explanation/review of asthma anatomy and physiology, using graphics and models. We use a graphic with a normal airway, one that is mildly inflamed and constricted and one with severe inflammation and bronchoconstriction (which, conveniently, aligns with the Green, Yellow and Red Zones of their AAP).
- » Step 2: Relate this back to the individual client's asthma control, e.g., if someone was recently hospitalized for an asthma exacerbation, you can identify what the airways looked like when they were in the ED in the red zone, where they are now and what the goal is in terms of control of inflammation, mucus and bronchoconstriction.
- » Step 3: Bring in the Asthma Action Plan and relate the different roles of controller and quick relief medications to the symptoms and graphics.
 - Review early signs of exacerbation, when to start yellow zone medications, when to call the clinic.
 - Importance of routine asthma follow-up at clinic based on severity and even when well-controlled to re-assess plan, anticipate seasonal changes, etc.
- » Step 4: Parents need to understand what it means to have wellcontrolled asthma.
 - While assessing the child's current asthma control, based on the Asthma Control Test or a similar instrument, the home visitor, the child and family members can discuss current thinking about asthma control. This includes the ability to exercise without limitation, few or no missed school days due to asthma, no more than 1 course of oral steroids/year, no or rare ED visits and no hospitalizations. We also use an easy to remember guide for the frequency of asthma symptoms or the use of Albuterol that should prompt a parent to call the clinic to re-assess a child's asthma control, called the "Rules of Two". Using this tool, parents learn to call their child's provider if the child requires:
 - Albuterol more than 2 times a week during the day,
 - wakes up with asthma symptoms more than 2 times a month at night,
 - or needs more than 2 refills of Albuterol in the course of a year

- We encourage feedback to providers if the child's asthma is not in good control before symptoms worsen. This also allows us to discuss the concept of parents being partners with the health care team in managing the child's asthma, as outlined in the NAEPP guidelines. By communicating with providers if the child's asthma symptoms increase or the prescribed medicines aren't controlling the child's asthma. This is particularly important, because some people stop controller medicine because it doesn't seem to be helping, rather than giving feedback to the provider, who could then adjust the Asthma Action Plan.
- Scheduling routine asthma visits every 3-6 months based on the child's asthma severity, seasonal triggers, etc. is another important measure in maintaining good asthma control.

Medication review and evaluation of adherence

We request a copy of the Asthma Action Plan or list of current medications as part of the referral process in order to compare this with the medications the family has on hand. We bring along a copy of the AAP in case the family can't find theirs. Also, it is helpful to assess literacy level of the parent/guardian before the visit.

Check what medications and devices are present, where they are stored, how long it takes to find them, understanding of how each medication works, routines for administration, how they are actually being given and by whom, as well as refill dates and counters.

Review device technique with repeat demonstration at each visit. Bring additional spacers in case the child's has been misplaced.

Sometimes this involves going through bags of old and expired medications, and with the families' permission, discarding multiple empty or expired medications, or those no longer being used, to reduce confusion. We also provide a shoebox-size plastic box to use as med box where only current meds and devices are stored (Sterilite 6-quart storage box, model #: 16428012) as well as a daily medication container with labeled days of the week if the medications are in pill form.

Assess adherence with open-ended questions and acknowledge that it is often difficult to remember to take a medication every day or twice a day.

Assess barriers to adherence (fears about medicine, complicated family schedule, e.g., parent works nights and child goes to different family member's house after school, can't afford medicine, no insurance/Medicaid, inactive due to not responding to request from Medicaid for updated information, has insurance but can't afford co-pay, competing demands, unrealistic expectations of child being in charge of medication administration, didn't understand or believe in importance of continuing controller.

- » Where are medications stored?
- » Who is administering the medications

- If a child, is the parent reminding the child? Observing the administration? (Reality check if refill date or counter doesn't reflect consistent use).
- Assessing parents' beliefs about when a child is ready to take on this responsibility
- Normalize need to continue to be involved with medication administration with most children to some extent through adolescence.

Adolescents

- » Empirically, one recommendation that's been successful is to put meds in a med box that is kept in the kitchen rather than the youth's bedroom.
- » Engaging adolescent in plan, exploring their feelings about controller meds (do they believe they help? Which ones do they "like" or not like and why-taste, delivery method, doesn't fit in with routine? Would once a day regimen help?)
- » Transition to control of administration by adolescent gradually with goal of independence by late teens
 - Identifying goals for asthma control, relationship to adherence
 - Tools, e.g., setting phone alarm, text messaging

Known or suspected triggers

After reviewing what parents/child perceive as triggers, we review potential or known triggers that they may not be aware of, using low-literacy materials with pictures.

Has child been allergy tested?

While allergy testing is not always necessary, the NAEPP guidelines recommend assessing all patients with persistent asthma for allergies by history and, as indicated, allergy testing. In particular, indoor allergies to pests, pets, house dust and dust mites and molds are difficult to diagnose without testing. Allergy testing can steer clinicians to more aggressive management of allergies in their overall medical management of a child's asthma.

We have found that allergy test results, when available, have been very helpful to our work, as well, in targeting the most important triggers for parents to focus on. Families, in general, are eager to learn more about their children's allergies and are often surprised by the results and feel empowered to take measures to control triggers, once they have this new information. A con-firmed allergy to the family pet is often necessary before a family considers giving the pet away.

Some payers also require evidence of allergies to dust mites or other indoor allergens in order to justify provision of bedding encasements or HEPA vacuums. In addition, documented allergies to mold, mice or cockroaches can be a powerful argument to convince a landlord to provide more effective pest management or repairs, or if the problem cannot be easily solved, for a housing authority to approve a transfer to a better apartment as a reasonable accommodation

Home environmental assessment

We generally conduct the initial home environmental assessment towards the end of the first visit after the education, since at that point we have, hopefully, established the foundation of a trusting relationship.

We assess for common triggers-mold, pests, clutter/dust, smoking, harsh cleaning products and air fresheners and pets

Clutter and dust

We explain that we are not there to judge someone's housekeeping, but to help identify together some possible triggers and ways to create a more "asthma-friendly" environment, e.g., we talk a lot about reducing dust collectors, whether clutter, curtains, uncovered toy boxes, as general ways to create an asthma-friendly home. We place particular emphasis on the child's bedroom.

Likewise, when realistic, we attempt to normalize conditions, e.g., a lot of people have clutter because they don't have enough storage space, and offering simple, inexpensive solutions (we provide plastic storage bins to help with clutter).

Environmental Tobacco Smoke

Children come into contact with secondhand smoke in many settings, including their own homes, apartment buildings, extended family and friends' homes, parks and neighborhoods. Within our population 18.3% of our patients lives with a family member that smokes cigarettes. We also specifically ask if there is other smoke exposure, such as neighbors in their buildings or other places where they spend a lot of time.

Home visitors assess for smoking at every visit and may employ a brief intervention, such as the 5 A's (listed below), to identify all patients/parents for smoking status and their readiness to quit.

Beyond this, we use a non-judgmental "motivational interviewing" (MI) approach in talking about smoking cessation and other behavioral change with parents/clients, promoting self-efficacy and building on the person's own motivations to change over time. Through this process many parents accept a referral to the state Quitline. Seattle-King County Health Department and the Massachusetts Department of Public Health have both incorporated MI modules into their Community Health Worker trainings.

In addition, parents or other family or household members who are not ready to quit are advised to institute a smoke-free home and car policy. Begin by assessing current smoking practices in the home. Many people believe that by smoking only in their bedroom, hallways/stairwells, or only when the child with asthma is not at home, they are employing safe practices.

- » Tobacco smoking in household or extended family
- » Assess all families-use 5A's
 - Ask–systematically identify all tobacco users at every visit

IPM Supplies

We provide every family with the following supplies, unless they already have them:

- » HEPA vacuum cleaner
- » Dustmite-proof bedding encasements that are cloth and washable: we provide one mattress encasement, two pillows and, optionally, one box spring encasing (vinyl)
- » Plastic storage bins (for clutter and to reduce harborage for pests)

IPM supplies offered to families

- » Covered kitchen trash can (Sterilite, Hefty, or Rubbermaid 52-quart spring top trash container)
- » Copper Gauze to fill in holes mice can squeeze through, e.g., around pipes coming through walls or floors (other related supplies are expanding foam and caulk, though we don't currently provide these, since these are easier to find in hardware stores)
- » Sticky traps for rodents and insects
- » Some programs provide cleaning supplies, such as mops and sponges or green cleaning materials, such as baking soda and white vinegar; we provide an empty spray bottle as a "starter kit" to try some of the green cleaning mixtures.

Three-visit schedule for home- visit protocol:

- » Initial visit: As soon as possible after triggering event or referral
- » Second visit: No more than four weeks after the initial visit
- » Third visit: no less than six weeks after baseline and up to 12 weeks from baseline
- » Follow-up phone call: Twelve months

- Advise-strongly urge all tobacco users to quit
- Assess-determine willingness to make a quit attempt
- Assist—aid the patient in quitting
- Arrange—schedule a follow-up contact

We discuss the Smoke-free Home Pledge with all families and utilize tools through the Boston Public Health Commission listed at

https://www.bphc.org/whatwedo/tobacco-free-living/smoke-free-homes/Pages/Boston-Smoke-Free-Homes.aspx

- » Motivational Interviewing, Third Edition: Helping People Change (Applications of Motivational Interviewing) [Hardcover] William R. Miller Phd (Author), Stephen Rollnick PhD (Author)
- » Refer to state or federal Quitline

Integrated Pest Management (IPM)-

"Integrated Pest Management (IPM) is a multidisciplinary approach to pest management that uses a range of pest control methods, including pest exclusion, sanitary practices, and minor structural alterations rather than relying on just one approach, such as pesticide application. Targeting pests in a variety of ways greatly reduces the dependency on the use of chemicals. There are four fundamental IPM principles:

1) Monitoring pest populations with sticky traps to find out where pests are living and hiding.

- 2) Blocking pest access and entryways.
- 3) Eliminating food and water.
- 4) Selectively applying low-toxicity pesticides to address problems."
 - » Ref: https://asthmaregionalcouncil.org/tools-and-resources/topics/healthy-homes/

IPM educational materials

There are excellent English/Spanish information sheets on IPM that we provide residents, as well as information for landlords/property managers at the following Web sites:

- https://cityofboston.gov/isd/housing/bmc/default.asp
- https://asthmaregionalcouncil.org/tools-and-resources/topics/healthyhomes/integrated-pest-management

(See Appendices-data collection forms used in home visits)

Mold and Moisture

We often encounter problems with mold, which can range from a little mold on the caulking around the tub, to major leaks from outside or inside the building, leading to very extensive, rapidly developing mold.

For smaller mold issues we review simple preventive measures, such as:

» Drying off damp walls after showering

- » Venting bathrooms, dryers, and other moisture-generating sources to the outside
- » Checking the exhaust fan (if there is one) in the bathroom to make sure it's drawing air (a simple trick is holding up a piece of tissue to the fan to see if it holds it up), and running the fan for 15-30 minutes after a shower to remove the humidity. If there is no fan or vent, a window should be opened for a similar amount of time.
- » Fixing (or reporting) leaks as soon as possible, so that mold doesn't have time to grow
- » Avoiding laying carpet directly on cement floors
- » Maintaining indoor humidity at 30-60%;
- » Using air conditioners and de-humidifiers;
- » Using exhaust fans whenever cooking, dishwashing, and cleaning

For living areas prone to mold and moisture, like basements (we encourage people to avoid basement apartments, if at all possible!), we do provide a humidity gauge (also called hygrometer), which is an inexpensive item that they can use to track the humidity and report excesses to the landlord. In Massachusetts, the state sanitary code specifies the acceptable range of humidity. This may vary from state to state.

For mold clean-up in small areas, we recommend using non-chlorine bleach (e.g. 1 cup non-chlorine bleach in 1 gallon of water). Clean-up of large areas generally involves a contractor to first remove the walls, carpeting or flooring affected by mold, then making repairs, so that the leak or other source of water is eliminated and having someone experienced in mold clean-up, wearing the appropriate protective gear, do the clean-up in a way that seals the affected area off, as much as possible, from the rest of the house and protects all household members.

An excellent source of information about mold is the EPA (https://www.epa.gov/).

Number and timing of visits

Our program is designed to follow a child over a 12-month period. We strive for 3 home visits, which may be 4-8 weeks apart, depending on the findings at the first home visit Since the program is tailored to the family's needs, we have maintained a degree of flexibility in terms of the number of visits families receive, with some families receiving fewer than three visits and some more. By increasing focus on the third visit and providing a \$20 gift card for completion of three visits, the average number of visits increased to 2.4. We also provide a significant amount of case management and care coordination over the phone, so contact with families often goes far beyond the number of home visits. Additionally, we do 6- and 12-month follow-up phone calls which we use to track the program outcomes.

Visit content

We (and the home visiting collaborative) have taken the approach of having a long first visit tailored to the individual, which covers asthma basics,

medication and environmental assessment and education. We have chosen this approach, since most families have significant issues in all areas, i.e., under- standing of what asthma is, how the medications work, adherence and environmental triggers. This makes for a long first visit of approximately one and a half hours.

The timing and content of subsequent visits is largely determined by the issues identified during the first visit, e.g., issues with adherence may call for a shorter follow-up interval, such as two weeks, to assess presence of meds, number of doses administered based on the counter.

We currently use a loose-leaf binder that has educational materials in plastic sleeves in the order that we, generally, walk through during the initial visit, as described in this manual. This notebook was developed as part of the Boston Asthma Home Visit Collaborative so that we all would use the same materials. It is a combination of educational materials and resources and contains:

- » Asthma Control Test (Also available in Spanish)
- » Asthma Control Goals
- » Graphic of airways (Krames Patient Education) Also available in Spanish.
- » Controller vs. quick relief medication comparison
- » Rules of Two
- » Blank Asthma Action Plan

» Boston Children's has available a collection of education materials and videos that can be accessed at: <u>bostonchildrens.org/asthmavideos</u>.

- » Triggers-general education sheet with all kinds of triggers: allergic, irritant, weather, illness
- » Safe cleaning handout (Also available in Spanish)
 - Ref: Handout re: other products with Volatile Organic Compounds (VOCs) and alternatives
- » Smoke-free housing pledges and other materials
- » Smoking cessation literature
- » Referral forms to smoking quit line
- » Integrated Pest Management materials (Also available in Spanish)

We minimize handouts and provide them selectively, as relevant. In general, all families receive a handout regarding safe cleaning methods, and then others at the discretion of the home visitor.

Educational materials

There are several good, published asthma materials, some of which are in multiple languages.

» Children's Health Fund Family Asthma Guide (free download in English and Spanish)--this is long, but you are able to pick and choose which pages you want to reproduce https://childrenshealthfund.org/publications/health-education-

groups/family-asthma-guide

- » The Environmental Protection Agency also has free literature on many asthma topics
- » Provide feedback in written reports to primary care providers and specialists regarding findings from home visits and other patient contact. This will include observations related to patient/family's understanding of asthma and medications, as well as adherence, home environmental triggers and other social needs.

Virtual Home Visits

In response to the COVID-19 pandemic, a virtual home visiting model was developed. Virtual home visits are divided into threepart visits, including: 1) initial intake and teaching, often conducted previously in-person, now conducted via telephone, 2) video visits, conducted by the CHW via Zoom, including as many asthma education elements of an in-person visit as possible; and 3) materials drop-off (e.g. vacuum, bedding encasings, storage containers, integrated pest management materials, etc.) to parents outside their homes, with masks and physical distancing measures.

Physical activity

For children living in urban centers, physical activity is problematic; a recent increase in community violence has left many parents concerned that allowing their children to play outside is unsafe, and indoor, organized recreational activities may be cost-prohibitive. Rates of childhood obesity and elevated body mass index, with their concurrent health problems, are on the increase. Not all recreational programs have staff that are aware of and educated about asthma. Providing additional asthma education to recreational programs may help increase access to exercise opportunities for children with asthma in the target neighborhoods.

» Asthma Swim at YMCA, Boys & Girls Club, Boston recreational facilities City of Boston

Training

There are many resources available for staff to gain both the asthma and healthy homes knowledge they need for a successful program.

The National Heart Lung Blood Institute's National Asthma Education and Prevention Program guidelines- Expert Panel Report 3 is by far the best resource available for clinicians, nurses and asthma educators.

Other training resources we are aware of include:

The Partners Asthma Educators Institute offers Becoming an Asthma Educator course online as a series of 10 video modules with related, exam-type questions and answers at https://asthmalearning.org.

For those who are interested in pursuing certification as an asthma educator, the National Asthma Educator Certification Board has developed a certification exam. To learn more about this process, go to https://naecb.com/index.php. This certification is designed for licensed or credentialed health care professionals, such as nurses, respiratory therapists and pharmacists, but non-licensed providers, such as health educators and community health workers are also eligible to take the exam by providing direct patient asthma education, counseling or coordination services with a minimum of 1,000 hours experience in these activities. This is verified through a letter from a supervisor.

There are review courses available throughout the country, including one that is sponsored by the American Lung Association: <u>https://www.nhlbi.nih.gov/sites/default/files/media/docs/EPR-</u> <u>3 Asthma Full Report 2007.pdf</u> (Original report); <u>https://www.nhlbi.nih.gov/health-topics/all-publications-and-resources/2020-</u> <u>focused-updates-asthma-management-guidelines</u>

There is also an online **Basic Skills for Working with Smokers** course through the University of Massachusetts Medical School.

The National Center for Healthy Housing holds trainings at locations throughout the country and, in addition, has an online **Integrated Pest Management course**.

You may also want to contact your regional Environmental Protection Agency office for other training opportunities in your area.

All regions also have Area Health Education Centers (AHEC) that provide courses and networking opportunities for community health workers.

Systemic change

Working in coalitions

- » We recommend that asthma programs work with existing asthma coalitions, as we did in Boston, or if one does not exist, begin to reach out to others working in the field to create a local or state coalition.
- » Identify champions in:
 - Health care institutions
 - Public health agencies
 - Housing agencies—e.g., community development corporations, tenant groups, local and state public health departments, public housing authorities (both leadership and at the property manager level), inspectional services, IPM contractors (identify those who practice a comprehensive IPM approach)
 - Legal services agencies that are working with low-income clients around housing, income support, etc.
 - Community health centers
- » Identify policy issues for the coalition, employing focus groups and needs assessments of the populations most impacted by asthma health disparities. Some of the issues that coalitions have addressed include:
 - Smoke-free housing
 - Asthma friendly new construction
- » Effective, safe pest management. This will include policies around the use of Integrated Pest Management in public and subsidized housing.
- » Strengthening the state sanitary code to support healthy housing efforts
- » Sustainable funding for asthma home visiting through reimbursement directly by payers or integration into the medical home and health care payment reform efforts.
- » Support for certification and recognition of community health workers as critical members of the health care workforce in order to provide culturally and linguistically competent care.

Boston Asthma Home Visit Collaborative

In Boston, we have a unique situation with multiple agencies conducting asthma home visits. This led to a collaborative, facilitated by the Boston Public Health Commission and funded by the Environmental Protection Agency to create a more coordinated approach.

The mission of this collaborative is to provide a coordinated CHW asthma home visiting program with potential outcomes that include:

- » Standardization of home visiting protocols
- » Centralized referral system
- » Coordination of training, purchasing, referrals
- » Data sharing and evaluation
- » Coordinated negotiations with payers
- » Culturally and linguistically competent workforce
- » Access regardless of health insurance or health care provider

Progress thus far has included:

- » Development of a standard home visiting protocol, which required everyone to make some changes in what they were doing
- » Standard educational materials
- » Electronic data collection and de-identified data-sharing; the forms were initially created as an Access database on Netbooks. Boston Children's is currently moving to a Web-based data collection system (REDCap).
- » Development of an evaluation plan

Role of Government Relations

Engaging your Government Relations department at the beginning of your programmatic efforts will allow them to be informed and ready to move on any policy or legislative action that can support your work.

Funding and sustainability of the program

There is no one formula for funding community programs, such as CAI on an ongoing basis. Our program has been funded by a combination of grants, philanthropy and, in large part, hospital community benefits funds since its inception in 2005. As a pediatric hospital, Children's recognized that asthma is the most common chronic disease of children and costs the health care system billions of dollars in largely preventable hospitalizations and Emergency Department visits, In addition, the pressing need to address asthma health disparities between Black and Latinx children and their white counterparts is an ongoing priority of the hospital's community mission.

The initiation of CAI also coincided with the passage of the original Massachusetts health care reform bill of 2006. The discussions in Massachusetts shifted to payment reform. Advocates in the state, including Children's, were engaged in discussions with policymakers about how to support preventative programs, such as asthma home visiting. Boston Children's was able to pilot a MassHealth Accountable Care Organization (ACO) in 2017 and establish a pediatric ACO in 2018. Thus far, the ACO has been able to provide funding for CAI relative to the percentage of Boston Children's ACO primary care patients followed by CAI through Delivery System Reform Incentive Payment (DSRIP) funds, which are additional funds to help with the transition to the new model of care. We anticipate continued support from the ACO, though the level of support may change when the DSRIP funds are no longer available.

As was the case at Boston Children's, programs that exist within non-profit hospitals should work with the community benefits department, as well as the fundraising arm of their institutions to help support your program. Additional funds may be identified from private foundations that do not represent a conflict of interest, to donate supplies, such as vacuums, or expand case management and home visiting services.

In general, in order to ensure sustainability of the community health initiatives, programs should: 1) ensure that programs are of high quality and demonstrate meaningful results; 2) attract mission-designated funds, which can be allocated where they are needed; 3) find creative ways to fund programs through third-party billing, whenever possible; and 4) try to build a philanthropic base or an endowment to provide ongoing programmatic support. The health outcomes and cost analysis results from the program will help to expand funding sources.

- » New programs should develop an approach to identifying potential funding sources, such as:
- » Collecting appropriate data to demonstrate the level of savings generated by the program in order to appeal to hospital administrators, insurers and policymakers.

- Develop a convincing business case that you can make about the cost-effective nature of the services provided.
- Work with insurers to develop innovative payment systems.
- Educate legislators about health disparities, disease specific issues and need for health care funding.
- » Build capacity and skills of staff at community-based organizations to provide asthma education services and guidance to children with asthma and their families.
 - Many primary care sites may integrate care coordinators and home visitors as part of primary care redesign.
- » Attract media attention to educate insurer, legislators and the public about the extent of health disparities related to asthma in your region and success of your program in addressing them. This will in turn call attention to the need for innovative payment systems to support your program and similar programs that provide services that are not traditionally reimbursable in a fee-for-service system.
 - Disseminate information about the program model in peerreviewed publications.
 - Speak regionally and nationally about the program.
 - Work with local and regional partners on system changes concerning the disease process.
 - Use social marketing approaches to change attitudes and norms about the disease process.
- » Private foundations and corporate foundations frequently provide funds for community programs.
 - Programs will need to work with institutional fundraisers to identify foundations and corporate foundations that may be interested in your program.
- » Develop subcontracts with collaborators:
- » Try to build a donation fund or endowment fund to provide for ongoing programmatic support.
 - Ongoing support is critical to complement specific funding sources, complement the federal and other time-limited funding, and tide over funding between grant efforts.

Community Asthma Initiative Program Logic Model

Context	Activities	Outputs	Ot Short Term Me (2007-2009) (2	utcomes edium Term 2009-2011)	Long Term (2011-2012)
Stage: High prevalence (12-16%) of Asthma, and the leading cause of hospitalization at Children's Hospital Boston. Inputs: Social and cultural determinants of health	Establish the CM position: CM will conduct outreach and recruit patients into CAI program from ED or Hospital Admissions. Education on medication and consent for services. Follow up to ensure patients are connected to a PCP. Establish connections with ED, Primary care and providers Collaborate with schools and head starts programs for asthma management.	Case Management (CM) Each year 100 children diagnosed with asthma are recruited for individualized CM services. Connect the children to their PCPs within 2 weeks into the program. Social determinants: Collaboration established with BAI (ESAC). Their outreach worker and the nurse CM makes home visits to at least 50 families per year.	- # daysto connect to PCP - # children with updated - AAP - Reduced ED visits and admi- assions at 6 mo. F/U	20% Reduced chool days t 12 mo. //U 50% Reduced ED risits and udmissions tt 12 mo. //U	50% Reduce ED visits and admissions at 24 mo. F/U
Socio- ecological model Empowerm ent theory Community- based participatory approach Resources: Community Asthma Initiative (CAI) program	Address social and cultural determinants of health by: Collaborate with BAI and work closely with their outreach coordinator, to inspect home environment to lessen asthma triggers. Outreach Coordinator and Nurse educators attend community events for training and distribution of culturally appropriate materials around asthma and asthma triggers.	Strengthen the Community Action Plan and provide culturally appropriate Community Education. Provide 14-15 educational workshops and trainings each year for providers, school nurses, family, and community members. Outreach to about 2500 members of the community every year.	Increased In knowledge k and a understand- uing about in asthma a	ncreased nowledge ind inderstand- ng about isthma	Increased asthma knowledge and awareness at multiple levels of the socio- ecological model
Boston (CHB) staff Boston Asthma Initiative (BAI) staff Culturally competent staff Community collaborations and CAP	Asthma Regional Council (ARC), Boston Urban Asthma Coalition, CHCs, families, schools, city, state etc. to develop shared policy goals and advocacy strategies. Advocate for legislation, An Act to Improve Asthma Management Increase policymaker awareness of asthma and propose solution. Evaluation: Maintain a data tracking System for evaluation and reporting.	Public Policy Advocacy Strengthen the coalition and involve more community organizations. Improve ability CHB and partner organizations to advocate for policy change. Increase in policymaker support for Legislation.	Strengthen CAP collaborat- ions	Support CAP decision making	 Improve multi-levels of socioecolo- gical model (SEM) Improved Insurance coverage and policies

Impact/final

Improve the control of asthma symptoms and severity among children in Roxbury and Jamaica Plain.

Program Monitoring and Evaluation

Logic Model

A logic model (also known as a logical framework) is a tool used commonly by managers and evaluators of programs to evaluate the effectiveness of a program. Logic models are usually a graphical depiction of the logical relationships between the resources, activities, outputs and outcomes of a program. While there are many ways in which logic models can be presented, the underlying purpose of constructing a logic model is to assess the "if-then" (causal) relationships between the elements of the program. For example, if the resources are available for a program, then the activities can be implemented, if the activities are implemented successfully, then certain outputs and outcomes can be expected. Logic models are most often used in the evaluation stage of a program; they can, however, be used during planning and implementation.

A logic model is an integral part of program planning and evaluation. It serves as a helpful visual representation of a program, and aids the development of a program's evaluation plans. Developing a logic model in the early stages of a program helps ensure that goals, objectives and data indicators are recognized from the beginning. The logic model represents a flow chart of what resources are available for the program, what the program plans to do and what it expects to achieve. The major components of a logic model are:

- » Inputs-what resources go into a program
- » Activities-what activities the program hopes to undertake
- » Outputs-what is produced through those activities
- » Outcomes/impact-the changes or benefits that result from the program

A logic model is developed in response to conversations and feedback with various stakeholders that include local partnering agencies and organizations, as well as information provided from the organization itself. Arrows represent the associations between program activities, outputs, short-term outcomes, intermediate outcomes, long-term outcomes and the final impact goals.

Logic models can be developed for specific aspects of the program. See the logic model for the Community Action plan for CAI.

Process indicators are monitored on a monthly basis and outcome indicators every six months. The following are core health indicators to be measured:

Monitor Monthly

- » Number of patient face-to-face meetings
- » Number of patients receiving case management
- » Number of home visits
- » Number of days to follow-up with primary care
- » Number of community programs and meetings
- » Number of training sessions
- » Number of patients who have Asthma Action Plans

Monitor every 6 or 12 months

- » Number of emergency department visits of patients managed (6 months or 1 year) and visits before the program (6 months or 1 year)
- » Number of hospitalizations (6 months or 1 year) and hospitalizations before program (6 months or 1 year)
- » Number of missed school days (last 6 months or 1 year) and missed school days before the program (6 months or

Tip: sections that follow are most useful for Evaluators and Program Directors.

Use and Share

Lessons

Learned

Evaluation Plan

Evaluation is based on the CDC's framework for program planning and evaluation.

It is based on the basic evaluation framework:

Engage Stakeholders

» Formative evaluation: identifying need, target population, ZIP
 codes for intervention, areas needing improvement

» Process evaluation: number served, reached, referrals made, triggers identified

» Outcome evaluation: environmental and health results.

An evaluation plan should be built into the asthma program during program formation. The program goals need to be clearly defined and have agreement from all the required stakeholders. The objectives should

Planning and Developing Program

an the required stateholders. The objectives should next be created and they should be SMART
 objectives, i.e., they should be specific, measurable, attainable, relevant and timely. The objectives will help frame the process and outcome measures as listed below.

The evaluation will be guided by a series of questions:

Process Questions

Evaluation The process evaluation will answer two basic questions, what was done? and how was it done?

How many clients are served by the initiative (i.e. case management, community education) and what are their characteristics?

To what extent are the program and its components implemented as planned? How, if at all, does the program deviate from the plan and why?

To what extent are the participants or the families satisfied with the program?

Are the participants satisfied with the education workshops?

How the program is staffed, and is the staffing adequate, in terms of training, expertise, language and FTE?

What are the highlights of the project?

What are the challenges and facilitating factors implementing this project?

Analysis and

Results



Outcome Questions

The outcome evaluation will answer the primary question what measurable change is detected as a result of this program?

To what extent does the asthma ED visits and hospitalizations and the missed school days change between before and after intervention?

To what extent does case management increase client connection with the required services?

To what extent does participating in the community education events increase knowledge of health risks, enhance advocacy techniques and increase awareness of available resources? How do we measure this?

To see the extent of disparity in asthma as related to being Black, White, Latino, Asians and Others over the three-year period? What are the next steps?

How many clients are there at the end of 1 year after recruitment into the Case Management services? (not lost to care or follow-up)

For the CAI program, data collection utilizes parent report at baseline, 6 months and 12 months, as well as hospital billing and administrative data for emergency department visits and hospitalizations before and after program intervention. Questionnaires should be designed to provide clinical and case management information to program staff and to assess asthma control through the number of hospitalizations or emergency department visits, day or nighttime symptoms, limitations in physical activity, missed school and parental work days, medication costs, adherence, and triggers. The program also uses pre- and post- evaluations at workshops and training sessions.

Data will be collected on an ongoing basis. Results of the project will be shared with the staff on a quarterly basis. Halfway through and at the end of the first project year the Advisory Board will review all results of the project and make recommendations.

The goal of evaluation of the program will be:

- » To determine the effectiveness of the program
- » To assess the achievement and progress toward reaching program objectives
- » To investigate components of the program that are performing optimally so they can be expanded, and also to share what works and does not work with others
- » To determine whether the funding is adequate and ensures sustainability
- » To ensure accountability
- » To build community capacity by including the voice of the community
- » To involve all partners and stakeholders from the beginning and onward
- » To allocate resources appropriately (cost/benefit)

Please refer to the papers published in *Pediatrics* and *MMWR* for our outcome results.

Woods ER, Bhaumik U, Sommer SJ, Ziniel SI, Kessler AJ, Chan E, Wilkinson RB, Sesma M, Burack AB, Klements EM, Queenin LM, Dickerson DU, Nethersole S. Community Asthma Initiative: Evaluation of a Quality Improvement Program for Comprehensive Asthma Care. Pediatrics. 2012;129(3):465-472.

Woods ER, Bhaumik U, Sommer SJ, Chan E, Tsopelas L, Fleegler EW, Lorenzi M, Klements EM, Dickerson DU, Nethersole S, Dulin R. Community asthma initiative to improve health outcomes and reduce disparities among children with asthma. In: Strategies to reduce health disparities: selected CDC-sponsored interventions–United States, 2016. MMWR Suppl. 2016;65(No. Suppl 1). Publication date 2/12/16. <u>http://www.cdc.gov/mmwr/ind2016_su.html</u>.

IRB Involvement

Boston Children's Internal Review Board waived the need for consent for the enhanced clinical care program, and approved access to case management data and hospital administrative databases for intervention and comparison groups with waiver of informed consent for the evaluation.

HIPAA compliant clinical releases were obtained to share information with providers and school nurses as needed.

Health Outcomes

The effectiveness of the intervention is assessed using the change in the number of ED visits and hospitalizations per patient between one year before and one and two years after the intervention.

For the comparison group, changes in the number of ED visits and hospitalizations per patient are similarly determined between the year prior and one year and two years after an index date. Since there is no intervention in the comparison group, an index date is chosen as the first date a child either visited the ED or is admitted to Boston Children's during the study period.

Since QOL data is only available for the intervention group this analysis is confined to CAI patients. For QOL measure, two parameters, the number of missed school days for children and the number of missed workdays for parents/caregivers, are used.

Cost Analyses

In determining efficiency, a number of studies use a conventional cost-benefit analysis based on return on investment (ROI).

In this case, the cost is to the hospital and funders, and savings are to insurers and society. However, the calculation of ROI does not adequately capture QOL improvements for individuals or for members of society. CAI calculates ROI and Social Return on Investment (SROI). Social Return on Investment (SROI) is an analytic tool that not only aids in measuring and accounting for a much broader concept of value, but also takes into account all benefits accrued to all members of society from an investment. Thus, SROI provides a more relevant analysis of any health and social sector investment, as it examines the overall impact the program has at different tiers; for individuals, families, payers, hospitals, or the overall community.

The cost savings from the intervention are computed using the difference in costs for ED visits and hospitalizations comparing one year before with one

year and two years after intervention. Similar cost changes for ED visits and hospitalizations between the year prior to the index date and one and two years after the index date are computed for the comparison group. Since both intervention and comparison groups are studied over the same time period, we do not adjust for inflation. The QOL improvement is measured by the reduction in the number of missed school days for children and the number of missed workdays for parents/caregivers. The cost of missing school days is calculated using the daily instructional cost incurred by the school district per student each day.

The imputed value of savings resulting from missed workdays is computed as a reduction in loss of earnings for patients/caregivers. Two efficiency parameters, Net Present Value (NPV) and SROI, are used to quantify the economic benefits resulting from the CAI intervention. For the computation of these parameters, all costs and benefits are converted into present value at the beginning of the year, on January 1, using an annual discount rate of 10% due to the high inflation rate for health care. The present value of both costs and benefits are computed over a two year period. The present value results are then used to determine both the SROI and the NPV, using the formula in the *Journal of Asthma* papers listed below.

Bhaumik U, Norris K, Charron G, Walker SP, Sommer SJ, Chan E, Dickerson DU, Nethersole S, Woods ER. A Cost Analysis for a Community-Based Case Management Intervention Program for Pediatric Asthma. *J Asthma*. 2013;50(3):310-317.

Bhaumik U, Sommer SJ, Giller-Leinwohl J, Norris K, Tsopelas L, Nethersole S, Woods ER. Boston Children's Hospital Community Asthma Initiative: Five Year Cost Analyses of a Home Visiting Program. *J Asthma*. 2017;54(2):134-142. http://dx.doi.org/10.1080/02770903.2016.1201837.

Benefits of using claims data

Analysis of benefits from interventions like CAI is based on the health care cost savings among patients from such interventions. However, most studies usually use cost reduction data from hospital databases that mainly include costs incurred in that facility, such as ED and hospitalization costs, and do not include other costs such as costs of primary care, outpatient services, specialist care, laboratory tests, and pharmacy costs. It also misses any cost incurred by patients in other health care facilities. Use of claims data from insurers includes all costs incurred for patients in any health care facility and helps determine a complete reduction of costs from the intervention studied. Moreover, these studies are used to make a business case to insurers for the provision of interventions like CAI and inclusion of all costs incurred by insurers will help to better demonstrate the benefits to insurers.

Bhaumik U, Sommer SJ, Lockridge R, Penzias R, Nethersole S, Woods ER. Community Asthma Initiative: Cost Analyses Using Claims Data from a Managed Care Organization. *J Asthma*. 2020;57(3):286-294.https://doi.org/10.1080/02770903.2019.1565825

Statistical Analyses



Cost Analysis: Total Cost Per Patient (2006 Data, N=102), Yields Return on Investment (ROI)=1.43 for ED Visits and Admissions (*Pediatrics*)



Woods ER, Bhaumik U, Sommer SJ, Ziniel SI, Kessler AJ, Chan E, Wilkinson RB, Sesma M, Burack AB, Klements EM, Queenin LM, Dickerson DU, Nethersole S. Community Asthma Initiative: Evaluation of a Quality Improvement Program for Comprehensive Asthma Care. Pediatrics Feb. 2012;129:465-472.

Sustainability

CAI provides an effective enhanced care model that could be included in a bundled or global payment system to reduce the cost of asthma care to society and improve the health and quality of the lives of children living with asthma. The CAI model can be used to respond to the health care reform call for "accountable care organizations" (ACOs) and expansion of care under the medical homes for patients with chronic illnesses. ACOs are responsible for the quality of care, as measured by standard outcome metrics, and would receive bundled or global payments for care with potential shared savings for providers and payers. CAI worked with Medicaid and other stakeholders to develop and implement a bundled payment pilot. However, this was not funded due to a shift towards developing Medicaid ACOs. More recently, for patients seen for primary care at Boston Children's some funding has been provided under DSRIP (Delivery System Reform and Incentive Payment) funding, but will reduce with regular ACO funding. The Office of Community Health, which has community benefits funding, has supported the remainder of the program that was not funded by ACO, grants and philanthropic funds.

Community Asthma Initiative Referral Form

Family Agrees to refe	rral: Yes	No	_ (if no, do not continue)
Lives in Boston: Yes_	No	_ (if no, prob	ably not, but we can talk)
Date of referral:			-
Referrer:		Referm	er phone #:

Patient Demographic Infor	<u>mation</u>	
Child's name		
2-? yo: Yes No		
Parent/caregiver name:		Language:
Address:		0 0
Home Telephone:	Cell:	
Insurance:		

Criteria for Referral (check all that apply)

Poorly-controlled persistent asthma as demonstrated by (one of these *must* be checked):

- ____Hospital admission for asthma exacerbation in last 12 months
- ____ER visit for asthma exacerbation in last 12 months
- ____Prescription for oral steroids in last 12 months

In addition please indicate if:

- ___Overuse of rescue medications
- ____Concerns about medication adherence
- ____Frequent Urgent Care visits
- ____Needs help with medication administration technique
- ____ Concerns about home environmental triggers in combination with poor control:

Parent/Guard	ian Smokes	_ Patient smokes
Other Second	hand Smoke Exposure	Roaches
MiceA	Animal Dander	
Chemicals (clo	eaning chemicals, pesticide	s) <u> </u>
Dust Mites	Other:	

Other pertinent information

Mice	_Roaches _	Dust mi	itesMo	olds	Other:
Positive alle	ergy testing re	esults:	_ Pollen	Cat	Dog
Allergy test	ing conducted	d: Yes	No		

Endnotes

- World Health Organization. Social determinants of health [cited 2010 Aug 8]. Available from: <u>https://www.who.int/health-topics/social-determinants-of-health</u>
- Woods ER, Bhaumik U, Sommer SJ, Ziniel SI, Kessler AJ, Chan E, Wilkinson RB, Sesma M, Burack AB, Klements EM, Queenin LM, Dickerson DU, Nethersole S. Community Asthma Initiative: Evaluation of a Quality Improvement Program for Comprehensive Asthma Care. *Pediatrics.* 2012;129(3):465-472.
- Woods ER, Bhaumik U, Sommer SJ, Chan E, Tsopelas L, Fleeger EW, Lorenzi M, Klements EM, Dickerson DU, Nethersole S, Dulin R. Community asthma initiative to improve health outcomes and reduce disparities among children with asthma. In: Strategies to reduce health disparities: selected CDC- sponsored interventions-United States, 2016. *MMWR Suppl.* 2016; 65 (No. Suppl 1). Publication date 2/12/16. <u>http://www.cdc.gov/mmwr/ind2016_su.html</u>.
- U.S. Department of Health and Human Services. Healthy People 2030. Available at: <u>https://health.gov/healthypeople</u>. Accessed May 17, 2013.
- Wright RJ, Mitchell H, Visness C, Cohen S, Stout J, Evans R, et al. Community violence and asthma morbidity: The Inner-City Asthma Study. *Am J Public Health*. 2004;94(4):625-32.
- Evans R, Gergen PJ, Mitchell H, et al. A randomized clinical trial to reduce asthma morbidity among inner-city children: results of the national cooperative inner-city asthma study. *J Pediatr*. 1999;135:332-8.
- 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 April; 95(4): 652-659.
- 8. Morgan WJ, Crain EF, Gruchalla RS, et al. Results of a home-based environmental intervention among urban children with asthma. *NEJM*. 2004; 351(11): 1068-80.
- Krieger JW, Jacobs DE, Ashley PJ, et al. Housing interventions and control of asthma-related indoor biologic agents; a review of the evidence. *J Public Health Management Practice*. 2010; 16(5): S11-S20.
- 10. Nicholas SW, Jean-Louis B, Ortiz B, et al. Addressing the childhood asthma crisis in Harlem: the Harlem Children's Zone Asthma Initiative. *AJPH*. 2005;95(2):245-249.

- Center for Disease Control and Prevention. Reducing childhood asthma through community-based service Delivery --- New York City, 2001-2004. *MMWR*. 2005;54:11-14.
- Bryant-Stephens T, Kurian C, Guo R, Zhao H. Impact of household environmental interventions delivered by lay health workers on asthma symptom control in urban, disadvantaged children with asthma. *Am J Public Health*. 2009:99(S3):S657-S665.
- National Heart, Lung, and Blood Institute. National Asthma Education and Prevention Program, Expert Panel Report 3: Guidelines for the Diagnosis and Management of Asthma. US Department of Health and Human Services, 2007.
- Lieu TA, Quesenberry CP, Capra AM, et al. Outpatient management practices associated with reduced risk of pediatric asthma hospitalization and emergency department visits. *Pediatrics*. 1997;100:334-341.
- 15. Institute of Medicine. The Future of the Public's Health in the 21st Century. Washington, D.C.: National Academies Press, 2003.
- Sommer S, Shurtleff J, Kelly P. Chapter 23: Asthma in Adults and Children. In: Lowenstein AJ, Foord-May L, Romano JC, eds. *Teaching Strategies for Health Education and Health Promotion: Working with Patients, Families, and Communities.* Sudbury, MA: Jones and Bartlett, 2009:425-458.
- Sommer S, Hoppin P, Gunturi N et al. Establishing a citywide system for providing asthma home visits: The Boston Asthma Home Visit Collaborative. Family and Community Health, 2012.
- Krieger JW, Philby ML, Brooks MZ. Better Home Visits for Asthma: Lessons Learned from the Seattle-King County Asthma Program. *Am J of Prev Med*. 2011;41(2S1):S48-S51.
- Sommer SJ, Queenin LM, Nethersole S, Greenberg J, Bhaumik U, Chan E, Wilkinson RB, Dickerson DU, Woods ER. Boston Children's Hospital Community Asthma Initiative (CAI): Using Outcomes to Drive Policy Change. *Prog. Community Health Partnersh*. 2011;5(3):327-335.

http://muse.jhu.edu/journals/progress_in_community_hea http://muse

- Rittenhouse DR, Shortell SM, Fisher ES. Primary care and accountable care - two essential elements of delivery-system report. *N Engl J Med.* 2009; 361(24): 2301-3.
- Porter ME. A strategy for Health Care Reform
 Towards a value-based system. N Engl J Med. 2009;361(2):109-12.
- 22. Commission on a High Performance Health System. Developing Innovative Payment Approaches: Finding the Path to High Performance. New York: The Commonwealth Fund, <u>https://www.commonwealthfund.org/programs/archivedcommission-high-performance-health-system</u> (accessed October 4, 2022), June 2010.
- 23. Massachusetts Executive Office for Administration and Finance. Recommendations of the Special commission on the Health Care Payment System, July 16, 2009.
- 24. A framework for approaches to SROI analysis. Social Edge. May 2005. <u>http://base.socioeco.org/docs/_sites_ccednet-</u> <u>rcdec.ca_files_ccednet_pdfs_2005-</u> <u>050624_sroi_framework.pdf</u> (Accessed October 18, 2022.)
- 25. Boston Public Schools at a Glance 2021- 2022. Boston Public Schools. November, 2021. <u>https://www.bostonpublicschools.org/cms/lib/MA0190646</u> <u>4/Centricity/Domain/187/BPS%20at%20a%20Glance%2</u> 02021-2022.pdf (Accessed October 18, 2022.)
- Bhaumik U, Norris K, Charron G, Walker SP, Sommer SJ, Chan E, Dickerson DU, Nethersole S, Woods ER. A Cost Analysis for a Community-Based Case Management Intervention Program for Pediatric Asthma. *J Asthma*. 2013 Apr; Vol. 50 (3), pp. 310-7. Date of Electronic Publication: 2013 Feb 14.
- Woods ER, Bhaumik U, Sommer SJ, Ziniel SI, Kessler AJ, Chan E, Wilkinson RB, Sesma M, Burack AB, Klements EM, Queenin LM, Dickerson DU, Nethersole S. Community Asthma Initiative: Evaluation of a Quality Improvement Program for Comprehensive Asthma Care. *Pediatrics.* 2012;129:465-472.
- Shreeve K, Woods ER, Sommer SJ, Lorenzi M, Monteiro K, Nethersole S, Bhaumik U. Community Health Workers in Home Visits and Asthma Outcomes. *Pediatrics*. Published online: 1 Apr 2021;147(4): e2020011817. (doi: 10.1542/peds.2021.011817). https://publications.aap.org/pediatrics/article/147/4/e2020 011817/180842/Community-Health-Workers-in-Home-Visits-and-Asthma

- Bhaumik U, Sommer SJ, Giller-Leinwohl J, Norris K, Tsopelas L, Nethersole S, Woods ER. Boston Children's Hospital Community Asthma Initiative: Five Year Cost Analyses of a Home Visiting Program. *J Asthma*. 2017;54(2):134-142. http://dx.doi.org/10.1080/02770903.2016.1201837.
- Penzias RE, Sanabia V, Bhaumik U, Sommer SJ, Shreeve KM, Woods ER. Parent Experiences with a Nurse-Supervised Community Health Worker Asthma Home-Visiting Program. *J Asthma*. 2019;56(12):1314-1324.

https://doi.org/10.1080/02770903.2018.1536144

- Dong Z, Nath A, Guo J, Bhaumik U, Chin MY, Dong S, Marshall E, Murphy J, Sandel M, Sommer SJ, Ursprung S, Woods ER, Reid M, Adamkiewicz G. Evaluation of the Environmental Scoring System in Multiple Child Asthma Intervention Programs in Boston, MA. *AJPH*. 2017;108(1):103-111. <u>http://ajph.aphapublications.org/doi/10.2105/AJPH.2017.</u> <u>304125</u>
- 32. Bhaumik U, Sommer SJ, Lockridge R, Penzias R, Nethersole S, Woods ER. Community Asthma Initiative: Cost Analyses Using Claims Data from a Managed Care Organization. J Asthma. 2020;57(3):286-294. <u>https://doi.org/10.1080/02770903.2019.1565825</u>
- Smith LA, Bokhour B, Hohman KH, et al. Modifiable risk factors for suboptimal control and controller medication underuse among children with asthma. *Pediatrics*. 2008;122:760-9. http://dx.doi.org/10.1542/peds.2007-2750.
- Nurmagambetov TA, Barnett SBL, Jacob V, et al. Economic value of home-based, multi-trigger, multicomponent interventions with an environmental focus for reducing asthma morbidity: A Community Guide systemic review. *Am J Prev Med.* 2011;41(2S1):S33-47.
- 35. Marshall ET, Jing Guo, Flood E, Sandel MT, Sadof MD, Zotter JM. Home visits for Children with asthma reduce Medicaid costs. *Prev Chronic Dis.* 2020:17;190288.
- Campbell JD, Brooks M, Hosokawa P, Robinson J, Song L, Krieger J. Community Health Worker home visits for Medicaid-enrolled children with asthma: effects on asthma outcomes and costs. *Am J Public Health*. 2015;105(11):2366-2372.
- Woods ER, Sommer SJ, Bryson EA, Shreeve KM, Nethersole S, Bhaumik U. Improved 10-year cost savings for patients served by the Community Asthma Initiative. J Asthma. Published electronically, December 14, 2021. Print version, 2022: 59(11);2258-2266, <u>https://doi.org/10.1080/02770903.2021.2010746</u>

Community Asthma Initiative

PROGRAM IMPLEMENTATION MANUAL

