

**Evidence-based Practice Center  
Technical Brief Protocol**

**Project Title: Characteristics of Existing Asthma Self-Management  
Education Packages**

**I. Background and Objectives for the Technical Brief**

Asthma is a chronic respiratory disease characterized by airway inflammation and a variety of symptoms including coughing, wheezing, and shortness of breath. More than 8% of both adults and children in the United States (U.S.) have asthma, and in 2016 asthma accounted for 1.7 million emergency department visits and more than 3,500 deaths.<sup>1</sup> Asthma significantly reduces patients' and families' quality-of-life and affects attendance at school, work, and participation in recreational activities. Half of adults and nearly 40% of children report poorly or uncontrolled asthma, although a wide variety of pharmacological and other interventions are available to improve asthma control and reduce the frequency and burden of symptoms.<sup>2</sup>

Patients and families can play a substantial role in minimizing the burden of asthma through careful medication management, reducing exposure to environmental triggers, and responding rapidly to exacerbations.<sup>3</sup> However, understanding the complex interaction between respiratory physiology, asthma triggers, short- and long-term medications, and rescue therapies necessitates significant education and training that can be challenging for patients and caregivers. Clinical practice guidelines developed by the National Heart, Lung and Blood Institute therefore emphasize formal and comprehensive asthma self-management education (AS-ME) as a key component of optimal asthma care.<sup>4</sup> National standards for AS-ME have been published,<sup>5</sup> and the Centers for Disease Control and Prevention (CDC) recently introduced a new technical package aimed at improving asthma control, EXHALE that highlights the importance of AS-ME as a vital strategy.<sup>6</sup>

Dozens of AS-ME packages have been developed and disseminated by various organizations and agencies, and these packages vary widely across many domains. For example, some focus on adults with asthma while others address adolescent patients or younger children. Many packages are designed for use directly by patients or their parents, and others incorporate clinicians, social workers, or peers in educational roles. Some are tailored to specific populations such as Spanish-speaking patients or inner-city families. AS-ME can also be implemented in a variety of clinical and nonclinical settings.

In addition to variation in population and setting, AS-ME packages use differing formats. Packages can feature high-tech educational platforms such as websites or apps, or use more traditional paper tools. Education can be delivered face-to-face in individual or small group settings, or remotely by telephone or computer, and can consist of single or multiple sessions of varying length.

The educational content of AS-ME can span a wide variety of skills and information. Asthma patients can be taught about the physiology of the lungs and airway functioning, and how to use multiple types of medications and devices. They may be taught how to measure peak flow and monitor their clinical symptoms for warning signs. Families can be instructed in the important role of environmental triggers, and learn how to reduce or avoid exposure to allergens and irritants. AS-ME packages can include toolkits and resources for patients such as asthma symptom trackers and written action plans.

AS-ME packages have been evaluated in many studies. A recent review of reviews<sup>3</sup> synthesized the findings of twenty-seven systematic reviews encompassing 270 randomized controlled trials (RCTs) of AS-ME packages. The authors found that AS-ME improves asthma control and reduces healthcare utilization, and can be implemented for diverse populations in varying settings. Other recent reviews have also suggested the value of AS-ME for improving asthma outcomes<sup>7</sup> and quality of life.<sup>8</sup>

Although AS-ME packages are frequently used and have been widely studied, there is uncertainty about their optimal design, characteristics, and implementation. Heterogeneity in content, format, delivery mechanisms, targeted populations, and other features complicates efforts to identify best practices in designing AS-ME packages. Additionally, different populations and types of learners may need different educational approaches and strategies. As the prevalence and burden of asthma continue to grow, there is increasing interest by clinical experts, patient advocates, public health leadership, and policymakers to identify and invest resources in effective interventions. Future packages would benefit from a structured framework delineating the current state of AS-ME practice, knowledge, and research.

This Technical Brief will map the ecosystem of current AS-ME packages. We will identify the different components that comprise selected AS-ME packages that are used in the U.S., and examine, compare, and organize their key characteristics to enable a better understanding of current practice. We will summarize important elements of their scope, design, content, and target audience, and include evidence, when available, addressing their effectiveness, feasibility, and user satisfaction. Our analysis will also highlight factors affecting implementation success, including public availability, user literacy, cost, timing, mode of delivery, and ease of use. Finally, we will identify key gaps in knowledge about optimal AS-ME packages, and illuminate the practical challenges to future work in this field. This Technical Brief will present an organized overview of current AS-ME practices designed to guide future program development, allocation of resources, and directions for further research.

## **II. Guiding Questions**

**GQ 1:** What are the characteristics of AS-ME packages, and how do they vary?

### Audience

- Who is included in the intended audience?
  - Recipients of education, e.g.: patients with asthma; parents/families/caregivers

- Providers of education, e.g.: clinicians; community health workers; social workers; school nurses
- Are packages focused on, or limited to, specific patient characteristics?
  - Adult/adolescent/pediatric patients
  - Social/cultural/economic factors
  - Asthma severity; comorbidity
- What level of literacy is required? Are packages offered in multiple languages?

Delivery and use of AS-ME packages

- What is the setting for delivery of education?
  - Home, school, other community site, healthcare setting
- Is education self-directed, or delivered by an instructor (if so, whom)?
- What aspects of the package are interactive?
  - Is there hands-on instruction of medications and devices?
  - What feedback is provided to recipients and/or instructors?
- What mediums are used to deliver education and facilitate communication?
  - Online, telephone, paper-based, face-to-face, texting, social media
  - How can recipients ask questions or request further information?
- What is the timeframe?
  - Number of sessions, length of sessions, total time expected for completion
- How are packages initially accessed? Is there a clinical gatekeeper (e.g., referral or login permission needed)?
  - Are recipients given their own materials?

Educational content

- What key content areas are addressed?
  - Framework for understanding asthma as a chronic disease; basic respiratory physiology
  - Use of asthma medications and devices
  - Self-monitoring symptoms and understanding clinical warning signs
  - Environmental triggers of asthma at home, school, work, other settings
  - Coordinating asthma management across all settings
- How do packages address cognitive, psychological, and/or emotional components of asthma and asthma self-management?
- What tools are provided to recipients as components of the packages?

- Asthma action plans, asthma control assessment tools, environmental questionnaires
- Checklists, evaluation materials
- Asthma trigger reduction supplies, spacers
- What evidence supports the validity of the content? Does the content align with national asthma guidelines?
- When were the packages designed/updated?
- Are explicit educational goals identified? How is individual learning/progress evaluated?

**GQ 2:** What is the context and implementation of AS-ME packages?

- Who develops the packages?
- Are packages publicly available? Is there a fee? Are they protected by copyright?
- How much does it cost to develop, produce, promote, disseminate, and use packages?
- Who pays for educational packages?
- Do recipients earn a certification of completion?
- Is there a process to sustain/support retention of learning over time?
- What factors are important facilitators and barriers to implementation of AS-ME?
- How is technology used to support implementation?
- If education is guided by an instructor, how are instructors identified and trained?
  - Clinical/educational background
  - Training process
  - Certification
  - Guidance in privacy rules, communication skills, other relevant areas
- Are current/future workforce resources adequate to provide instruction?
- How is implementation evaluated?

**GQ 3:** What is the current evidence addressing AS-ME packages?

- What asthma outcomes are measured? Are packages associated with good outcomes?
  - Asthma control
  - Asthma-related health care utilization
  - Asthma-related medication adherence
  - Asthma-related quality of life

- What patient-centered outcomes are measured? Are packages associated with good outcomes?
  - Ease of use
  - Acceptability
  - Patient/family/instructor satisfaction
- What implementation outcomes are measured? Are packages associated with good outcomes?
  - Feasibility
  - Adoption
  - Fidelity
- How applicable is current evidence to various populations and settings?

**GQ 4:** What future research is needed to close evidence gaps regarding AS-ME packages?

- What additional evaluation is needed on existing AS-ME packages?
  - Identifying optimal population, setting, instructor, etc.
- Are different evaluation approaches needed to assess AS-ME?
  - Interviews, focus groups, other qualitative or quantitative evaluation techniques
- What new types of packages, or components and features of packages, may be needed?
- Is further evaluation needed focusing on specific patient populations? Are some populations not adequately addressed by current packages?

### **III. Methods**

#### **1. Data Collection:**

##### **A. Discussions with Key Informants**

The Key Informants (KIs) will have expertise in one or more of the following areas: adult and pediatric asthma; AS-ME; environmental allergens and irritants; community-based interventions; and populations at high risk for significant asthma morbidity and poor outcomes. KIs will be queried on the content of AS-ME packages, and how design features of educational materials could be improved. They will be asked about the challenges encountered when implementing AS-ME packages, and how to facilitate the delivery of education. KIs will also provide insight into how AS-ME should be evaluated, and how education interacts with other types of asthma interventions.

KI input will help inform GQ 1, 2 and 4. KI input will also be used to refine the systematic literature search, identify grey literature resources, provide information

about ongoing research, confirm evidence limitations, and recommend approaches to help fill these gaps. Table 1 presents potential questions that would be asked to the KIs.

**Table 1. Potential KI Questions**

<ol style="list-style-type: none"> <li>1. What do you see as the most important features of AS-ME packages?</li> <li>2. What types of educational content are best delivered through AS-ME? Are certain content areas less conducive to AS-ME?</li> <li>3. What are the relative advantages and disadvantages of self-directed AS-ME compared with instructor-delivered education?</li> <li>4. What types of professionals (e.g., physicians, nurses, community health workers, social workers) are best trained to provide instruction in AS-ME? Should other groups of professionals play a greater or different role in delivering AS-ME? How does this vary by patient population?</li> <li>5. How should packages be accessed by patients? How might online/mobile technology be incorporated into design/delivery of AS-ME?</li> <li>6. What are the most important clinical and psychosocial goals for patients who engage in AS-ME? How should outcomes be assessed?</li> <li>7. How can/should packages address population differences such as age, literacy, social/cultural/economic factors, and high-risk patients?</li> <li>8. What operational factors (e.g. ease of use, availability, time frame) are important to consider when delivering AS-ME? Which factors are the biggest barriers?</li> <li>9. What confounding factors pose a challenge to interpreting research and evaluation studies on the design, implementation, use, and assessment of AS-ME, and how can future research/evaluation be designed to minimize these confounders?</li> <li>10. Where do you think are the most important gaps in current knowledge, and can you recommend approaches to help fill these gaps?</li> <li>11. In addition to published literature, what unpublished resources could help inform our analysis?</li> <li>12. Can you suggest strategies we might use to organize, present, and disseminate our findings?</li> </ol>
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## **B. Grey Literature search**

Grey literature will be critical for identifying AS-ME packages (GQ 1 and GQ 2), and finding descriptions and evaluations of AS-ME packages implemented by individual hospitals, health systems, provider groups, community organizations, or public health agencies. The following gray literature sources will be searched using text words: Centers for Disease Control and Prevention (CDC), ClinicalTrials.gov, ECRI Guideline Trust, Medscape, National Academy of Medicine, and the web sites of organizations and agencies including the Allergy and Asthma Network (AAN), American Academy of Allergy, Asthma & Immunology (AAAAI), American Association for Respiratory Care (AARC), American Academy of Pediatrics (AAP), American College of Allergy, Asthma, and Immunology (ACAAI), American Lung Association (ALA), American Public Health Association (APHA), Association of Asthma Educators (AAE), Association of State and Territorial Health Officials (ASTHO), Asthma and Allergy Foundation of America (AAFA), Asthma Community Network, Children’s Hospital Association (CHA), Environmental Protection Agency (EPA), Healthcare Anchor Network, National Association of County and City Health Officials (NACCHO), National Association of School Nurses (NASN), National Asthma Educator Certification Board (NAECB), National Environmental Education Foundation (NEEF), National Heart, Lung, and Blood Institute (NHLBI), and

Regional Asthma Management and Prevention (RAMP). We will also search for patient apps and other online AS-ME tools. Finally, input from the KIs will be used to identify other grey literature sources.

### **C. Published Literature search**

Published literature will be used to answer GQ 3. Literature searches will be performed by Medical Librarians within the Evidence-based Practice Center (EPC) Information Center, and will follow established systematic review protocols. We will search the following databases using controlled vocabulary and text words: MEDLINE, PubMed (unprocessed records only), EMBASE, CINAHL, and the Cochrane Library. Searches will cover the literature published from January 1, 2007 through 2019. Search dates may be adjusted based on the quantity and quality of the available literature. Appendix 1 presents a sample search strategy.

Literature screening will be performed in duplicate using the database Distiller SR (Evidence Partners, Ottawa, Canada). Literature search results will initially be screened for relevancy. Relevant abstracts will be screened in duplicate. Studies that appear to fit the scope of the brief will be retrieved in full and screened again in duplicate. All disagreements will be resolved by consensus discussion among the two original screeners. The literature searches will be updated during the Peer Review process, before finalization of the review.

### **D. Inclusion of AS-ME Packages and Published Literature**

Specific AS-ME packages will be included only if they contain an interactive component, describe a methodology for use or implementation, and are available for use in the U.S. Packages will be excluded if they consist only of paper materials, slides, checklists, or other materials without any interactive element, do not include guidance for how they should be used, or are used exclusively outside of the U.S.

Published studies will be included if they present post-intervention data on asthma patients in the U.S. who used an AS-ME package, and are full-length English language publications. We will not require that studies have control groups. Studies will be excluded if they are available only as abstracts or only examined patients outside the U.S. If a study contains an AS-ME intervention used in multiple countries including the U.S., we will include it if at least 50% of patients were in the U.S., or if patient data were stratified by country.

## **2. Data Organization and Presentation:**

### **A. Information Management**

Descriptive characteristics will be abstracted from AS-ME packages and published studies, and tabled. Factors to be abstracted from AS-ME packages will include, but may not be limited to, the characteristics described above in GQ 1 and 2 (factors relating to audience, delivery, content, and context). Factors to be abstracted from published studies will include PICOTS categories (population, intervention, comparator, outcomes, timing, setting). We will highlight outcome measures that are used in these studies, and the applicability of their results to various populations. KI

interviews will help refine which data points should be abstracted, and how they might be organized. KI interviews will be documented during each call by a designated member of the project team. Notes will be reviewed and discussed by the investigators to evaluate how KI input provides insight on design features of AS-ME packages, and facilitators and barriers to implementation of asthma education.

## **B. Data Presentation**

We will design an analytic framework that visually communicates the integration of AS-ME into patient care. This will include the roles and relationships of those who design, implement, use, and assess AS-ME packages, and the interaction of AS-ME with short- and long-term clinical and evaluative outcomes.

Characteristics of AS-ME packages and outcomes of published studies will be presented in searchable evidence tables. We will also highlight the features of existing AS-ME packages, the current state of knowledge regarding AS-ME evaluation and research, and important evidence gaps that require further study and assessment, using evidence maps or other data visualization approaches as appropriate. Finally, significant perspectives and insights gathered from the KIs will be summarized narratively.

## **IV. References**

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## **V. Definition of Terms**

Not applicable.

## **VI. Summary of Protocol Amendments**

There are no amendments.

## **VII. Key Informants**

Within the Technical Brief process, Key Informants serve as a resource to offer insight into the clinical context of the technology/intervention, how it works, how it is currently used or might be used, and which features may be important from a patient or policy standpoint. They may include clinical experts, patients, manufacturers, researchers, payers, or other perspectives, depending on the technology/intervention in question. Differing viewpoints are expected, and all statements are crosschecked against available literature and statements from other Key Informants. Information gained from Key Informant interviews is identified as such in the report. Key Informants do not do analysis of any kind nor contribute to the writing of the report and have not reviewed the report, except as given the opportunity to do so through the public review mechanism

Key Informants must disclose any financial conflicts of interest greater than \$5000 and any other relevant business or professional conflicts of interest. Because of their unique clinical or content expertise, individuals are invited to serve as Key Informants and those who present with potential conflicts may be retained. The TOO and the EPC work to balance, manage, or mitigate any potential conflicts of interest identified.

## **VIII. Peer Reviewers**

Peer reviewers are invited to provide written comments on the draft report based on their clinical, content, or methodologic expertise. Peer review comments on the preliminary draft of the report are considered by the EPC in preparation of the final draft of the report. Peer reviewers do not participate in writing or editing of the final report or other products. The synthesis of the scientific and grey literature presented in the final report does not necessarily represent the views of individual reviewers. The dispositions of the peer review comments are documented and will be published three months after the publication of the Evidence report.

Potential Reviewers must disclose any financial conflicts of interest greater than \$5000 and any other relevant business or professional conflicts of interest. Invited Peer Reviewers may not have any financial conflict of interest greater than \$5000 Peer reviewers who disclose potential business or professional conflicts of interest may submit comments on draft reports through the public comment mechanism.

### **IX. EPC Team Disclosures**

EPC core team members must disclose any financial conflicts of interest greater than \$1,000 and any other relevant business or professional conflicts of interest. Related financial conflicts of interest that cumulatively total greater than \$1,000 will usually disqualify EPC core team investigators.

### **X. Role of the Funder**

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### Appendix 1. Sample Search Strategy

Set #	Concept	Search Statement
1	Asthma self-management education	'asthma self-management education' OR 'asthma self management education'
2	Specific AS-ME packages	'a breath of life' OR 'asthma control for my child' OR 'asthma 101' OR 'asthma basics for children' OR 'asthma education for the community health worker' OR 'breathe well, live well' OR 'community health worker training manual' OR 'open airways for schools' OR 'power breathing' OR 'wee breathers'
3	Asthma	asthma/mj OR asthma*:ti
4	Self Care	'self care'/mj OR 'self help'/mj OR self*:ti
5	Education	education/mj OR (educat* OR program* OR train*):ti
6	Combine Concepts	#1 OR #2 OR (#3 AND #4 AND #5)