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## Development of a Patient-centered Outcome Measure for Emergency Department Asthma Patients

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## Development of a patient-centered outcome measure for emergency department asthma patients

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### Abstract

**Background**—Measuring outcomes of emergency care is of key importance, but current metrics, such as 72-hour return visit rates, are subject to ascertainment bias, incentivize over-testing and over-treatment at initial visit, and do not reflect the full burden of disease and morbidity experienced at home following ED care. There is increasing emphasis on including patient-reported outcomes, but the existing patient-reported measures have limited applicability to emergency care.

**Objective**—To identify concepts for inclusion in a patient-reported outcome measure for ED care, and assess differences in potential concepts by health literacy.

**Design/Methods**—A three-phase qualitative study was completed using freelist and semi-structured interviewing for concept identification, member checking for concept ranking and cognitive interviewing for question development. Participants were drawn from three tertiary care EDs. Parents of patients (pediatric) or patients (adult) with asthma completed a demographic survey and an assessment of health literacy. Phase 1 participants also completed a freelist exercise and qualitative interview regarding the definition of success following ED discharge. Phase 2 participants completed a member checking survey based on concepts identified in Phase 1. Phase 3 was a pilot of trial questions based on the highest-ranked concepts from Phase 2.

**Results**—Phase 1 enrolled 22 adult patients and 37 parents of pediatric patients. Phase 2 enrolled 41 adult patients and 200 parents. Phase 3 involved 15 parents. Across all demographic / literacy groups, Phase 1 participants reported return to usual activity and lack of asthma symptoms as the

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most important markers of success. In Phase 2, symptom improvement, medication use and access and asthma knowledge were identified as the most important components of the definition of post-ED discharge success. Phase 3 resulted in 5 questions for the proposed measure.

**Conclusions**—A step-wise qualitative process can identify, rank, and formulate questions based on patient-identified concepts for inclusion in a patient-reported outcome measure for ED discharge. The 4 key concepts identified for inclusion: symptom improvement, medication access, correct medication use and asthma knowledge are not measured by existing quality metrics.

### Keywords

emergency department; discharge process; asthma; patient-centered; quality

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### Background

Measuring outcomes of acute care is of crucial importance to improve care.<sup>1</sup> Previous studies have used a range of metrics to measure outcomes following discharge from the emergency department (ED), but none fully capture the patient's experience. Mortality is rare<sup>2</sup> and hospitalization on repeat visit<sup>3</sup> may capture changes in admission decisions based on the fact of the return visit rather than based on the clinical condition. Most studies have used a combination of medication adherence,<sup>3-5</sup> attendance of a follow-up appointment<sup>4-9</sup> and return ED visits to evaluate post-ED success. Medication adherence is difficult to measure, and may be less relevant for conditions (such as viral syndromes) where supportive care is all that is recommended. Adherence to follow-up and return to the medical home are important, but do not capture the burden of disease at home.

Most often, absence of a return visit has been used as a measure of ED quality,<sup>6,8,10-18</sup> with a range of time frames from 48 hours<sup>19</sup> to 9 days.<sup>20</sup> However, returns within 72 hours may not be associated with disease severity,<sup>21</sup> and return visits may represent appropriately parsimonious testing at their initial visit with good teaching about return precautions. In addition, patients may return to a different hospital,<sup>22</sup> complicating ascertainment in single-center studies.<sup>23</sup> Finally, counting only those patients who return to the hospital does not account for the burden of disease faced by patients and families at home.<sup>24</sup> Very few studies have used any quality of life or functional<sup>24</sup> measures as part of the definition of success.

There has been increasing emphasis on the importance of patient-centered, clinically meaningful outcomes measures for patients receiving acute care,<sup>25</sup> and recognition of the importance of patient-centered outcomes research in emergency care.<sup>26</sup> However, the most commonly used patient-reported outcome measures have been developed outside of the ED setting and have limited applicability for measuring outcomes from emergency care. For example, as part of the Patient-Reported Outcomes Measurement Information System (PROMIS), a pediatric asthma impact score has been developed to assess symptoms, functional limitations and emotional burden.<sup>27</sup> However, that measure asks about symptoms over the past 7 days, limiting its ability to assess recovery after ED care. Sinha et al<sup>28</sup> used Delphi techniques to identify appropriate outcomes for clinical trials in childhood asthma, interviewing clinicians, parents and children >13 years of age, but with a focus on research trials rather than clinical experience.

Asthma, as a common condition accounting for a large number of initial<sup>29</sup> and repeat<sup>30</sup> visits to the ED for both children and adults, is an excellent model system for studying ED patient reported outcomes. Patients and parents usually have enough experience with the disease to answer questions about anticipated and ideal outcomes. High rates of symptom persistence and functional disability have been reported following ED visits,<sup>24</sup> but may not be captured by existing metrics. In addition, limited health literacy is of particular importance for ED patients,<sup>31</sup> and may affect patient perception of outcomes of care. For example, parents with limited health literacy may perceive a greater burden from their child's asthma, despite similar healthcare utilization.<sup>32</sup> There is limited literature to describe how health literacy may influence identification of measures of success of after acute care

The goals of this research were (1) to use a diverse and iterative set of qualitative methods to identify and prioritize components of a patient reported outcome measurement for asthma patients being discharged from the ED, and (2) to assess differences in potential measure components by health literacy.

## Methods

### Overall approach

We completed a three-phase qualitative study to (1) derive items for inclusion in a PROM for patients being discharged from the ED for asthma (2) rank those items by importance and (3) conduct cognitive interviews to ensure items were understandable and usable in practice (Figure 1). In Phase 1, participants completed a freelist exercise, followed by a semi-structured interview. Freelist is a qualitative technique used by anthropologists to understand how a particular domain is defined, and to measure the relative importance of components of the definition.<sup>33</sup> Participants provide a list of terms in response to a prompt or question and a saliency score can be calculated from the relative length of the lists, position of a term on the list and number of lists on which a term appears. The combination of freelist and a semi-structured interview with focused questions regarding success after ED discharge allowed us to ascertain potential items for inclusion in a PROM for ED patients with asthma. However, these techniques do not provide information regarding the relative importance of each item.

Phase 2 was a member-checking process in which those components were ranked by a larger sample of parents and patients. Member checking is a process by which qualitative results are presented to the population of interest to understand the relative importance of items and make sure no important items are missed. The top 10 concepts from phase 1 were incorporated into a survey, and were ranked in order from 1–10 to identify which of the concepts were most important for inclusion. Once the appropriate items for inclusion were identified, questions were developed for testing in Phase 3.

Phase 3 involved pilot-testing the proposed questions using a cognitive interviewing technique. Cognitive interviewing allows one to examine “whether respondents’ interpretations of self-reported items are consistent with intended meanings [and] is fundamental for judging whether survey results provide valid interpretations.”<sup>34</sup> Interviews were conducted using a hybrid model of (1) ‘think-aloud’ where the participant is asked to

describe their thought process and (2) ‘verbal probing’ where the interviewer asks specific questions about the participants experience with the survey,<sup>34</sup> focused around clarity, ease of understanding and ability to respond via text message. In addition, Phase 3 was conducted in a demographically different ED population to ensure question comprehension and relevance beyond the derivation population.

### **Participants: Phase 1 and 2**

Participants were recruited from two tertiary care EDs, one pediatric and one adult. Parents of children were eligible for inclusion if the child was aged between 2 and 11, had an English speaking guardian to give consent, a diagnosis of asthma and no chronic conditions other than asthma, and was being treated for asthma with planned discharge home. One parent per child was enrolled. We chose the age range to reflect a time period when the parent, as opposed to the child, would reasonably be expected to assess the child’s symptoms and manage their post discharge care and the child would be more likely to have an established diagnosis of asthma, rather than viral wheezing. Children with complex chronic conditions<sup>35</sup> likely have very different experiences of education and discharge from the ED and so were excluded from our sample. Adult ED patients were eligible for inclusion if they were undergoing asthma treatment with plan for discharge home and had no significant medical comorbidities. Because of the high frequency of clinical overlap, adults with chronic obstructive pulmonary disease (COPD) in addition to the diagnosis of asthma were eligible for participation. Attending providers of eligible patients were approached for completion of the provider portions of the study. This protocol was approved by the Children’s Hospital of Philadelphia IRB (Protocol number: 14-011274).

### **Participants: Phase 3**

During Phase 3, alternate wordings were tested for questions assessing the items identified in Phases 1 and 2. For the purpose of the cognitive interviewing, we needed to ensure that the questions were understandable and capturing the specific domains defined in Phase 2, and therefore needed only a sample of adults with some experience with asthma care. As we anticipated the questions being answered by parents of pediatric patients or adult patients, we chose to complete the Phase 3 process with parents of children in a pediatric ED. Participants were enrolled from an urban, tertiary care pediatric ED in a different geographic area from Phase 1 and 2. Parents were eligible for inclusion if they had a child >2 and <16 who was being treated in the ED and has a history of asthma and were fluent in English. Families of children undergoing emergent treatment, or whom the clinical team feels are inappropriate for enrollment were excluded. The Phase 3 protocol was approved by the Massachusetts General Hospital IRB (Protocol # 2016P001860)

### **Phase 1**

For both Phase 1 and Phase 2, parents of patients (pediatric) or patients (adult) with asthma were enrolled during hours where a research assistant was available (7a–11p). All participants completed a demographic survey and the Newest Vital Sign, a well-validated assessment of health literacy.<sup>36,37</sup> Interviews were conducted in the ED during the episode of asthma care.

In Phase 1, potential components of a patient-reported outcome measure for asthma discharge were derived through freelisting and semi-structured interviews. The interview guide was designed to build on our prior work identifying unmet needs at the time of ED discharge, which focused on challenges around the ED discharge process,<sup>38</sup> and focus particularly on post-discharge markers of success. As such, questions were developed to ascertain patient definitions of the successful ED discharge and optimal outcomes at home. Questions and prompts were developed by team consensus and then pilot tested with patients and parents in the ED. Our initial questions and prompts were modified for ease of understanding until we developed the following three prompts: What do you want to be able to do/want your child to be able to do at home? What are the things that help you or your child do well at home? What are the things that make it hard for you or your child to do well at home? Following completion of the freelisting, participants underwent a semi-structured interview addressing their experience with the ED discharge process and post-ED care at home (Please see Table 1 for interview domains and sample questions). The interview guide was designed to separate out the process of being discharged from the ED from potential indicators of discharge success at home following a visit, and elicit potential concepts for inclusion in a patient reported outcome measure for use following ED discharge for asthma.

Both the freelisting questions and the interview guide were pilot tested and then further revised after the first four interviews. Study staff were trained in freelisting and interview techniques, and debriefed by the investigators after their initial patient encounters and review of interview transcripts. Providers were asked to complete the freelisting and a written survey based on the patient interview guide. Patient data on return visits to the ED and subsequent outcomes of care was collected via a phone survey and medical record review completed 10–14 days following the ED visit.

Saliency scores were calculated from the freelisting data (Anthropac, 4.98, Analytic Technologies, Lexington, KY). Saliency scores incorporate the position of an item on the list, the length of the list and the number of lists an item appears on to create an overall ranking of the importance of concepts. Freelisting data were analyzed by saliency score by site (adult or pediatric), literacy level (adequate, inadequate) and participant type (parent, patient, provider). From the saliency scores, inflection points were identified to mark a drop-off in saliency between groups of concepts.

Interviews were transcribed and were double coded by two trained coders using NVivo (QSR International, Melbourne, Australia). In addition, 10% of transcript coding was reviewed by the principal investigator (MSK) to ensure consistency and monitor for coder drift. Candidate concepts were identified by team consensus based on freelisting results and reading transcripts with codes related to the following: anticipated outcome, short term revisits, barriers, facilitators, choice of ED as care location.

## Phase 2

In Phase 2, we used a modified pile-sort method to ensure ability of participants with limited literacy to complete the member checking survey. Participants were given a ranking board with areas marked 1-Most important to 10-least important, and cards with plain language description of the concepts to place on the ranking board. A research assistant was present,

read each card aloud, and volunteered to read any card the participant wanted again. Providers completed a written version of the ranking task. We aimed to enroll approximately 2% of eligible asthma patients or parents of patients with asthma at each center. Survey results were analyzed by calculation of saliency scores from the list of ranked items.

### Phase 3

Parents completed a brief set of demographic questions (age, gender, race/ethnicity) and a single question assessment of health literacy (“How confident are you filling out medical forms by yourself?”) that has been shown to detect limited and marginal health literacy in multiple studies.<sup>39,40</sup> Parents underwent a cognitive interview while answering the proposed instrument questions. During the cognitive interview, parents were asked to ‘think aloud’ about how they were understanding the questions, and prompted for feedback on the questions using probes such as “How do you understand this word/phrase?” “What made you decide to answer in this way?” and “How can we make this question less confusing?” Parents ranked the overall survey on clarity/ease of understanding and ability to respond via text message using Likert scales and completed questions about their willingness to receive such messages after an ED visit for asthma, and how helpful they would anticipate them to be.

## Results

### Enrollment

**Phase 1**—A total of 37 parents were enrolled from the pediatric ED, of whom we were able to obtain follow-up data on 20 (54%). From the adult ED, 22 patients were enrolled, with 12 (55%) reached for follow-up. Of the 29 parents with complete data, 26 (90%) were African American and 22 (85%) children had Medicaid or no insurance. Of the 19 adult patient participants with complete demographic data, 13 (68%) were African American and 10 (52%) had Medicaid or no insurance. Of the participants who completed the literacy assessment, 66% of the parents and, 42% of the patients had limited health literacy.

Pediatric patients had made an average of 2.6 visits to the ED within the last year (range 0–7). Within the 14-day follow-up period, no pediatric patients returned to the ED, 2 visited the PCP and there were no specialist visits. Adult patients had an average of 1.4 ED visits in the past year (range 0–3). In the 14-day follow-up, one adult patient returned to the ED, 1 visited the primary care provider and 2 had specialist visits.

25 providers of enrolled patients completed the provider portions of the study (17 pediatric providers, 8 adult providers).

**Phase 2**—In Phase 2, we approached 51 adults and 267 parents, of whom 41 adults and 200 parents were eligible and enrolled, accounting for approximately 2.5% of patients at each center. 80% were African-American, over 80% were female and over 80% had state insurance. Of the adult patients, 70% had limited literacy, as compared to 58% of the parents. We enrolled 26 pediatric providers and 17 adult providers.



**Phase 3**—We conducted 3 rounds (5 participants each) of cognitive interviewing for a total enrollment of 15 parents of patients with a history of asthma undergoing ED treatment for any reason. 13% were African-American and 47% were Hispanic. 93% of participants had adequate health literacy, using standard question scoring.<sup>40</sup>

### Phase 1: Freelisting

Lack of asthma symptoms and return to activity were the most salient concepts among parents and adult patients in both literacy groups. Providers focused more on medication compliance and comprehension of instructions than parents and patients did. Figure 2 compares the items with the highest saliency scores by literacy and population.

### Phase 1: Qualitative interview

Table 2 shows concepts identified during the semi-structured interview with parents and patients, and representative quotes. Identified concepts included process factors (follow-up from ED provider or PCP, access to medications, absence of return visit to ED), clinical outcomes (return to normal activity, symptom resolution, return to work and school) and psychological outcomes (consequences of illness, comfort and reassurance). Concepts did not differ meaningfully by health literacy.

Persistence of recovery was mentioned by fewer participants than many other concepts, and medication usage was discussed in much more detail in the interviews with parents than in those with patients. In addition to the key concepts delineated in the table, participants also discussed issues of distrust with their providers [“How bad is my asthma? Are they telling me things I don’t want to hear, are they hiding things from me to keep me comfortable or is it just that my insurance can’t cover what it takes to get me where I’m supposed to be at. That’s what goes through my mind all the time, to be honest with you” (Patient, Limited literacy)] and disagreement with providers [“I explained to her...I don’t feel comfortable going home yet. He’s still coughing. His heart rate is still high. She said, well, there’s nothing much we can do here...And I explained to her, well, I’m not comfortable with him going home. So she came in with the discharge papers, signed the discharge papers. Okay. I’m going to say four hours later, I ended up back in the emergency room. So that’s the difficult part like before, because just like your word – it’s like you’re trying to tell the physician or doctors something is not right and they’re going about what they have observed and I’m going by experience.” (Parent, High literacy)]

Concepts elicited from providers freelisting and written responses included patient understanding and knowledge, returning when appropriate, and following the treatment plan, including following up with the correct provider. In addition, a number of adult providers discussed the importance of patient motivation, access to care and financial resources in discharge success. Pediatric providers added concerns about school allowing availability to albuterol and busy home environments limiting home care. Generally, providers identified concepts that related to completing processes or actions, but not relating to health outcomes at home. Unlike parents or patients, providers did not often mention returning to baseline health as a marker of a successful discharge.

Ten candidate concepts were identified from these results for potential inclusion in a patient-centered definition of the successful ED discharge (Table 2). The candidate concepts were:

1. Breathing Better/Less Wheezing/Coughing
2. Return to Normal Activities/Sleeping Well
3. Follow-Up with Primary Care Doctor
4. Able to Get Medication and Supplies
5. Knowing Enough About Asthma and Your Plan
6. Feeling Less Worried/Feeling Less Stressed
7. Getting a Call From ER Nurse or Doctor
8. Not Needing to Go Back to the ER
9. Taking Medications Right
10. Return to Work/Return to School/Return to Daycare

### Phase 2: Member checking

Overall, 51.4% of participants ranked “Breathing Better/Less Wheezing/Coughing” as the most important, followed by “Knowing Enough About Asthma and Your Plan” at 12% and “Taking Medications Right” at 10.8%. We examined saliency scores for specific pre-specified groups, including by health literacy status. The top 3 items were the same for the overall cohort and the examined subgroups: parents v. adults, high v. limited literacy (Table 3). In addition the top 3 items were the same for providers and parent/patient participants.

### Phase 3: Cognitive interviews

Table 4 shows the original questions, representative feedback from the cognitive interviews and revised wording of the proposed 5 question assessment. The final proposed assessment is:

1. Compared to when you went to the emergency department, are your/your child’s asthma symptoms better today (for example breathing better, less wheezing or coughing)?
2. Were you able to get the asthma medications and supplies your emergency department doctor recommended?
3. Did you/your child take steroids (prednisone or dexamethasone) today?
4. Did you/your child take albuterol today?
5. Do you know enough about your/your child’s asthma and care plan?

Participants were asked to assess the potential questions on a 5 point Likert scale (extremely, quite a bit, somewhat, a little bit, not at all), where extremely or quite were counted as a positive answer. 14/15 participants reported that the questions were easy to understand and would be easy to respond to by text message. 15 patients reported willingness to answer

such questions after ED discharge and 13/15 reported they expected these questions to be helpful after discharge.

## Discussion

A rigorous qualitative process involving freelist, semi-structured interviews, member checking and cognitive interviewing identified 4 key concepts for inclusion in a patient centered outcome measure for ED patients being discharged for asthma: (1) Symptom improvement (2) Access—to medications and supplies (3) Implementation—correct medication use and (4) sufficient knowledge (Figure 3).

The importance of the member checking process was emphasized by the fact that the importance of ‘getting a call from the ER nurse or doctor’ was mentioned repeatedly in the semi-structured interviews, but was ranked in the bottom spot by every study group. Ending the analysis after the interviews and freelist might have caused us to attribute undue importance to this concept. This finding emphasizes the importance of using multiple methods in qualitative research to triangulate at the most accurate answer.

To the best of our knowledge, these data provide the first report of a patient-derived measure for ED patients with asthma. As discussed above, the PROMIS measures require a 7 day look-back period for response, making them less useful for measuring post-ED recovery.<sup>27</sup> Sinha et al<sup>28</sup> used Delphi techniques to identify appropriate outcomes for clinical trials in childhood asthma, interviewing clinicians, parents and children >13 years of age. Clinicians identified nocturnal symptoms, exacerbations and quality of life as the most important outcomes. Parents reported ‘death’ as the most important outcome, followed by the same 3 identified by the clinicians. Interestingly, in our data, clinicians were much more focused on process measures instead of symptoms or quality of life, perhaps representing the recognition that ED care for asthma is most likely to impact short term functional status rather than overall disease course. These differences underscore the importance of developing and using measures specific to ED care.

The qualitative methods used in this study provide a potential template for the development of further patient-reported outcome measures for ED care. Using freelist and in-depth interviewing, we were able to sample the domain of potential concepts for inclusion; member checking allowed us to ascertain the overall importance of particular concepts and the cognitive interviewing process allowed us to refine those concepts into questions for inclusion in a potential measure. In addition to efforts to further validate this measure, future research should focus on the development of other ED-centered patient reported outcome measures to capture a more relevant assessment of post-ED outcomes than is included in current metrics.

## Limitations

There are several demographic limitations to the study, including the ability to recruit only during hours of RA availability, and the high rates of African-American and Medicaid patients in Phase 1 and 2. However, there is no reason to suspect that candidate concepts for measure inclusion would differ based on time of presentation, and Phase 3 demonstrates that

the questions are potentially understandable and reasonable in a very different demographic setting. We had limited participation in follow-up, but the follow-up was performed to provide a more detailed description of the cohort and is not critical for concept listing or ranking at the time of ED discharge. In addition, we enrolled adults and parents of children, but did not sample adolescents, who may have differing definitions of success. Finally, although we have identified candidate concepts and questions, further work is needed to validate this assessment. Once completed, however, a patient-reported outcome measure for patients being discharged from the ED could be used for quality measurement, process improvement, to investigate disparities in post-ED outcomes, and to capture patient-relevant outcomes in clinical trials of interventions designed to improve ED asthma care.

## Conclusion

Existing ED discharge metrics fail to capture the concepts that are important to patients and families. A 3 step qualitative process has the potential to identify patient-relevant concepts, rank them, and refine assessment questions for concept measurement, beyond standard interview and focus group techniques. Our data suggest that a patient-centered outcome measurement for ED patients being discharged with asthma should include assessment of symptom improvement, medication access, medication use, and asthma knowledge. Such a new, patient-centered, measurement can also improve our ability to test interventions aimed to improve ED discharge success and post-ED outcomes.

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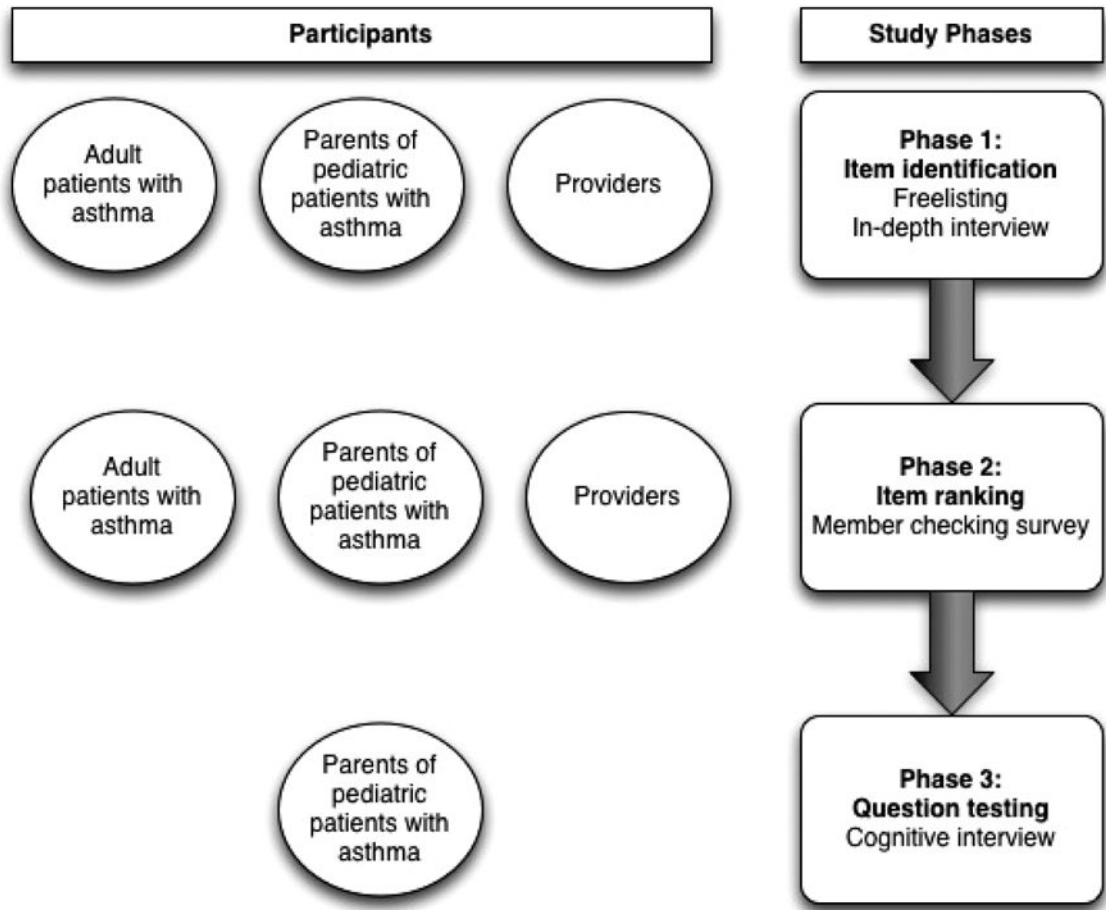
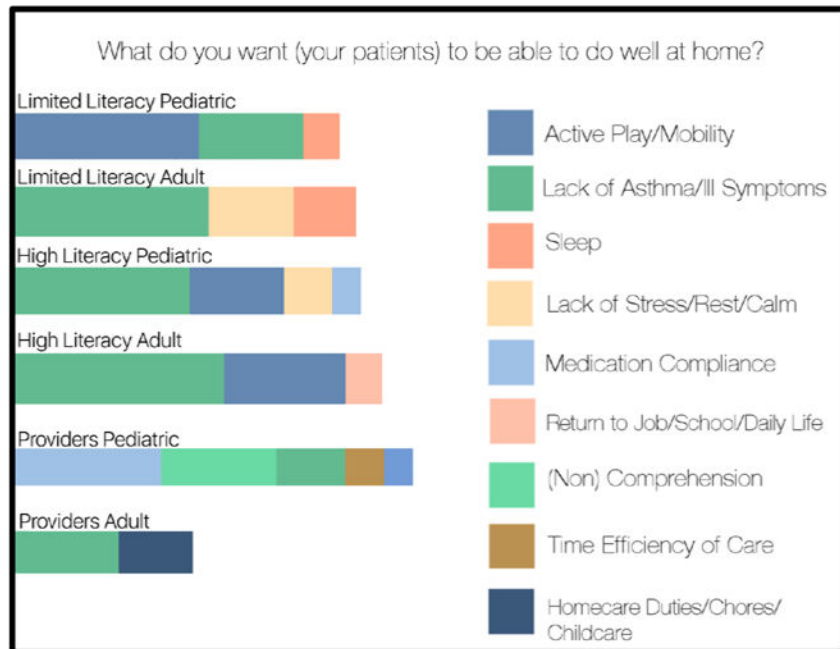


Figure 1.



**Figure 2.**  
Freelisting results by category of respondent



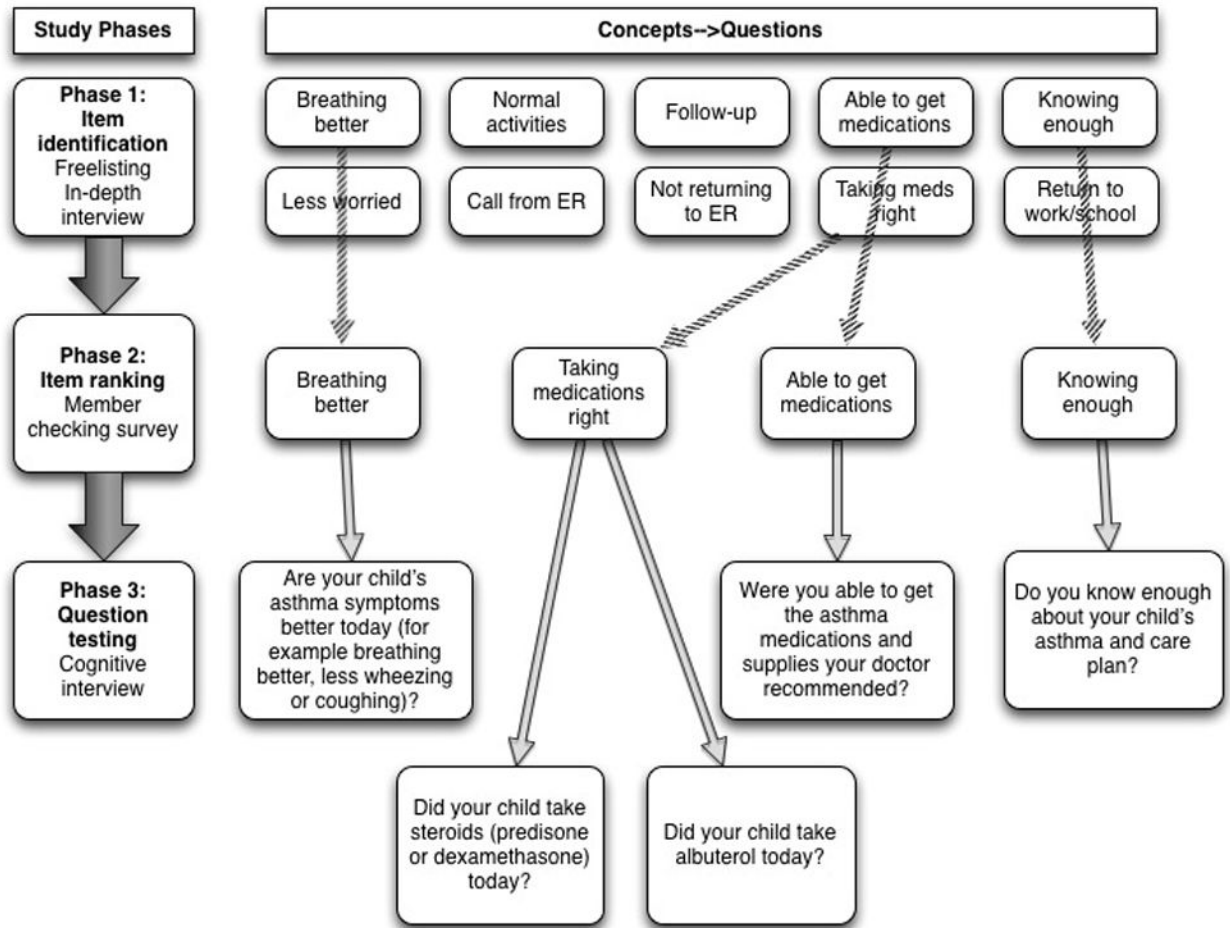


Figure 3.

**Table 1**

## Phase 1 interview domains and sample questions

Interview domain	Sample questions
ED discharge processes	<ul style="list-style-type: none"> <li>• What makes that process of discharge—preparing to go home and getting your paperwork--work well?</li> <li>• What do you want to learn from the teaching at the end of an ED visit?</li> <li>• How would you define a good ED discharge process?</li> </ul>
Post-ED discharge experience	<ul style="list-style-type: none"> <li>• Can you think back to a time when you went home from the ED and things didn't go well? What was that like?</li> <li>• If we were going to visit your house after your ED visit, how would we be able to tell that you/your child was doing well?</li> <li>• What would help people not need to come right back to the ED?</li> </ul>
Experience with asthma care	<ul style="list-style-type: none"> <li>• Do you/your child have to take any medications every day for asthma?</li> <li>• Have you/your child ever had to stay the night in the hospital for asthma?</li> </ul>

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Table 2

Representative quotes by group

Concept	Patient	Parent
Ability to return to normal activity, including normal sleep	I'd be at work if I were doing well...I would be able to be doing my regular activities, which I'm not. (High literacy)	He can't sleep... He's having a tough time breathing at night. He wakes up several times throughout the night saying he can't breathe. (Limited literacy) When he can run outside without coughing and play. Usually when he plays outside he can't run as fast because he'll get chest pain or he'll start wheezing. So I want him to be able to keep up with boys his age... That's most important (High literacy)
Symptom resolution, particularly breathing	No more wheezing. No more out of breath. No anything. No symptoms, basically. I won't even have to take the inhaler anymore (Limited literacy) If I would continue to wheezing and shortness of breath. Prior to my visit I couldn't walk up the steps or down the steps without losing my breath. So, if that still occurred, then I would know that something was wrong. (High literacy)	And obviously not having any more of the symptoms that brought him into the ER. And also, just not having the symptoms, but also not having them for the extended periods of time. Not just initially after, but in the days and weeks after as well. (High literacy) He's just a lot more active. He can just be himself. And, so, those are main ways – the things – active, speaking clearly. He's usually a very proper-speaking five-year-old. So, he can speak very clearly when he's not having breathing trouble. So, those are the things you'll notice. (Limited literacy)
Work and school consequences of illness	I can't afford to do a lot of sick days because I am a single mom. So I think, for me, sometimes being sick is not possible... Now if I go to work, if I can't breathe, because I've been at my job for a long time, they know that, you know, I'm good at my job, I never miss days, so if I do miss a day or two, it's understandable for me... If I don't work, I can't take care of my children. So working, for me, is an absolute must. (Limited literacy)	The multiple call-outs is automatically write-ups and warnings... cause he was sick. Last week and he was sick a couple of times, I would have to call out... So if I have to lose my job because my son is sick, that's fine, I will lose my job because my son is more important. (Limited literacy)
Persistence of recovery	If I continue the regimen that I'm given and my symptoms continue to stay the same, that's when you know it didn't go very well. (High literacy)	Explain what to do when he's trending off from certain medication... So what to do after he's finished with the Prednisone, what's the best thing to do to keep his asthma under control (High literacy)
Absence of return visit to the ED (cost concerns)	If I don't have to come back to the ER, that's a definite measurement that I'm feeling better (High literacy)	Just for my child to remain well, healthy, happy. That's what – and for him not to have to go back to the ED department. So, that's – just to avoid a return visit. That's my, that's the ultimate goal. We just don't want him to go back (High literacy)
Availability of ED or PCP f/u or call	I think more support because once they give you your paperwork and they tell you, they give you the instructions, they don't, like I said, no one calls you to check on you to see how you're doing after or anything. So basically once they discharge you, you're basically on your own. (Limited literacy)	Once we got home, that evening, the following evening I would have liked to have had one of the doctors or the nurses maybe say if you have any questions in the next couple of days, or something, you can call. (High literacy)
Comfort and reassurance, less stress, anxiety, safety concerns	Having another asthma attack. Or my main concern is being attacked and can't defend myself because I can't breathe. That's what I worry about all the time. (Limited literacy)	Knowing that my son is okay and the reassurance they're giving me to let me know that it's okay to take my son home. (Limited literacy)
Medication usage	I need to continue with my followup care and make sure to take my medicines and avoid triggers. (High literacy)	Well, I do notice that when he's getting his pump in the morning and before bed, and the pump before activity, that helps. He can sleep throughout the night. He can – once he, when he's getting it regularly every day, Monday through Friday, not missing any times, he's fine. (Limited literacy)
Supplies, equipment and scripts	So I don't have to pay as much as I used to pay for my medication anymore, but that was why sometimes I wouldn't be able to afford the preventive inhaler, because the preventive inhalers are more than the rescue inhalers. So I would just sometimes hold off on getting a preventive inhaler and just have my rescue. (High literacy) Another thing I would say is medications, because for some people, it's not cut and dried. Some people don't have insurance, so they need the medicine	It is good to go home with equipment when you need one because if you just get a script for the nebulizer, for example. Then you have to find somewhere where they have a medical supply store and stuff like that. Because they don't have those at the pharmacies. So then it may be – it may take time before you actually get what you need. So it's good when you can go home with equipment. Like today I'm going home with the spacer – instead of having to go to the pharmacy (High literacy)

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<b>Parent</b>	<b>Patient</b>	<b>Concept</b>
	that is prescribed for them, and although they might have given them maybe a dose or whatever while they were there, they don't have the medications to treat themselves once they get home (High Literacy)	

**Table 3**

Ranked concepts by saliency score

Concept	Parents		Patients	
	<i>Limited literacy</i>	<i>High literacy</i>	<i>Limited literacy</i>	<i>High literacy</i>
Breathing Better/Less Wheezing/Coughing	1	1	1	1
Taking Medications Right	2	2	2	3
Able to Get Medication and Supplies	3	3	3	2
Knowing Enough About Asthma and Your Plan	4	4	4	5
Follow-Up with Primary Care Doctor	5	7	5	8
Return to Normal Activities/Sleeping Well	6	5	6	6
Feeling Less Worried/Feeling Less Stressed	7	8	7	9
Not Needing to Go Back to the ER	8	6	9	4
Return to Work/Return to School/Return to Daycare	9	9	8	7
Getting a Call From ER Nurse or Doctor	10	10	10	10

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**Table 4** Cognitive interviewing questions and sample responses for each round of interviews

	Round 1		Round 2		Round 3		Final questions
	Question wording	Interview responses	Question wording	Interview responses	Question wording	Interview responses	
1	Are your child's asthma symptoms better (for example breathing better, less wheezing or coughing)?	Multiple parents asked questions about timing; today, in general, after the ED visit?	[Unchanged]	Multiple parents asked questions about timing	Are your child's asthma symptoms better today (for example breathing better, less wheezing or coughing)?	One parent asked "Better than when?"	Compared to when you went to the emergency department, are your child's asthma symptoms better today (for example breathing better, less wheezing or coughing)?
2	Were you able to get the medications and supplies your doctor recommended?	Multiple parents asked questions about non-asthma medications;	Were you able to get the asthma medications and supplies your doctor recommended?	No questions, parents reported easy to understand	[Unchanged]	One parent asked "Do you mean my pediatrician?"	Were you able to get the asthma medications and supplies your emergency department doctor recommended?
3	Is your child taking their medications correctly?	Multiple parents asked questions about non-asthma medications and time-frame; also about about if parent would be able to identify correct v. incorrect	Did your child take steroids (predisone) today?	No questions, parents reported easy to understand	[Unchanged]	Most parents understood; one asked "What about other steroids?"	Did your child take steroids (predisone or dexamethasone) today?
4	Do you know enough about your child's asthma and care plan?	No questions, parents reported easy to understand	Did your child take albuterol today?	No questions, parents reported easy to understand	[Unchanged]	Very clear. No questions.	[Unchanged]
			[Unchanged]	No questions, parents reported easy to understand	[Unchanged]	Very clear. No questions.	[Unchanged]