

Original Research Article
**Conducting Patient and Clinician Participatory
Design Sessions to Create a User-Centered
Mobile Application for Adults with Asthma**

ABSTRACT

Objective: ASTHMAXcel is a patient-facing mobile health self-management application associated with improvements in asthma knowledge and clinical outcomes. The goal of this study was to gain feedback from adult patients and primary care clinicians regarding the ASTHMAXcel mobile app for asthma patients.

Materials and Methods: We conducted two participatory design sessions; one with underserved adult patients and one with outpatient primary care clinicians. Participant attitudes were assessed regarding current asthma care gaps, the usefulness of asthma apps, and desired features of an app. Thematic maps were used to qualitatively analyze the data and structured using affinity diagrams.

Results: Nine patients (67% F, mean age 48.0) and seven clinicians (71% F, mean age 54.6) participated in the study. Qualitative analyses of both groups suggested the improvement in asthma education, self-tracking, peer support, and motivational content. All participants acknowledged that patients miss signs of asthma exacerbations and lack the knowledge for appropriate self-management. Both patients and clinicians recommended adding specific educational content including medication side effects and breathing exercises. They sought the ability to track symptoms, medications, and visits across hospital systems. Patients suggested social engagement as a way of reducing stigmatization related to asthma.

Conclusion: Participatory design sessions enabled subject feedback to guide the refinement of ASTHMAXcel and facilitated the development of ASTHMAXcel PRO, an updated app encompassing many of the discussed features. Main updates include self-tracking patient-reported outcomes (PROs), tailored medication reminders, and a user leaderboard to encourage the collection of PROs.

Keywords: Asthma; Mobile Health; Technology; Participatory Design Session; Patient Education; Asthma Knowledge; Underserved Population

1. INTRODUCTION

Asthma is a serious global health problem affecting approximately 262 million individuals worldwide, with 416,000 deaths attributed to the disease yearly[1-3]. Asthma education significantly improves disease control and reduces emergency department visits and hospital admissions[2, 4]. Mobile health (mHealth) technologies have great potential to educate and encourage asthma self-management. Many U.S. and international societies currently recommend mHealth tools as an option for patient self-management given the widespread usage of smartphones and its increasing accessibility to the general population[5]. Since the onset of the COVID-19 pandemic, patient-facing mobile applications (apps) have become extremely relevant to current virtual care workflows.

We previously developed and validated ASTHMAXcel, a patient-facing mobile app that delivers guideline-based asthma education for adults with asthma[6, 7]. This tool was designed to assist in the accessibility of asthma education and improve outcomes. Since then, an enhanced version (ASTHMAXcel PRO) has been created and launched, thereby allowing for the streamlined collection of patient-reported outcomes (PRO) by its users. To ensure the user-centered nature of ASTHMAXcel PRO, this study conducted a series of participatory design (PD) sessions to assess patient and clinician perspectives regarding the app.

2. MATERIAL AND METHODS

2.1 Study Design and Participants

This prospective, qualitative study consists of three in-person PD sessions, which were conducted at a single outpatient Montefiore Medical Group primary care site in November 2018. Two of the three sessions consisted of patients and one contained outpatient primary care physicians (PCP). To ensure a diverse array of viewpoints, each patient only participated in one PD session, and there were no PD sessions with overlapping patients.

Inclusion criteria for patients were: (a) adults aged 18 years or older with a clinical history (i.e. physician diagnosed) of asthma; (b) use of daily controller inhaler medication; and (c) English-speaking. Exclusion criteria consisted of severe cognitive and/or psychiatric conditions, which would preclude patient understanding and participation in the PD session.

Inclusion criteria for PCPs were: (a) board-certified physicians specializing in internal medicine or family medicine; (b) practices in an outpatient setting; and (c) manages patients with asthma in the outpatient basis.

All PD sessions were conducted with a study facilitator at the Montefiore Asthma Center, a specialized asthma clinic in the quaternary Montefiore Health System, to manage the disproportionately high asthma burden in the Bronx, NY. This study was approved by the Institutional Review Board at the Albert Einstein College of Medicine.

2.2 ASTHMAXcel Mobile Application

ASTHMAXcel consists of educational videos and summaries with eleven chapters of information. These are based on the National Asthma Education and Prevention Program (NAEPP) guidelines, the 2019 British Thoracic Society (BTS), the Scottish Intercollegiate Guidelines Network (SIGN) guidelines and the 2018 Global Initiative for Asthma (GINA) guidelines[4, 5, 8]. The educational content in ASTHMAXcel was developed and reviewed by a team of physicians who provide care to asthma patients (internists, allergists/immunologists, and pulmonologists), asthma educators, and a behavioral scientist to ensure consistency with the NAEPP, BTS/SIGN, and GINA guidelines. Based on the patient's response, a personalized algorithm is used to display certain educational content for each participant to allow for a user-centered experience. ASTHMAXcel is available free of charge on both iOS and Android application marketplaces. Prior studies have outlined initial pilot testing and refinement of the ASTHMAXcel application[6, 7, 9].

2.3 Participatory Design Sessions

For both patient and clinician PD sessions, PD facilitators had permission to participate in the session, take notes, and audio-record the session for later transcription and analysis. Transcription of the audio recordings was done through a voice-to-text transcription service

and was then manually verified. The PD facilitators also debriefed all participants by delineating the purpose and goal of the study (i.e., obtaining subject feedback on ASTHMAXcel for adaptation and use in primary care settings). Written informed consent was also obtained from each participant. Each session lasted approximately 30 minutes.

In each patient PD session, facilitators asked participants to provide a list of desired features (i.e., a 'wish list') that would improve the asthma mHealth application followed by limitations and constraints in primary care regarding asthma. Facilitators then demonstrated the ASTHMAXcel application as a tutorial, which the patients were then able to use. Afterward, the patients reflected on the user experience with the application and compared the experience with their initial 'wish list' to produce a final list of potential refinements for the next version of ASTHMAXcel.

In the clinician PD session, facilitators would similarly ask for a list of desired features and limitations they face in daily practice regarding asthma management. Another goal for the PCP session was to obtain feedback regarding possible future integration into electronic medical record systems to provide PROs to their respective clinicians. Given this goal, PCPs were specifically asked how this information would be most useful in guiding clinical decision-making and how it would be useful in daily workflow. As in the patient PD sessions, the facilitator then demonstrated the ASTHMAXcel application, followed by hands-on use by the clinicians. Feedback from clinicians was collected and compared with their initial 'wish list' to arrive at a final list of suggestions.

2.4 Qualitative Analysis

Thematic analysis was used to analyze the data in a deductive approach [10, 11]. Two researchers participated in the analysis and independently generated lists of initial codes, after which were compared and combined. Based on the initial code list, different codes were sorted into potential, overarching themes using an affinity diagram [12]. From our review of the transcripts and the qualitative analysis, concept saturation was determined to be reached during the design sessions.

3. RESULTS

We conducted two PD sessions with nine patients (Table 1) and one session with seven clinicians (Table 2) to understand the current use of ASTHMAXcel in the primary care setting and to envision the design of an ideal asthma app. The mean age in the patient group was 48.0 (range 34-62) and 54.6 (range 41-61) in the clinician group. Among the patients, the majority were covered by Medicaid (56%), a U.S. healthcare program for those with limited income, or Medicare (22%), a healthcare program for those over the age of sixty-five. The race/ethnicity of the patient group was largely Hispanic (33%) and non-Hispanic Black (56%). Baseline characteristics did not differ significantly between males and females.

Table 1. Participating patient characteristics.

Parameter	All (n=9)	Male (n=3)	Female (n=6)
Age, Mean (SD, Range), years	48 (10.6, 28)	44.3 (13.1, 25)	49.8 (10.0, 28)
Race/Ethnicity, n (%)			
African American	5 (55.6)	2 (66.7)	3 (50.0)

Hispanic	3 (33.3)	0 (0.0)	3 (50.0)
White	1 (11.1)	1 (33.3)	0 (0.0)
Insurance, n (%)			
Medicaid	5 (55.6)	2 (66.7)	3 (50.0)
Medicare	2 (22.2)	0 (0.0)	2 (33.3)
Fidelis	1 (11.1)	1 (33.3)	0 (0.0)
United Healthcare	1 (11.1)	0 (0.0)	1 (16.7)

Table 2. Participating clinician characteristics.

Parameter	All (n=7)	Male (n=2)	Female (n=5)
Age, Mean (SD, Range), years	54.6 (7.5, 20)	59 (1.4, 2)	52.8 (8.4, 20)

From thematic maps generated from the patient and clinician PD sessions, we identified four primary themes: asthma education, self-tracking, social networking, and motivation. These themes were used to guide the development of ASTHMAXcel PRO, an updated app version of ASTHMAXcel (Figure 1).

Figure 1. Selected Images from ASTHMAXcel PRO

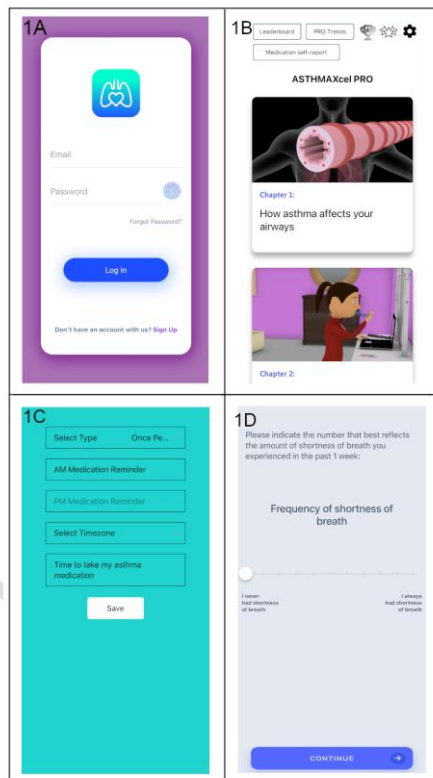


Figure 1A: ASTHMAXcel PRO Log In Screen

Figure 1B: Main navigation screen for users to scroll and select chapters. Users can view current leaderboards (“Leaderboard”) and select “PRO Trends” to view personal progress.

Figure 1C: After selecting the settings icon, patients can customize their medication reminder times.

Figure 1D: Example of a PRO question assessed by the app.

3.1 Asthma Education

While the participants were satisfied with the user interface and the chapter topics, they expressed interest in learning more about asthma itself and proper management. Despite having asthma for years, many patient participants still do not recognize signs of asthma exacerbations and do not understand appropriate management. Additionally, many patients misconstrue long periods of asthma inactivity as having "grown out of it." Clinicians likewise cited a lack of patients' familiarity with their asthma symptoms. For example, during the session, patients remarked that they often confused asthma exacerbation symptoms with a cold, including coughing, shortness of breath, and chest tightness. This lack of education ultimately causes a delay in treatment and subsequent hospitalizations.

When discussing the management of exacerbations, patients also expressed interest in non-pharmacologic strategies. They reported being instructed by their clinicians to perform breathing exercises. Study participants suggested video demonstrations to address this issue. When discussing ASTHMAXcel specifically, one patient noted how one chapter addresses this topic, but requested that it be more comprehensive.

Proper medication use of inhalers was a frequent topic of discussion throughout all PD sessions. Patients recalled being prescribed inhalers, but often lacked the proper knowledge on how to use them. Clinicians indicated that their patients often demonstrated inadequate inhaler technique and incorrect use of peak flow meters, and recommended including demonstrations of proper inhaler usage in the app and elucidating the differences among different medication formulations (e.g. nebulizer versus inhaler). The adverse effects of each medication were also a concern amongst subjects. Several participants mentioned that knowing the side effects would help them better use the medications (e.g. mouth rinsing after use), especially amongst children.

3.2 Self-Tracking and Alerts

Participants described the following tracking needs: 1) triggers; 2) symptoms; 3) medication use; and 4) healthcare utilization (e.g. emergency department visits, hospitalizations). Most of the patients expressed wanting to track their respective unique asthma triggers (e.g. potent perfume, certain foods). Focusing on personalized triggers would encourage communication between patients and clinicians, and with further education on avoidance of these patient-specific triggers, there can be better control of each individual's asthma.

While some patients realized that their asthma management was often impacted by their environment, they generally found that it was difficult to keep track of environmental triggers, such as local pollen counts. A few patients found this to be a knowledge gap and suggested this for additional content to ASTHMAXcel. Patients gave positive feedback regarding the chapter on smoking. The group was generally aware of the negative impact of smoking; however, it better emphasized the increase in hospitalizations and deaths in patients with asthma.

Both patients and clinicians emphasized the importance of tracking asthma symptoms. In order to maximize patient adherence, alerts and notifications were suggested to remind patients to take their medications. Patients recognized that evaluating the trend of their asthma symptoms allows for finer medication titration to improve the trajectory of their

asthma. Additionally, by rating the severity of symptoms in real-time, patients could more accurately relay their symptoms to their physicians. Clinicians cited rescue inhaler use as another desirable feature as a proxy for worsening severity. If there is an increasing need compared to baseline, including nighttime awakenings, the patient should be warned about a possible ongoing exacerbation.

Many clinicians expressed the benefit of tracking healthcare utilization by their patients. However, due to the lack of unity of hospital medical records, this was not a viable option. A solution proposed by clinicians was to track the number of medical visits within the app and integrate it through a patient-centered approach. Another recommendation was the ability to track the amount of hospital visits and steroid use in a year. Facilitators suggested the addition of sensor-based data collection, in addition to manual inputs, to reduce the burden associated with exorbitant logging activities.

3.3 Social Engagement and Data Sharing

The management of chronic disease often has a significant impact on social relationships and interactions. During the sessions, patients discussed the societal stigmas they faced when growing up. They recommended multiple ways in which individuals could find support through the app including the use of forums. Patients recommended a feature that would enable them to share asthma information with their family and friends. Additionally, patients desired the ability to share their treatment regimen with teachers or providers in the hospital in the form of a barcode that could be scanned to produce a list of medications. Clinicians were also interested in data-sharing features through the app.

3.4 Motivation

The clinicians' main concern was patient adherence to the application. Therefore, they recommended financial incentives for patients. Patients indicated that updating the app to keep it engaging will help encourage patient use.

4. DISCUSSION

Asthma education plays an important role in asthma management to ensure proper inhaler administration while recognizing and addressing a possible exacerbation. This study highlights the challenges that patients and outpatient clinicians may encounter to deliver comprehensive asthma education. ASTHMAXcel was designed to provide patients with user-friendly, educational, guidelines-based content to assist in bridging this gap. ASTHMAXcel has been linked to an improvement in asthma knowledge, control, and quality of life as well as reduced ED visits, hospitalizations, and prednisone use at 6 months after initial use [7]. Based on the results from these PD sessions, an enhanced version of ASTHMAXcel has been created. ASTHMAXcel PRO is an updated and interactive app with guideline-based content that enables patients to directly input information regarding their asthma management.

There are a growing number of studies that created user-centered applications based on qualitative interviews and direct patient feedback[13-18]. A review conducted by Huckvale, et. al, explained the poor quality and high turnover rates of asthma apps, and the potential mismatch between feature availability and patient needs[18]. Using qualitative sessions to facilitate routine updating of mHealth apps may be a viable way to ensure continued high-quality content. Over the past few years, several groups have designed mHealth apps using direct feedback from relevant stakeholders, either focusing on patients only, or involving clinicians as well[13-17, 19]. Additionally, patients favorably reviewed the mobile app in the

final stages of the study, likely a byproduct of being involved in its early development[13, 14]. The original version of ASTHMAXcel had high satisfaction rates having been developed after qualitative focus groups elicited patient suggestions and feedback[7, 8]. These studies demonstrate that qualitative feedback is an effective method to identify features for the development of future versions of applications. By synthesizing the opinions of both stakeholders (clinicians and patients), ASTHMAXcel PRO may act as a conduit, bridging patient care both in and out of the office.

The four integral themes discussed in the PD sessions were asthma education, self-tracking, social engagement, and patient motivation. Educational programs improve outcomes in asthma control, self-management, and medication compliance, which can ultimately reduce healthcare spending[7, 20-24]. This study emphasizes the importance of consistently addressing these knowledge gaps.

Self-tracking and monitoring are amongst the most common features in asthma mHealth applications. One review of asthma apps identified that 61% of patients tracked peak flow measurements, 58% medication use, 50% symptoms, 47% triggers, and 29% sleep[25, 26]. Given the multitude of suggestions by patients, ASTHMAXcel PRO was designed to provide patients with a way to track multiple categories, allowing for more comprehensive data aggregation.

The impact of social engagement through social media platforms on mHealth efficacy remains to be seen. Recruitment through social media platforms appears to be effective in early periods with a higher user download rate than other recruitment methods. This dwindles quickly as 83% of those recruited by social media no longer use the app at 30 days[26, 27]. However, social media is an effective way of quickly disseminating asthma-related information from clinicians to patients [28]. Self-monitoring and self-tracking have had positive impacts on user activity, while also reducing rates of app inactivity [29, 30]. One subject in our study highlighted the social isolation associated with asthma, echoing a study that suggested the ability to share stories with others or participate in forums as potential desired features[16, 17]. The ability to input data and view progress over time in ASTHMAXcel PRO may increase user retention, and in return increase asthma education. The exact nature of this effect will require future prospective studies. However, social engagement remains controversial given the potential risks of cyberbullying and worsening of mental health.

One of the main limitations of this study was that the population was from a single healthcare system, therefore the generalizability of this study might be limited. However, the similarities among the viewpoints of our patients and previous studies imply that the themes identified here are widely applicable [13, 15, 16, 19]. A second limitation is the small sample size; however, concept saturation was reached during multiple rounds of the analysis process. Future studies should increase the sample size and increase the clinicians to assess statistical significance more accurately.

5. CONCLUSIONS

Our PD sessions provided useful data on clinician and patient experiences on asthma management. These discussions resulted in four themes: asthma education, self-monitoring, social engagement, and user motivation. PD sessions are a useful approach to ensure that updates in mHealth design meet stakeholder expectations and needs. These findings facilitated the development of ASTHMAXcel PRO, designed to allow users to gain asthma knowledge and track their symptoms, medication use, and healthcare utilization. The

inclusion of self-tracking PROs enables not only a user-centered design, but also the possibility for virtual cohort studies, thereby streamlining remote monitoring and analysis.

CONSENT

All authors declare that written informed consent was obtained from the study participants. A copy of the written consent is available for review by the Editorial office/Chief Editor/Editorial Board members of this journal.

ETHICAL APPROVAL

This study was performed in compliance with the World Medical Association Declaration of Helsinki on Ethical Principles for Medical Research Involving Human Subjects and was reviewed by the Albert Einstein College of Medicine Institutional Review Board.

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