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Developing pictorial asthma action plans to promote self-management and health in rural youth with asthma: A qualitative study

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ABSTRACT

Objective: Asthma action plans (AAPs) provide asthma management instructions to families; however, AAPs typically are written at a 7th–9th grade reading level, making them less useful in lower literacy families. There is a need to develop simpler AAP formats and content to optimize their utility across all families, including those who are rural and may be at a risk for literacy concerns. Because using pictures can simplify and enhance health education, our study's aim was to develop a pictorial AAP through a series of focus groups with key stakeholders – youth with asthma, caregivers, and physicians. **Methods:** Fourteen caregiver/youth dyads and four physicians participated in separate focus groups where their preferences for pictorial AAP structure and content were obtained. Focus groups were audio recorded, transcribed, coded with ATLAS.ti, and analyzed for themes. **Results:** Youth and their caregivers prefer that the AAPs include simple, cartoon-like pictures customized to the patient. Physicians emphasized AAP's capability to display pictures of controller medication given its importance in preventing asthma exacerbations. A stoplight format, currently used in most written AAPs, received positive reviews. Specific suggestions for pictures showing symptoms, medications, and how to take medication were suggested. Words and short phrases accompanying the pictures were thought to add clarity. **Conclusions:** Key stakeholders viewed pictorial AAPs as positive and potentially effective alternatives to standard written AAPs. It is expected that low literacy youth and caregivers would more easily understand a pictorial AAP presentation, which should facilitate better medication adherence and asthma outcomes in these children.

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Asthma is the most prevalent chronic illness in youth [1], and although there are no known methods to prevent or cure it, the symptoms can be managed effectively through medications and avoidance of triggers [2]. The treatment regimen can be complex, including multiple medications administered at various times throughout the day [2]. Due in part to regimen complexity, more than half of youth are non-adherent to their treatments [3], resulting in uncontrolled symptoms, significant school absences [4], hospitalizations, and even death [5].

Rural families of children with asthma can be particularly disadvantaged for a number of reasons. First, although asthma is often associated with urban populations, there has been some evidence of greater asthma risk in children of low socioeconomic status (SES) living in rural areas in the United States [6,7]. Second, families living in rural areas can have a more difficult time accessing crucial healthcare [7]. Specifically, only 9% of U.S. physicians practice in rural areas that are home to 21% of the U.S. population [7], resulting in greater demand than

supply. Additionally, 25% of children in rural areas live below the poverty line, compared to only 21% of non-rural families [1]. Barriers to adequate healthcare are exacerbated by poverty, making it more difficult for some families to travel longer distances to receive care outside of their rural communities. These health care access issues may result in less desirable asthma outcomes for rural children as research has shown that greater distances to receiving care is associated with poorer health outcomes and increased mortality and morbidity [7]. Other studies have found similar findings of economic inequalities, supply disparities, and discrepancies in health outcomes and rates of mortality and morbidity among rural patients, including those with asthma (e.g., [7–10]).

Because of the problems associated with not following the prescribed treatment regimens, efforts have been made within the scientific and clinical communities to improve adherence. Most of these efforts have focused on behavioral and/or educational interventions that directly target the patient [8], without focusing on

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provider behavior or the treatment regimen. Unfortunately, the most recent review of these interventions indicated that half were unsuccessful in changing adherence behaviors [8]. Those studies in which positive change was noted were methodologically flawed, primarily due to the use of patient self-report as the sole measurement method for both adherence and treatment outcomes [8]. Studies involving young people with asthma and their caregivers have demonstrated the benefits to psychosocial and asthma-related outcomes associated with provider behavior, particularly communication style (e.g., [12]). Therefore, studies examining and influencing provider, patient, and family behaviors are ideal in improving support for asthma self-management.

Despite the limited efficacy of behavioral interventions and education programs, one method that has been found to improve adherence in children is the routine use of asthma action plans (AAPs), which are written treatment plans that include specific, individualized instructions to help patients keep track of both daily and emergency asthma care [9]. The use of AAPs has been associated with more symptom-free days and nights, fewer emergency room visits, and fewer school absences [10]. Unfortunately, a major limitation of most AAPs is that they are typically written at a 7th–9th grade reading level [11], rendering them difficult to use, or even useless, for a large percentage of families. In fact, a recent survey found that 35% of adults (aged 16–65) in the United States had limited or poor literacy levels (below a 5th-grade reading level) [12]. Additionally, children of parents with low literacy have a high chance (72%) of being at the lowest level of reading ability [13]. This problem is exacerbated by the fact that families at risk for low literacy are the same families at a higher risk for asthma, particularly in rural regions [4]. Moreover, low literacy skills not only impede the utility of written AAPs, but also impact whether physicians offer them to patients in the first place [14].

The utility of AAPs may also be limited to families with high reading literacy skills. General literacy is only a small component of health literacy, which refers to an individual's ability to comprehend basic health information in order to make proper health decisions and act on instructions given by providers [15]. For instance, someone with high general literacy may be able to read the words on an AAP, but may not understand medical terminology or may not feel confident enough to apply the written information to health behaviors [14]. In addition, even if patients or families have excellent health literacy levels, a text-laden AAP likely is less practical as a reference in day-to-day asthma management, particularly in the potentially stressful circumstance of an asthma exacerbation. Consequently, a streamlined and simpler AAP

would seem to be a more beneficial alternative for asthma self-management.

One method for simplifying patients' education is the use of pictures to reinforce written instructions. In fact, using pictures has been effective in improving patients' attention to and recall of written health information [16]. The use of pictures is also more appropriate for low-literacy families than fully text-based treatment instructions. Consequently, it is proposed that a picture-based AAP could serve as a useful and effective alternative to the standard written AAP. To support this idea, two key phases to testing a new pictorial AAP are required: development of pictorial AAP via key stakeholder (patient, parent, and physician) input, and testing the effectiveness of this approach versus a standard written AAP in terms of asthma-related outcomes and family satisfaction. This current study is focused on the initial phase of determining what physicians consider essential information for inclusion in a proposed pictorial AAP and determining the content and format that would make this information the most usable and acceptable for patients and their families. The findings of this study will guide the development of a software program through which physicians can quickly generate a personalized pictorial AAP; the efficacy of this pictorial AAP approach will be tested in future research.

Methods

The West Virginia University Institutional Review Board approved this study. We designed and conducted a series of focus groups with caregivers and patients from two clinic settings in State, as well as with physicians from four clinic settings across the United States. Caregivers and patients were recruited from pediatric pulmonology clinics, including outreach clinics, providing care to rural families. Focus group physicians were recruited through professional networking. They varied in their professional expertise (i.e., general pediatrics, pediatric pulmonology, and pediatric allergy/immunology), but all had substantial experience in providing care to rural pediatric patients with asthma. The main objective of the focus groups was to understand caregiver, patient, and healthcare provider perspectives and preferences regarding AAPs and pictures to use in a new pictorial-based action plan, subsequently contributing to the iterative development of Pictorial Asthma Action Plan (PAAP) prototypes. Focus groups were conducted over a 6-month period with caregivers and patients participating in four in-person focus groups, and physicians participating in three web-based focus groups. Focus groups were audio recorded, transcribed, and analyzed, by coding transcripts according to themes and preferences using *ATLAS.ti* software.

Sample and recruitment

Clinic staff reviewed the patient database in pediatric asthma and allergy clinics at West Virginia University Health Sciences Center to identify those patients meeting the following inclusion criteria: (a) aged 10–17, with a diagnosis code for asthma; (b) prescribed a daily controller asthma medication; (c) English speaking; and (d) having a parent or guardian who spoke English. Staff mailed recruitment letters to the caregivers of eligible patients to invite families to participate in the focus groups. More than 200 letters were sent out, requesting caregivers to call the project coordinator to complete a screening questionnaire to assess eligibility for the study and to gather contact information. A total of 27 patient/caregiver dyads were screened for focus groups; four were ineligible based on the patient no longer using a daily controller medicine and eight did not make follow up contact to arrange involvement in a focus group.

Fourteen patient/caregiver dyads completed all four focus groups ($n = 28$); fifteen dyads were scheduled, but one dyad did not show for the first focus group. Each participant received \$75 for each of the three focus groups; those who attended the fourth focus group were given an additional \$50. Four physicians, from three different states (i.e., OH, NV, and WV), participated in a series of web-based focus groups. Similar questions were asked across patient, caregiver, and physician focus groups to enhance consistency in elicited information. Physicians were paid a modest consulting fee for their time and input.

Focus group guide and analysis

Focus group sessions lasted approximately 20–45 min each. A semi-structured discussion guide was used; however, follow-up questions not included in the guide were asked to clarify or elaborate upon information discussed at each focus group. Table 1 displays an overview of

Table 1. Overview of focus groups aims and topics for caregivers, youth, and providers.

Focus group	Session aim	Topics
Round 1	To discuss opinions and preferences of participants related to the content and appearance of a pictorial AAP.	1. What information should be included in an AAP? 2. What kind of pictures would you like to see in an AAP? 3. How should the AAP be laid out?
Round 2	Participants were presented with flipbooks containing images (*) selected based on discussion in focus group 1. The aim was to select images for pictorial AAPs that accurately reflected the intended messages of AAPs and fit participant's preferences. Sample AAPs were produced after this round.	Look at each picture [in the flipbook]. For each picture, write what you think it means when thinking about 1. How your child's/patient's body feels 2. How your child's/patient's asthma care should be done Completion of flipbooks was followed by general discussion of the content and lay out of pictorial AAPs.
Round 3	To present sample pictorial AAPs to participants to get feedback on content, layout and comprehension to guide decision-making.	Feedback questions: 1. How clear is this AAP? 2. How well do you understand this AAP? 3. What do you like? 4. What do you not like? Comprehension questions related to 4 sample AAPs: 1. When is [name of child in sample ZZP] in the Green Zone? 2. What is [child's name] treatment plan in the Green Zone? What should they do? 3. When is [child's name] in the Yellow Zone? 4. What is [child's name] treatment plan in the Yellow Zone? What should they do? 5. When is [child's name] in the Red Zone? 6. What is [child's name] treatment plan in the Red Zone? What should they do?
Round 4	To present sample pictorial AAPs to participants, revised based on feedback in focus group 3 for final review of content, layout and comprehension.	Feedback questions: 1. How clear is this AAP? 2. How well do you understand this AAP? 3. What do you like? 4. What do you not like? Comprehension questions related to 4 sample AAPs: 1. When is [name of child in sample ZZP] in the Green Zone? 2. What is [child's name] treatment plan in the Green Zone? What should they do? 3. When is [child's name] in the Yellow Zone? 4. What is [child's name] treatment plan in the Yellow Zone? What should they do? 5. When is [child's name] in the Red Zone? 6. What is [child's name] treatment plan in the Red Zone? What should they do?

*Pictures or images related to the following categories: emotions, times of day/night, symptoms, medications, service providers, and actions.

focus group aims and topics for caregivers, youth, and providers, along with some example questions. In the first round of focus groups, patients, caregivers, and physicians were asked questions to identify what information they want to see in an asthma action plan, how they want pictures to look, and what the layout of the asthma action plan should be. Based on this information, flipbooks of pictures were developed and used to guide the second round of focus groups. One flipbook asked participants to provide definitions for pictures within the context of asthma care, while another flipbook asked participants to rank groupings of pictures based on which picture they liked best. The completed flipbooks, along with information discussed during the focus groups, was then used to develop four sample pictorial AAPs, which were used in the third round of focus groups. Participants were given the samples and asked questions about clarity, comprehension, and what they liked/disliked about the AAPs. Changes were made to two of the sample AAPs based on participant feedback and then shown to participants during the fourth focus group. The fourth focus group involved the same set of questions from the third focus group to verify that participant feedback had been adequately integrated into the sample pictorial AAPs. No further focus groups were required as it was determined that the aim of developing understandable and appealing pictorial AAPs had been reached.

Focus group recordings were transcribed by a third party and de-identified by a member of the research team. The data were analyzed using a coding approach that involved highlighting units of meaning in each transcript, related to the preferences described by participants in this study. Both inductive and deductive coding methods were utilized to develop the codebook [17]. Initial codes were created based on the questions included in the semi-structured interview guide using a deductive process [18]. During coding, additional codes were devised and discussed by the research team to determine if they should be added to the codebook using an inductive process. Two members of the research team reviewed and independently coded two of the transcripts and compared results to establish initial reliability and refine any unclear codes or definitions. Any disagreements were discussed with the lead researcher (first author) to reach consensus. All transcripts were then coded by the primary coder; a subset of transcripts (22%) was cross-coded by two trained and supervised undergraduate research assistants for reliability with a kappa of 0.83.

Results

There were five overarching themes that emerged from the series of focus groups with physicians, caregivers, and

patients: (1) a stoplight format in landscape orientation is easily understood; (2) AAPs tailored to the individual patient will be especially useful; (3) incorporating some words and phrases will further clarify what pictures are conveying; (4) physicians want emphasis placed on the green zone; and (5) patients prefer and understand simple cartoon-style pictures.

AAP format/structure

Physicians, caregivers, and patients all said they liked the stoplight format already in use with written AAPs because it is a concept that is (for the most part) universally understood.

Physician: ...the one thing that the green, yellow, red does is that it does follow the health literacy principle where you tied something to something that people are familiar with in everyday life so that whole green, yellow, red stoplight is so familiar to people that I think it's an easy concept that they can tie the severity of their symptoms to.

When asked about whether the AAP should have a landscape or portrait orientation, most caregivers thought a landscape orientation made sense because English is read from left to right; therefore, having the AAP in the same orientation would make it easier to look at and comprehend. Some also liked the landscape orientation because it was what they were used to seeing with current written AAPs.

Caregiver: I guess because you read left you right, I just...thought the horizontal was much easier than vertical.

Individualized AAPs

Caregivers and physicians both agreed that AAPs tailored to their specific child/patient would be most useful. Written AAPs may contain information that is not relevant to a child, and caregivers find it frustrating to have to read through all of this information to find what applies specifically to their child.

Caregiver: If they did it on the computer, they could just pull them and print them. Like they say, we are all different. The kids are different, their asthma is different. No one's [plan] is the same.

Patients also said they want to see AAPs that show images of children that look like them because it will make the AAP feel more relevant to them and their asthma experience. Physicians thought customizing the AAPs would make it more likely that the caregivers and patients would actually use the AAPs, especially if the physician discussed the AAP with the caregiver and patient before

they left clinic (i.e., including the AAP in their treatment plan discussion with the family).

Physician: The other comment I had on the pictures is that ...you have a child's name there and some are clearly boys, some are girls. I just wondered if the pictures should all be the same sex, so you have the boys and girls kind of personalize it and make it relevant.

Words/phrases to accompany pictures

After being shown sample AAPs in the third round of focus groups, which were created based on feedback taken from the first and second focus groups, caregivers expressly stated that simple words and short phrases were needed to supplement what some of the pictures were conveying. They thought including simple words and phrases would help them and their children understand exactly what should be done in each zone. Caregivers also said this would help newly diagnosed children and their caregivers understand the AAP because they would have very little or no background information on asthma treatment.

Caregiver: Add the word "puffs" underneath it [inhaler picture]. Yeah, that way it gives it ...because if you look at that and you know if you're not paying attention, you see times two every four hours you're thinking, "Okay, two or three?"

Green zone emphasis

Physicians voiced that it was important to highlight the green zone given that following the directions in this zone will reduce the chance a patient will experience an asthma exacerbation. Moreover, during clinic visits, physicians usually stress with caregivers and patients the importance of following the green zone in their treatment plan discussions.

Physician: They always remember to take their rescue medicine, but they never remember to take their maintenance [medication], so for the green zone I think the picture needs to emphasize the maintenance part of it.

Caregivers said the green zone needed to be very clear because older children are often solely responsible for taking their daily medications. Having pictures to show them how and when to take their green zone medications will help youth stay adherent to their medication regimen. An emphasis was also placed on pictures showing how and when to take medications before sports or other physical activity given that the majority of patients participating in the focus groups were involved in at least one sport.

Caregiver 1: Our doctor never specified. He just said, "Do it before sports." That's really a good one [pointing to

a picture of a child playing sports next to picture of an inhaler].

Caregiver 2: Ours [physician] told us if he's going to play any sports, give it to him 30 minutes prior, that way it takes the medicine ...it can be in his system so by the time he starts his game, he's well-oxygenated.

Simple cartoon-like pictures

Patients and caregivers both said the pictures used in the AAPs should be simple, without too much extraneous detail, to make them easy to understand. The pictures should let patients know what they should be doing if they are in a particular zone.

Patient: Like the pictures, if you're in the red zone. The pictures would help, so you wouldn't have to read every single thing. You just have to look at the pictures, and it will tell you what to do.

Patients also said they wanted to see cartoon-like pictures because that draws their attention. At the beginning of each zone, a face (similar to the faces used in a pain scale) or symptom-based picture (e.g., a picture of a child coughing for the yellow zone) was used to describe how the patient might be feeling in each zone. Caregivers brought up that having both the face and symptom-based picture at the beginning of each zone would be helpful because the patients would relate to the face picture and the caregivers could use the symptom-based picture to determine which zone their child was in.

Caregiver 1: And I like the faces and the kids.

Caregiver 2: I did too. I like the two pictures [symptom-based and face picture] better than just the faces.

Prototype development

Results from the first two focus group meetings were used to draft prototypes of sample Pictorial AAPs. These prototypes were then shared with and reviewed by stakeholders during the latter two focus group meetings to refine their content. See Figure 1 for one of the prototypes resulting from this process. These prototypes are serving as the basis for software development.

Discussion

Using a health literacy approach, this study aimed to address issues of accessibility to care and appropriate education that are currently acting as barriers to optimal asthma management and outcomes. Specifically, we engaged with stakeholders, including youth with asthma, their caregivers, and physicians treating pediatric asthma patients, to develop prototypes of a novel asthma education tool – picture-based AAPs. Creating



Figure 1. Prototype sample for a pictorial asthma action plan.

clear and simplified PAAPs is intended to target the accessibility and utility issues associated with traditional, text-laden, written AAPs. The findings of this study indicate that a PAAP would be acceptable to youth with asthma, their caregivers, and physicians. Strong and sometimes differing preferences emerged between youth and caregivers, and physicians in relation to the content and structure of PAAPs. For example, while youth and caregivers frequently described the importance of having practical information included in the PAAPs, providers often focused on the importance of motivating the use of daily controller medication through PAAPs. In all, stakeholders preferred simple, appealing, and personalized images, with small amounts of key text, to replace the large amounts of text usually included in written AAPs.

Multiple barriers exist to accessing asthma care and education among youth and families, particularly those from rural backgrounds, including the potential for SES-related barriers and low access to specialist services [6]. Previous research highlights challenges to understanding and remembering complex self-management instructions. For example, previous studies in a rural population suggested that parents and children tend to focus on the rescue plan recommendations in AAPs, and then do not recollect verbal or written physician recommendations regarding the maintenance plan [19]. PAAPs have the potential to foster better physician–patient communication during consultations by summarizing each patient’s

customized AAP in a form that facilitates understanding, even for children. Although previous research has focused on patient and family behavior to better understand non-adherence and health outcomes [8], a relative lack of research exists in relation to understanding and changing service provider behavior (e.g., [12]). Studies have shown that physician practices, including asking young people more asthma-related questions during consultations, demonstrating the use of medication devices, and asking young people to repeat the demonstration, were associated with better self-efficacy among young people and greater self-management skills [20–22]. However, implementation of service-based changes is a consistent barrier to service providers’ ability to change the way in which they engage with patients and caregivers, and barriers such as short consultations, long waiting times, and low continuity of care are frequently reported [23,24].

Integration of PAAPs into routine pediatric asthma care has the potential to produce change in patient, caregiver, and service provider behavior, by facilitating improved communication to both caregivers and patients in relation to what asthma is, optimal treatment, barriers to treatment, and customized treatment plans. Youth and families with enhanced knowledge and understanding of asthma management may be more likely to engage in daily self-management, and reducing the need to access health services, which may not be readily accessible for rural dwelling families. Consequently, the provision of education using a customized PAAP may result in less need for

emergency follow-up, contributing further to clinic efficiency and reductions in unnecessary health care costs.

Engaging stakeholders

The purpose of PAAPs is to make asthma treatment plans useful and manageable to youths so that they understand their asthma and are motivated to engage in daily self-management. The pictorial tool is also intended to facilitate providers discussing the plan with their patients and caregivers, due to the simplicity and accessibility of the tool as well as the tailored nature of each PAAP. The involvement of stakeholders in this study was crucial in achieving the aim of producing an acceptable tool for improving asthma treatment. In addition to producing a tool that youth and caregivers are likely to use, consulting with stakeholders ensures the perceptions and experiences of the family and the context within which youth live with their asthma is taken into account. In previous research, agreement between caregivers and physicians has been found to play a central role in determining the wellbeing of parents of children with asthma and the quality of their child's asthma management and outcomes [25]. Therefore, family dynamics must be taken into account when planning a patient's treatment plan, and in the design of educational tools and techniques. The current study integrated stakeholder input into the design of PAAP prototypes, creating a tool that would facilitate ongoing stakeholder involvement and engagement with asthma management.

The use of concrete examples and recognizable, everyday symbols and cues has been recommended as part of effective health communication tools [26]. Preferences described by participants in this study reflect these recommendations for producing accessible health information tools, e.g., the traffic light format and the use of cues, such as the inclusion of images representing the symptoms associated with each zone, and prompts for taking medication (e.g., using a rescue inhaler 15 min before exercise). NIH guidelines note that AAPs should be tailored to the needs of the patient, teaching identification of basic asthma symptoms and medications as well as self-management skills [2]. Our study found that a qualitative, stakeholder-led approach enabled the development of a simple communication tool for low-health literacy patients that remains accessible to all users, and yet is capable of accounting for highly complex regimen information.

Limitations

Though the current study has direct relevance and implications for the medical community, children and families

managing asthma, and areas of public health, there are some limitations to be considered. First, the qualitative nature of the study prohibited the use of other analytical methods to provide additional statistical evidence to support the findings. Second, the current study focuses on rural youth within a specific geographic region and lacks significant racial and ethnic diversity, which may potentially influence the generalizability of findings in other populations (e.g., racial/ethnic minorities, urban-residing youth and families).

Implications for research and practice

The findings of this study will facilitate future research aiming to improve adherence to asthma management by youth and their caregivers and subsequent health outcomes, by delivering an accessible tool for enhancing their communication with asthma providers and subsequently their asthma care knowledge and understanding. Specifically, a software program is being developed based on the findings of the current study and the resulting prototypes (see Figure 1), to enable providers to produce PAAPs that can be tailored to each young patient. This program will be tested in a randomized controlled trial (RCT). The primary aim of this planned RCT is to assess the acceptability, feasibility, and effectiveness of PAAPs in improving asthma self-management and key outcomes relative to standard care or written AAPs. Using PAAPs within routine pediatric asthma care may improve asthma education and subsequent daily asthma self-management and outcomes by facilitating better communication [27], personalizing treatment [28,29], improving knowledge and skills, and addressing misperceptions related to asthma and treatment [30]; however, these assumptions first need to be tested in this future RCT. The findings of the future study will inform improvements and adaptations to the PAAP software, including the possibility of producing a mobile application or online version.

The findings of the current and future research could also have significant implications for practice. The PAAP prototypes produced by stakeholders in this study may enable young people with asthma and their caregivers to overcome barriers to accessing and utilizing asthma education. This tool may also encourage service providers to prescribe AAPs more frequently and to engage in collaborative discussion related to asthma and asthma management with patients and caregivers. Moreover, during focus group sessions, caregivers repeatedly discussed the challenges they face having a child with asthma in school. Future research, particularly school-based intervention research, is necessary to address the needs of youth in school settings. Research should address the concerns of parents, as well as teachers in relation to supporting youth

to engage fully with school activities and asthma management. A PAAP may be an effective way to communicate with school nurses regarding a student's prescribed treatment and physical education needs.

Conclusion

Despite high rates of asthma and of non-adherence to the treatment regimen, AAPs are under-utilized by providers and people with asthma. In this study, youth and caregivers emphasized the need for practical information, while providers strongly emphasized the importance of motivating the use of daily controller medication through PAAPs. PAAPs were received positively by participants in this study and may be an effective strategy for engaging youth and their families in asthma education and management. The stakeholder-led approach used in this study will enhance the likelihood that future intervention research will be acceptable, feasible, and effective in improving asthma-related outcomes including knowledge and symptom control. The findings of this study will inform the development of a software program for rapid generation of tailored PAAPs suitable for routine use in asthma clinics, which will be tested in a future study.

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Declaration of interest

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

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