

## **TITLE PAGE**

**Title:** Pediatric Patient Engagement as a Criteria for Meaningful Use Stage 3 (1R18HS022689)

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## **ABSTRACT (250 word maximum)**

**Purpose:** To inform Meaningful Use (MU) Stage 3, we evaluated the feasibility in primary care of using a patient portal for pediatric asthma, its impact on management, and barriers and facilitators of use.

**Scope:** The federal government allocated >\$27 billion to fund a staged program to foster the meaningful use of EHRs. Stage 3 prioritized submission of patient-generated health information, yet data are lacking on how best to achieve this goal in pediatric primary care settings.

**Methods:** We conducted a mixed-methods implementation study in 20 practices (11 states). Using the portal, parents of children with asthma aged 6-12 years completed monthly surveys to communicate treatment concerns and goals and report symptom control, medication use, and side effects. We evaluated child characteristics associated with portal adoption and changes to asthma management associated with portal use. Clinician focus groups and parent interviews explored barriers and facilitators of use.

**Results:** We invited 9,133 families to enroll and 237 (2.6%) used the portal (practice range: 0.6-13.6%). Children of parents/guardians who used the portal were significantly more likely to be younger, have persistent asthma, and to be prescribed a controller medication, and less likely to have public insurance. Portal users with uncontrolled asthma had significantly more medication changes and primary care asthma visits after using the portal relative to the year prior. Qualitative results revealed the importance of practice organization (asthma coordinators, workflows), family (asthma severity) and innovation (ease of use) characteristics to implementation success.

**Key Words:** Asthma; Patient Portal; Electronic Health Records

## **PURPOSE**

The objective of this study was to inform the policy objectives of Stage 3 of the Meaningful Use Program. This study evaluated the implementation of an electronic health record (EHR)-linked patient portal to support collection of patient-reported data from families of children with asthma.

The aims of the study included:

- 1) To study the feasibility for pediatric primary care practices of using an EHR-linked portal to provide education and enable families to communicate treatment concerns and goals and report symptom control, medication use and side effects for children with asthma;
- 2) For a subset of children with poorly controlled asthma or medication side effects, to assess the impact on asthma management resulting from gathering data from families through the portal and sharing them with the primary care clinical team;
- 3) To describe barriers and solutions to improve the adoption, sustainability, and impact on clinical care of implementing portals across practice settings.

## **SCOPE**

The federal government allocated >\$27 billion to fund the federal Meaningful Use program, which aims to improve health through promoting the adoption and use of electronic health records (EHRs). The Office of the National Coordinator for Health Information Technology established criteria for implementing meaningful use of health information technology, including EHRs, in three prioritized states. Stage 3 MU objectives include supporting novel models of care that are team-based, outcomes oriented, address national health priorities, have broad applicability, and are achievable, reasonable, and feasible given the capabilities of existing products and organizational systems.<sup>1</sup> In particular, MU3 prioritized that patients and families have the ability to submit patient-generated health information to improve health care performance on priority conditions and improve engagement in care. However, data are lacking on how best to achieve these goals in pediatric primary care settings.

Patient portals, online healthcare applications that enable patients to communicate and interact with their healthcare providers outside the office,<sup>2</sup> offer a promising approach to achieve the goals of MU3. However, while patient portal use has increased in recent years,<sup>3</sup> portal adoption has not been rapid,<sup>4</sup> and overall rates of sustained portal use remain low.<sup>5</sup> Research suggests that several important barriers at the practice and patient level need to be overcome for MU3 patient engagement incentives to be effective. Practice-level barriers that prevent portal adoption include leadership concerns, marketing difficulties, and lack of staff engagement.<sup>6</sup> At the patient level, prior research (primarily among adults) found that patients with a greater disease burden were more likely to use a portal than others.<sup>7, 8</sup> In addition, white patients have been more likely to use portals than patients of other races/ethnicities,<sup>5, 8-10</sup> suggesting that improvements to current portals and enrollment strategies may be needed to effectively engage patients of minority racial/ethnic groups.

Pediatric asthma, an AHRQ priority condition, is an ideal condition in which to evaluate the potential for patient portals to effect patient care through collection of patient-reported information. Asthma is the most common pediatric illness in the United States, affecting over 7

million children.<sup>11</sup> Negative outcomes of asthma include lower quality of life,<sup>12, 13</sup> missed days of school for children and work for parents,<sup>13-15</sup> higher rates of emergency department visits and hospitalization,<sup>16</sup> and death.<sup>17</sup> Portals may be particularly effective at facilitating communication and shared decision making between families and the primary care practice due to the high level of variability in attendance at pediatric primary care follow-up office visits,<sup>18, 19</sup> and the time constraints of office visits which limit time available for clinicians to address families' concerns and goals related to asthma treatment. However, the feasibility of using portals to collect patient-generated health information and the impact on clinical care in pediatric primary care has not been established.

### *Setting*

This study took place within two practice-based research networks: the Pediatric Research Consortium (PeRC) of The Children's Hospital of Philadelphia (CHOP) and electronic Pediatric Research in Office Settings (ePROS) of the American Academy of Pediatrics (AAP). PeRC is a two-state (Pennsylvania and New Jersey), hospital owned primary care practice-based research network including 31 primary care practices serving more than 200,000 children<sup>20</sup> and PROS includes 728 practices and 1,831 clinicians across the United States and Canada. In this study, a convenience sample of 20 practices (9 PROS practices and 11 PeRC practices) were enrolled. Practices were eligible to participate if they met MU3 criteria ( $\geq 20\%$  of children insured by Medicaid or the Children's Health Insurance Program (CHIP)).

### *Study Population*

Eligible study participants included English-speaking parents/guardians of children aged 6-12 years who received treatment at a participating primary care practice in PeRC or PROS, who had had an office visit during the past 12 months and had an asthma diagnosis at the time of recruitment.

## **METHODS**

### *Study Design*

This study was a single-group intervention trial.

### *Recruitment*

Study practices were contacted by investigators, invited to participate, and received an in-person or remote presentation of study procedures. Once practices were enrolled, eligible children were identified using rosters generated from the EHR. Because of technical differences in the portals used in PeRC and PROS, different recruitment strategies were used in each setting. In PeRC, the study team mailed up to two letters to all eligible families, inviting them to call the study team to enroll. Parents provided verbal consent by phone and members of the study team signed them up for the portal. In PROS, families were mailed letters with a link to the portal website where families could enroll and provide consent. In both networks, telephone recruitment was used for a random sample of 50 families at each practice who did not respond to the letters. These phone calls were made by the study team in PeRC and by the primary care practice clinicians and staff in PROS. In addition, informational cards and posters were on display in participating practices throughout the study period.

### *The MyAsthma Portal*

The MyAsthma portal was designed to facilitate shared decision making in asthma. The portal was developed and pilot-tested at CHOP<sup>21, 22</sup>. MyAsthma includes the following functions: 1) provision of education material to families, 2) sharing of families' treatment concerns and goals, asthma symptoms, medication adherence, and side effects with the primary care practice, 3) tracking asthma control over time in a shared interface available to families through the portal and clinicians through the EHR, and 4) decision support provided to both families and clinicians regarding asthma control and side effects based on the results of a monthly survey. At CHOP, MyAsthma is embedded within an existing patient portal (MyChart, Epic, Verona, WI) already implemented by the CHOP care network. In PROS, MyAsthma was available to families as website provided through the Integrated Health Connect System, developed by the University of Colorado. Families interacted with the portal through a web interface, and decision support was provided on screen to families and via fax to the primary care providers.

### *Outcomes*

The primary outcomes included adoption (completion of at least one portal survey during the study period) and sustained use (completion of at least two surveys) of MyAsthma and were informed by an evidence-based conceptual model of factors influencing implementation success (Figure 2).<sup>22</sup> We assessed additional outcomes (having an asthma office visit or an asthma medication refill/change within 30 days of survey completion) in a subgroup analysis among children who had uncontrolled asthma during their first survey completion. These data were extracted from each child's EHR. In addition, parents and guardians reported whether they were more or less likely to 1) speak to their child's doctor, 2) make a change to their child's medication dosage, or 3) make a change to their home environment after using the portal using a 5-point Likert scale.

### *Covariates*

The following patient-level covariates were extracted from the EHR: patient age, sex, race/ethnicity, and asthma controller medication use at the study start (including inhaled steroids, montelukast, combination inhaled steroid/long-acting  $\beta$ -agonists, and oral steroids). In PeRC only, asthma severity (mild intermittent, mild persistent, moderate/severe persistent) and insurance status (private versus public) were also extracted. Parent-level covariates were collected via survey from enrolled participants and included age, race/ethnicity, educational attainment, employment status, and relationship to the child. Practice level covariates included urbanicity (rural, suburban, or urban based on practice self-report) and U.S. census region (Northeast, South, Midwest, West).

### *Statistical Analysis*

The study population was described using proportions, means, and standard deviations. Chi-squared and t-tests were used to compare characteristics of children whose parent/guardian completed the portal survey were compared to those of children whose parent/guardian did not. Fisher's exact tests were used for categorical data with sparse cell counts, and Mann Whitney U tests were used as a non-parametric test for skewed continuous variables. In addition, characteristics of children with sustained use were compared to those of children whose parent/guardian only completed the portal survey once. Multivariable logistic regression

modeled the association of patient covariates and practice site with portal adoption in order to identify factors independently associated with adoption. The proportion of families completing the portal was compared between those who enrolled in after receiving a mailed letter and those who enrolled after receiving a telephone call.

To evaluate the impact of portal use on asthma care, in a subgroup of patients with uncontrolled asthma, we described the proportion of children with an asthma office visit or medication refill/change within 30 days of survey completion. We then compared these results to the same 1-month period a year prior for each child in order to assess if rates of office visits and medication adjustments changed from baseline. 95% confidence intervals were constructed around the change in proportions between years using logistic regression with the margins command in Stata. Parent responses to the survey regarding their likelihood of taking actions based on the portal and changes in asthma management resulting from portal use were described.

All analyses were completed using Stata version 13.1 (StataCorp, College Station, Texas). The Institutional Review Boards at the American Academy of Pediatrics and The Children's Hospital of Philadelphia approved this study. In this study, all parents provided informed consent and child assent was waived.

### *Qualitative Study*

In order to evaluate implementation success and identify barriers to and facilitators of portal adoption, we conducted 22 qualitative interviews with parents (14 enrolled in the study, 8 unenrolled) and 10 focus groups with 46 clinicians. All interviews were transcribed and coded using NVivo10 (QSR, Cambridge, MA) and interpreted in the context of our conceptual framework.<sup>24</sup> Any coding differences were resolved by team consensus.

### *Limitations*

Although this study enrolled primary care practices from 11 states and practices varied greatly in adoption, slightly more than half were from a single health system, which may limit generalizability. In addition, the portal was implemented in the context of a research study. As a result, findings may not completely reflect the results that would be observed if practices implemented a portal themselves. Third, the follow-up period was relatively short, limiting our ability to assess sustained portal use over a longer timeframe. Finally, this study focused on a single condition; however, asthma is the most prevalence pediatric chronic disease and is a condition for which clinical trial evidence supports improved outcomes associated with portal use.<sup>21</sup>

## **RESULTS**

### *Adoption and Sustained Use*

Only a small proportion of families invited to participate used the portal. 237 (2.6%) out of 9,133 eligible participants completed the portal survey at least once (adoption), and 156 (66% of portal adopters) completed the survey more than once (sustained use). Adoption and sustained use varied widely across practices from 0.6 to 13.6% and from 0.0 to 13.6%, respectively.

In multivariable logistic regression, several factors were independently associated with portal adoption. Receipt of a controller medication at baseline and greater asthma severity were

positively associated with portal adoption, and older child age and public insurance were negatively associated with adoption.

### *Recruitment*

Participant reported how they learned about the portal. Overall, 208 out of 237 received a letter, 17 received a phone call, 35 heard about it from their child's doctor, nurse practitioner, or nurse, and 3 from an informational card at the practice.

### *Effect of Portal Use on Asthma Management*

Parents of children with uncontrolled asthma commonly planned changes in management following portal use. After completing the first survey, 16% reported an intention to change their child's asthma medication, 27% to contact their child's doctor and 20% to make a change to their child's environment, with more than one third (27 parents, 36%) reporting an intention to take at least one action. On follow-up surveys, 22% reported a medication change, 41% reported contacting their child's doctor, and 16% reported making a change to their child's environment.

### *Qualitative Results*

Qualitative results revealed the importance of practice organization, family and innovation characteristics to portal adoption. Few health system factors were discussed. For practices/clinicians, three themes emerged: the need for well-defined workflows, the importance of practice responsiveness to portal surveys, and challenges related to using the EHR to identify children with asthma, which resulted in the recruitment of children without active asthma. In terms of workflow, portal implementation was facilitated at practices with a care coordinator. A perceived need for more training diminished enthusiasm at some sites. Echoing enrollment results, parents of children with well-controlled asthma were less likely to use the portal, and to find less utility in MyAsthma if they did enroll. At the innovation level, features of MyAsthma that families and clinicians valued included facilitation of communication, increasing families' awareness of and responsiveness to uncontrolled asthma, and ease of portal use.

### *Discussion*

We conducted a mixed methods, multisite implementation study involving practices from 11 states in order to assess the feasibility for pediatric primary care practices of using a portal to facilitate communication between clinicians and families regarding asthma treatment, to assess the impact of portal use on asthma care for children with poorly controlled asthma, and to assess barriers and facilitators of portal adoption and sustained use. Overall, we found low rates of portal adoption and sustained use that varied across study practices. However, for children with uncontrolled asthma, parent use of the portal was associated with changes to asthma management. Qualitative methods underscored the importance of coordinated practice workflows and responsiveness to portal surveys to implementation success. Parents, especially those with children with uncontrolled asthma, were motivated to continue using the portal since it facilitated a better understanding and tracking of asthma control.

Researchers and health systems have described low rates of portal adoption in other pediatric settings.<sup>23, 24</sup> Although prior studies found that patients with chronic diseases were more likely to register for or use a portal than others,<sup>25, 26</sup> the adoption rate in our population of children with asthma was quite low. Our qualitative results revealed that the low participation rate resulted at least in part from the inclusion of children with well-controlled asthma. These



results are consistent with studies in diabetes that found that patients who believed their disease was well controlled felt that entering information over time was unnecessary<sup>27</sup> and were less likely to enroll.<sup>28</sup>

Adoption may also have been limited by practices' infrastructure and workflow for managing electronic receipt of patient-reported information. In our qualitative study, both clinicians and families highlighted the importance of coordinated and responsive workflows to implementation success. Workflow issues have been described previously as a challenge to portal implementation.<sup>6, 27, 29</sup> For example, prior research in family medicine practices found that workflow resulted in rates of portal use exceeding 25% of patients.<sup>26</sup>

Concern remains whether the MU program, by fostering adoption of EHRs and related tools, can improve care and outcomes.<sup>30</sup> Although adoption of the portal was low, portal use was associated with increased family and practice engagement in asthma management. These results are consistent with our prior pilot trial of MyAsthma, in which clinical outcomes including frequency of asthma flares and days of work missed by parents improved significantly among families who used the portal.<sup>21</sup> Our qualitative interview results suggest that portal use may support disease management by improving patient-provider communication.<sup>33-36</sup> Collectively, the results of this study suggest that the Federal Meaningful Use Program should set modest targets for the use of portals to support chronic disease management in pediatrics and that achieving these goals likely depends upon existing practice infrastructure focused on disease management.

### *Conclusions*

Results suggest that achieving high-levels of portal adoption will likely require improved care coordination, redesigned workflows, and targeted outreach to families of children with poor control. In early implementation years, MU3 policies should maintain low or no enrollment thresholds for pediatricians to receive incentives for portal use.

### **LIST OF PUBLICATIONS AND PRODUCTS:**

Miller D, Noonan K, Fiks AG, et al. Increasing pediatrician participation in EHR incentive programs. *Pediatrics* 2015 Jan;135(1):31-4. PMID: 25548326.

Fiks AG, duRivage N, Mayne SL, Finch S, Ross M, Giacomini K, Suh A, McCarn B, Brandt E, Karavite D, Staton E, Shone L, McGoldrick V, Noonan K, Miller D, Lehmann C, Pace W, Grundmeier RW, "Adoption of a Portal for Managing Pediatric Asthma: Implications for Meaningful Use," Submission to *Pediatrics* expected 12/15.

duRivage N, Ross M, Mayne SL, Suh A, Weng D, Grundmeier RW, Fiks AG, "Asthma Control Test: Validity of Parent Proxy Reporting for Children 6 to 12 Years," Submission to the *Journal of Asthma* expected 12/15.

Invited Lectures:

- Oct, 2015 "Pediatric Patient Engagement in Meaningful Use Stage 3," Agency for Healthcare Research and Quality National Research Meeting, Washington, DC.
- Jan, 2015 "Spurring Adoption of Patient Portals to Collect Patient-Reported Outcomes: Lessons Learned," Agency for Healthcare Research & Quality: Practical Insights on Meeting Objectives of Meaningful Use III, National Webinar.

Abstracts:

Fiks AG: "Spurring adoption of a patient portal to foster family and clinician engagement in managing asthma" North American Primary Care Research Group Practice-Based Research Network Annual Meeting June 2015.

A Fiks, N duRivage, S Finch, K Giacomini, M Ross, B McCarn, C Lehmann, R Grundmeier: "Determinants and Outcomes of Provider and Family Participation in a Multi-State Asthma Portal Implementation" Poster Presentation at the 2015 Pediatric Academic Societies Annual Meeting, San Diego, California. April 2015.

**PROGRESS RELATED TO INCLUSION OF AHRQ PRIORITY POPULATIONS**

This study focused on asthma, an AHRQ priority condition, in three AHRQ priority populations: children, low income, and special health care needs. As only practices with at least 20% of children insured by Medicaid and CHIP were enrolled, we focused on practices serving relatively large proportions of low-income families. And as the intervention focused on pediatric asthma, all families enrolled included children with special health care needs.

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