UCLA UCLA Previously Published Works

Title

Partnered decision support: Parental perspectives of completing a pre-visit pediatric asthma questionnaire via the patient portal

Permalink https://escholarship.org/uc/item/7hx078rm

Journal Pediatric Pulmonology, 57(1)

ISSN 1054-187X

Authors

Ross, Mindy K Friedman, Sarah Radparvar, Ilana <u>et al.</u>

Publication Date 2022

DOI

10.1002/ppul.25735

Peer reviewed



HHS Public Access

Author manuscript *Pediatr Pulmonol.* Author manuscript; available in PMC 2023 January 01.

Partnered Decision Support: Parental Perspectives of Completing a Pre-Visit Pediatric Asthma Questionnaire via the Patient Portal

Mindy K. Ross, MD¹, Sarah Friedman, MPH¹, Ilana Radparvar², Gery Ryan, PhD³

¹Department of Pediatrics, University of California Los Angeles, Los Angeles, CA

²University of California Los Angeles, Los Angeles, CA

³Kaiser Permanente Bernard J. Tyson School of Medicine, Pasadena, CA

Abstract

Background: Collection of patient-reported data has been demonstrated to improve asthma outcomes. One method to collect information is through the electronic patient portal. In practice, patient portal use in pediatrics and, specifically for asthma management, has had low uptake.

Objective: To understand parental/caregiver experience of pediatric asthma care management, and perceptions of the use of patient portal questionnaires before the clinic visit.

Methods: We conducted semi-structured interviews with caregivers of children 5-11 years old with asthma in the UCLA Health System. We included patient portal "users" (n=20) and "non-users" (n=5). Interview questions were developed based on clinic visit workflow with a focus on perceived usefulness and ease of use to complete pediatric asthma questionnaires in the patient portal before the visit. Interviews were audio-recorded, transcribed, and codes were generated from themes using constant comparative analysis.

Results: We identified eight themes related to caregiver-physician communication, perception of portal questionnaires, facilitators, and barriers to portal questionnaire use. A salient finding was that caregivers considered the portal questionnaire as a tool to be integrated into the visit to facilitate a conversation about their child's asthma. Caregiver portal-based questionnaire use was more likely if the ongoing data entered was accessible to caregivers to track and update, and if caregivers were reassured the clinicians would use questionnaire responses during the visit.

Conclusion: Caregivers of children with asthma are more likely to complete a patient portal intake questionnaire before the visit if they trust their responses will be used during the visit to inform care.

Keywords

Pediatric Asthma; Electronic Health Records; Patient Portal; Qualitative Analysis

Corresponding Author: Mindy K. Ross MD, 10833 Le Conte Ave, MDCC 22-387B, Los Angeles, Ca 90095; T. (310) 825-0867, F. (310) 794-7338; mross@mednet.ucla.edu.

Conflict of Interest: The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the paper.

Introduction

Self-reported data from patients about their condition and treatment, also known as patient-reported outcomes (PROs), are especially relevant for patients with chronic medical conditions¹⁻³. Several studies have demonstrated benefits of PROs for asthma management⁴⁻⁶. Asthma is an ideal condition to incorporate patient-reported information because of symptom variability and socioenvironmental factors that contribute to symptom control⁷. A clinician's comprehensive understanding of these factors is crucial to deliver optimal care⁸.

Technology can facilitate collection of this patient-reported data, ideally entered through the electronic patient portal to file directly into the patient's medical record^{9,10}. Capturing data within the electronic health record (EHR) before the visit allows the healthcare provider to integrate the patient reported information immediately into the visit and focus on the care plan rather than asking the patient or caregiver information-gathering questions during the limited encounter time. Health questionnaires completed via patient portals in pediatrics have not been studied extensively and there is concern the concept has not been widely accepted¹¹. In a multicenter study of a patient portal for pediatric asthma management, consistent use of the resource was low at $<3\%^{12}$. Usability has been recognized as a key feature for end-user adoption of clinical informatics tools and should be a driver of the implementation approach¹³⁻¹⁶.

Currently, a knowledge gap exists in our understanding of how to increase parental/caregiver (referred to as "caregiver" throughout manuscript) engagement of the portal for patiententered data entry in the domain of pediatric asthma management. To this end, we chose the consolidated framework for implementation research (CFIR), with particular focus on the individual, to guide our inquiry into this gap¹⁷. The goal of our study was to learn the current caregiver experience surrounding pediatric asthma care management and perceptions of completing questionnaires about their child's asthma through the patient portal before the clinician visit.

Methods

Participants

We conducted semi-structured interviews¹⁸ with caregivers of 5-11-year-old children with an asthma diagnosis (based on ICD code and caregiver confirmation) from November 29, 2020 to June 3, 2021. All children had UCLA Health System outpatient clinic visits within the last two years. To ensure we included caregivers with a wide range of portal experience, we interviewed portal "users" and "non-users" proportional to our portal activation rates, which increased during the COVID-19 pandemic. All clinics use a common electronic health record (EHR) vendor, Epic Systems. The patient portal is Epic Systems' "MyChart" branded as "MyUCLAhealth" for the UCLA Health System and will be referred to as the "patient portal" throughout the manuscript. At this time, the patient portal is available in English-only; therefore, our study included only those who participated in English.

Setting

The UCLA Health System in Southern California includes 27 primary care clinic sites that serve pediatric patients (18 family medicine or medicine/pediatrics, 9 pediatrics) and 8 subspecialty locations, including allergy and pulmonology. We recruited across these 35 clinics that represent a mix of payers including private (primarily PPO or UCLA network) and community-based (primarily Medicaid) insurance.

Data Collection

We first developed research questions based on our goals to understand caregiver experiences with questionnaires, as well as to understand key concepts like perceived usefulness and ease of use of the patient portal to answer asthma questionnaires. The authors developed the interview content based on the pragmatic experience of a caregiver preparing for a pediatric asthma visit through group consensus discussion; and guided by our research questions, we generated the final interview guide (See Appendix Text). For the purposes of this study, pragmatism refers to the direct connection between the study methods and the research goal of learning actionable ways to modify processes that affect caregiver experience, and to explore perceptions of an existing patient portal with design and use constraints. This is grounded in the Creswells' description of pragmatism as "truth is what works at the time" as we explored parents' interactions with their physicians, patient portal use, and visit questionnaires.¹⁹

Interviews were conducted via Zoom video/telephone service with 1-3 participants per session. Two members of the research team were present, a facilitator (S.F.) and note-taker (M.K.R.). Participants chose pseudonyms and were instructed to avoid using their child or clinician's names during the discussion to protect confidentiality. Interviews were audio-recorded and transcribed with any personal identifiers removed. Participants were consented for this UCLA IRB approved study prior to participation (IRB# 20-000347). Data sharing is not applicable to this article as no datasets were generated or analyzed during the current study.

Analysis Plan

Two team members (S.F. and I.R.) independently reviewed the transcripts with a constant comparative methods two-step analysis approach^{20,21}. First, the transcripts were reviewed to apply general themes based on the content of the interview guide. Next, the transcripts were sorted by theme and then coded independently. Coding refers to the process of further defining the broader themes in to detailed sub-themes (i.e., codes). Group consensus was used to finalize the code definition and application with differences adjudicated via discussion, and with the input of a third team member (M.K.R.) as needed. Finally, we identified themes that appeared to be the strongest drivers to increase the likelihood of caregiver use of the portal to answer portal questionnaires before the visit. We also noted questionnaire features recommended by participants to facilitate ease completing the questionnaire. Dedoose version 8.0.35, a web based application for qualitative and mixed method research data analysis, was used to manage data coding²².

Results

Twenty portal users and five portal non-users were interviewed. Participants were from a variety of backgrounds in Los Angeles County (Table 1). Most participants were female, with an age range of 28 to 53 years. A small percentage of participants (28%) were confirmed to have completed an asthma or other questionnaire via the portal before the clinician visit. All had reliable internet connections whether via laptop, desktop, or mobile device at home.

Overall, there was overwhelming support for the idea of completing an electronic questionnaire on the portal that files responses directly into the child's electronic health record before the patient visit. Caregivers deemed it efficient and "*convenient*" due to the direct transmission of information to doctors for review as well as the ease of access on MyChart. Key themes are reported below with details of all themes and codes defined in Table 2.

Perceived purpose and utility of questionnaires

Caregivers had a variety of opinions about the utility of medical visit questionnaires. Some imagined the doctor prepared a care plan based on the questionnaires, but most viewed them as a perfunctory step within the clinician visit. "*I will scramble to get it through as quickly as possible. If the scribbles are not legible, I don't really care…it's taking away from the valuable time with the doctor.*" Often caregivers were unsure what happens to questionnaires after the visit and queried if doctors ever read or enter them into the medical record: "*They don't ask you any questions about what you filled out; I don't know how that survey's being used.*"

It was acknowledged that asthma questionnaires can serve as an educational tool for both caregivers and clinicians. For caregivers, the questions indicate what is important to evaluate at home, identify knowledge gaps, and assist behavior change that could help their children. One participant highlighted "*it helped me understand the doctor's thought process…on how asthma is treated and what's important…and differences between the rescue medication and maintenance medication and so forth.*"On the other hand, some caregivers pointed out that the standardized content could serve as a topic guide during the visit to keep the clinician on track. "*I would actually find a lot of value in that form, because those are questions that really weren't addressed (by the doctor about my child's asthma).*"

Intrinsic motivators and facilitators to complete questionnaires

The most salient motivator for caregivers to complete the questionnaire before the visit is whether the caregivers trusted their child's clinician would review the answers to the questionnaire with the caregiver during the visit, "*it's a two-way street that contributes to the process*" and one participant noted "*if it's a good doctor, they're probably double-checking it.*" One participant suggested if: "*The doctor could summarize, 'Okay, it seems like these are the triggers. Is this correct what you wrote on the form?' Then, they can say, 'Is there anything else that you want to discuss that maybe wasn't on the form?'"* If the questionnaire was not supplemented by discussion and review with them, the caregivers felt disappointed.

Caregivers noted that the clinician reviewing the questionnaire responses is what gives the questionnaire actual purpose and provides "*positive reinforcement*" if the information will be used.

Many caregivers communicated that an important motivator to complete questionnaires before the visit would be if they were informed of a reason to complete it, such as it could save time during the clinic visit or help them remember what they wanted to review at the visit. Caregivers would be "*incentivized*" to complete the portal questionnaires before the visit if the clinic "*communicated the value or importance (of the questionnaire) to the parent.*" Caregivers supported the possibility of the clinician spending less time asking them questions during the visit, and instead could focus on their child and caregiver priorities for the visit. The portal questionnaire could be an opportunity for caregivers to contemplate their answers and to reflect on questions to ask the clinician they otherwise may forget at the visit. Many caregivers conceptualized an open-ended repository for their own notes in the portal to store their thoughts in preparation of the visit because sometimes caregivers arrive with "*a blank mind and just go off instinct of what we're there for today instead of remembering what happened a few days ago.*"

Another motivator to complete the questionnaire via the portal before the visit was the benefit of being able to carefully answer questions without distractions in the clinic. Many caregivers illustrated hectic scenes in the waiting room, trying to balance a clipboard and their children, while struggling to remember medical history details. We perceived a tone of ease when discussing the idea of a "pre check-in" or completing forms and questionnaires ahead of the visit. They imagined less pressure and frustration if they could complete the questionnaire at their own leisure and would be less likely to make mistakes. Regarding the pre check-in questionnaires commonly used at UCLA, one participant shared, "when we get the notifications, we try to do those ahead of time, just so that we don't need to worry about it there."

In addition, the idea of completing serial questionnaires as part of a system for tracking their children's asthma experience or related events, and medication use was attractive to many caregivers. Caregivers' desire to understand what treatment is and is not working, and what environmental context affects their child's asthma illustrated with the information they are reporting already. Caregivers noted the portal questionnaire was more likely to be completed if their child's asthma symptoms were not controlled or they had worsening asthma so some imagined the information could serve as a dashboard for parents/caregivers and clinicians to track their child's health and medication effectiveness over time. Access to the tracked information is considered reciprocation for taking the time to input the information as one participant explained: "Maybe that's a little bit of a selfish advantage, but I think that's something as parents to get the validation we're making the right choices and see it with actual data."

Barriers to completing questionnaires

The most common reason caregivers did not use the patient portal was because they were unaware it existed. These caregivers said they would be interested in using a portal in general and to complete questionnaires prior to visits. One non-user perceived a negative

attitude from the front desk staff which deterred them from signing up for the portal, even though they had intended to enroll after the visit.

Another barrier was discomfort disclosing sensitive information. Caregivers felt selfconscious that responses could expose less than perfect care of their children and unflattering realities of home life. "*I have the feeling of parental guilt and think 'Oh, no, did I give (his medication) to him every day?*" Some topics are easier to discuss than others; caregivers acknowledge difficulty "*opening up*" about allergens such as cockroaches in the home. One participant reflected, "*I don't care if it's embarrassing, I just want to help my child*" but pointed out that others may not feel the same. Two caregivers expressed some hesitation that their health information in the portal may not be secure, but that would not deter their use overall.

Most caregivers, portal users and non-users, imagined they would access the portal via the MyChart smartphone app but would prefer to sit down at a computer to complete longer questionnaires. Finding time to complete the questionnaire was seen as a potential but not major barrier. The primary concern was procrastination "*some people are procrastinators and just forget,*" so forgetting to complete questionnaires was seen as the most likely barrier. To address this, reminders to fill out the portal questionnaire are appreciated "*with everybody*'s *busy schedule, constant (subtle) reminders help.*"

Caregiver suggestions

Technical specifications/features—Reminder notifications to complete the portal questionnaire were strongly encouraged, as mentioned above. Caregivers preferred reminders via text message, ideally with a direct link to the questionnaire. The most common preference was to be informed about the questionnaire at the time the visit is scheduled, then at one week, 72 hours, and 24 hours before the visit if the questionnaire had not been completed. One caregiver suggested a countdown display of days left until their child's doctor will review the chart before the visit. A personalized message with an explanation of the portal questionnaire's purpose was preferred "*if in the appointment reminder there was a line that the survey will specifically 'help Dr. X in your child's care,' as opposed to the nurse or the generic reminder.*" They also would like to be informed about how much time they should expect to spend on the questionnaire before they start to fill-it out. Caregivers suggested a progress tracker in the questionnaire to know how many of the questionnaire in multiple sittings if needed and would that option before they begin completing the questionnaire.

Caregivers value efficiency as they complete online questionnaires. One example suggested was the questionnaire auto-populate with pre-existing medical and demographic data contained in the EHR data. Caregivers expressed frustration about having to write-in the fields of existing visit questionnaires' repetition of static medical questions such as medications and family history "*I still get asked the same questions about information that has not changed*." Caregivers also want the questionnaire interface to include anything that reduces the number of clicks.

Flexibility of the questionnaire function and layout is also important to caregivers. While pre-written responses to designate with one-click are preferred, caregivers also recommend the option to enter free-text answers. They felt strongly about describing the reason for their visit in their own words and what was happening at home with their child's asthma.

While the MyChart and electronic patient portals are convenient for most, caregivers recognize that not everyone has access to reliable Wi-Fi or a cell phone data plan. Caregivers were aware of the "digital divide" and highlighted that those who were not technologically savvy, did not have access to technology (including hardware or internet), or were unable to use the portal in English would be at a disadvantage. They suggested considerations be made such as mailing a print version with a return envelope or to complete the questionnaire over the phone with a staff member prior to the visit.

Integration of questionnaires into the clinical encounter—As highlighted above, it was very important to caregivers that clinicians acknowledge answers provided in the questionnaire and address their primary concern: *"I think it does start from surveys like that, where you can address it with your pediatrician."* Caregivers suggested this would encourage sustained use of the portal questionnaires over time, encourage a sense of teamwork, and build trust. One participant noted, "*If the doctor goes over it with you, then you feel like it was worth the time and effort versus if you go in and they don't. If I'm filling out a form that's 11 pages, I'm going to hope that the doctor looks at it."*

The more caregivers trust their clinician and feel that the clinician values what they share, the better the chance for open communication channels, which one participant highlighted: *"There's a lot of back-and-forth making sure she (the doctor) understands what the situation...I don't feel we're being talked down to, or she's being preachy so I'm comfortable enough to ask the questions."* When caregivers feel a rapport with the clinician, they are more comfortable asking important questions, answering honestly, and identifying shortcomings in areas they may need to focus on. This was summarized by one participant as *"if the parent doesn't feel like you (the doctor) trust them, the parent's not going to trust the physician."*

Discussion

Caregivers of children ages 5-11 years old with asthma in the UCLA Health System support the concept of completing an asthma questionnaire through a patient portal before their child's asthma visit if they see the information is incorporated into the visit. They envision the portal questionnaire as a tool to enhance the relationship with the provider and care for their child's asthma. While this is a paradigm shift for patients to provide information ahead of the visit, motivators to complete the questionnaire before the visit include its convenience, a distraction-free option to answer questionnaires, the possibilities of tracking data, and an opportunity to feel like a partner and team member in their child's asthma care.

Of critical importance for long-term use would be for caregivers to observe the proven value of answering questionnaires before the visit and how it will contribute to their child's asthma management. Ideally, they would witness clinicians incorporate the caregiver-supplied

data into the visit and actively discuss the reported concerns. Our participants reported barriers to complete questionnaires that include a lack of awareness about the portal, embarrassment about living conditions, fear of reporting incorrect information, preferring phone or assistance with the questionnaire, and busy lifestyle/procrastination.

During our interviews, caregivers strongly emphasized that understanding *why* they are being asked to complete questionnaires before the clinic visit and knowing clinicians would use the information during the visit to improve asthma care would encourage the portal questionnaires' use and build trust. This is consistent with the patient-reported outcome (PRO) literature that an important factor to build trust is if the medical practitioner models the most conscientious effort possible.^{23,24} In recent years, training for clinicians regarding best practices to implement PROs into a clinical encounter have been developed primarily in oncology, but easily translated to other conditions such as asthma.^{25,26} This approach of involving the families is aligned with the NIH asthma guidelines that emphasize a "partnership in care" as a primary pillar of management²⁷.

Eschlar et al's group highlighted the importance of a positive relationship with the clinician to encourage form completion²⁸ and this is especially important with sensitive topics. such as living conditions, financial strain, stress, and adherence. Choosing questionnaire wording can also ensure families feel comfortable responding. Clinicians can ameliorate caregivers' discomfort by acknowledging topics can be sensitive, and they ask not to judge but to ultimately help the child's asthma.

Recommendations of preferred portal features from participants include the ability to record observations about their child's asthma between visits as well as track and display their child's asthma progress over time. Encouraging families to take notes and ask clinicians questions about their care has been demonstrated to improve communication with clinicians in the inpatient setting²⁹. The increased use of information technology (IT) to capture PRO data longitudinally has been implemented through various methods including web-based, inhaler trackers, social media, text messages, mobile applications, portal^{30,31}.

Our study was limited in that it was a small cohort performed at a single academic teaching hospital and in English only. While we attempted to interview a diverse range of families, we did not capture a representative number of Hispanic/Latino participants within the UCLA System or Southern California. All participants had reliable access to internet and were above the federal poverty level. Caregivers who agreed to participate in our study over Zoom may be different than families who declined. Participants may have felt pressure to participate in the study or answer favorably if their child was currently a patient in the UCLA Health system. Due to the COVID-19 pandemic, we conducted our interviews over Zoom rather than in-person, which may have limited our ability to discover rich information through deeper discussions.

While electronic portals have demonstrated improved asthma management, uptake and regular use can be suboptimal^{12,32}. Barriers reported in previous studies include difficulty learning a new process, lack of computer or reliable internet access, poor clinician relationship, difficult interface, and the sentiment that the medical team should be in

charge of collecting information; facilitators include personalization, easy-to-use interface, efficient, and encouraging family involvement with the healthcare team^{12,28,33-35}. Our findings highlight the importance of understanding the end-users' needs and expectations beyond the technical build. Built-in feedback loops and an iterative design philosophy that incorporates quality improvement and implementation science approaches as well as user experience design are more likely to lead to a successful implementation and sustainability.

Caregivers are likely to complete a patient portal asthma questionnaire before their child's visit if they understand the questionnaire purpose, and if clinicians acknowledge and discuss caregiver answers related to the care plan during the visit. Caregivers are also interested in features to track their child's asthma medications and symptoms over time. Future directions include studying adolescent self-reported data. Currently we are designing a patient portal intake questionnaire to deliver patient-entered data into an EHR-based clinical decision support (CDS) system to deliver recommendations to the healthcare provider for discussion with the family during the visit. We prefer to frame this approach beyond the traditional concept of CDS as a "partnered" decision support by using caregiver-informed data to provide recommendations to clinicians and families for enhanced pediatric asthma management.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgements:

The UCLA study participants, the NIH NHLBI, Alex Bui, and Peter Szilagyi.

Funding:

The work was supported by the National Institutes of Health under Grant 1K23HL148502-01A1

Data Availability Statement:

Data sharing not applicable to this article as no datasets were generated or analyzed during the current study.

References

- 1. Page AE, Adler NE. Cancer care for the whole patient: Meeting psychosocial health needs. 2008.
- Basch E. Patient-Reported Outcomes Harnessing Patients' Voices to Improve Clinical Care. N Engl J Med 2017;376(2):105–108. DOI: 10.1056/NEJMp1611252. [PubMed: 28076708]
- Cella D, Yount S, Rothrock N, et al. The Patient-Reported Outcomes Measurement Information System (PROMIS): progress of an NIH Roadmap cooperative group during its first two years. Medical care 2007;45(5 Suppl 1):S3.
- Ehrs PO, Nokela M, Stallberg B, Hjemdahl P, Wikstrom Jonsson E. Brief questionnaires for patient-reported outcomes in asthma: validation and usefulness in a primary care setting. Chest 2006;129(4):925–32. DOI: 10.1378/chest.129.4.925. [PubMed: 16608940]
- 5. Liu AH, Zeiger RS, Sorkness CA, et al. The Childhood Asthma Control Test: retrospective determination and clinical validation of a cut point to identify children with very poorly controlled

asthma. J Allergy Clin Immunol 2010;126(2):267–73, 273 e1. DOI: 10.1016/j.jaci.2010.05.031. [PubMed: 20624640]

- 6. Worth A, Hammersley V, Knibb R, et al. Patient-reported outcome measures for asthma: a systematic review. NPJ Prim Care Respir Med 2014;24:14020. DOI: 10.1038/npjpcrm.2014.20. [PubMed: 24964767]
- Yeatts KB, Stucky B, Thissen D, et al. Construction of the Pediatric Asthma Impact Scale (PAIS) for the Patient-Reported Outcomes Measurement Information System (PROMIS). J Asthma 2010;47(3):295–302. DOI: 10.3109/02770900903426997. [PubMed: 20394514]
- Expert Panel Working Group of the National Heart L, Blood Institute a, coordinated National Asthma E, et al. 2020 Focused Updates to the Asthma Management Guidelines: A Report from the National Asthma Education and Prevention Program Coordinating Committee Expert Panel Working Group. J Allergy Clin Immunol 2020;146(6):1217–1270. DOI: 10.1016/j.jaci.2020.10.003. [PubMed: 33280709]
- Snyder CF, Aaronson NK, Choucair AK, et al. Implementing patient-reported outcomes assessment in clinical practice: a review of the options and considerations. Qual Life Res 2012;21(8):1305–14. DOI: 10.1007/s11136-011-0054-x. [PubMed: 22048932]
- 10. Aaronson N, Choucair A, Elliott T, et al. User's guide to implementing patient-reported outcomes assessment in clinical practice. International Society for Quality Life Research 2011.
- Bush RA, Connelly CD, Fuller M, Perez A. Implementation of the Integrated Electronic Patient Portal in the Pediatric Population: A Systematic Review. Telemed J E Health 2016;22(2):144–152. DOI: 10.1089/tmj.2015.0033. [PubMed: 26258289]
- Fiks AG, DuRivage N, Mayne SL, et al. Adoption of a Portal for the Primary Care Management of Pediatric Asthma: A Mixed-Methods Implementation Study. J Med Internet Res 2016;18(6):e172. DOI: 10.2196/jmir.5610. [PubMed: 27357835]
- Stead WW, Haynes RB, Fuller S, et al. Designing medical informatics research and library-resource projects to increase what is learned. J Am Med Inform Assoc 1994;1(1):28–33. DOI: 10.1136/jamia.1994.95236134. [PubMed: 7719785]
- Kilsdonk E, Peute LW, Jaspers MW. Factors influencing implementation success of guidelinebased clinical decision support systems: A systematic review and gaps analysis. Int J Med Inform 2017;98:56–64. DOI: 10.1016/j.ijmedinf.2016.12.001. [PubMed: 28034413]
- 15. Friedman CP, Wyatt J. Evaluation methods in biomedical informatics: Springer Science & Business Media, 2005.
- Yen PY, Bakken S. Review of health information technology usability study methodologies. J Am Med Inform Assoc 2012;19(3):413–22. DOI: 10.1136/amiajnl-2010-000020. [PubMed: 21828224]
- Damschroder LJ, Aron DC, Keith RE, Kirsh SR, Alexander JA, Lowery JC. Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. Implement Sci 2009;4:50. DOI: 10.1186/1748-5908-4-50. [PubMed: 19664226]
- Kontio J, Lehtola L, Bragge J. Using the focus group method in software engineering: Obtaining practitioner and user experiences. 2004 International Symposium on Empirical Software Engineering, Proceedings 2004:271–280. (In English) (<Go to ISI>://WOS:000223848800027).
- 19. Creswell JW, Creswell JD. Research design : qualitative, quantitative, and mixed methods approaches. Fifth edition. ed. Los Angeles: SAGE, 2018.
- Glaser BG. The Constant Comparative Method of Qualitative-Analysis. Soc Probl 1965;12(4):436–445. (In English). DOI: DOI 10.1525/sp.1965.12.4.03a00070.
- 21. Mathison S. Encyclopedia of evaluation: Sage publications, 2004.
- 22. Dedoose. SocioCultural Research Consultants. (https://www.dedoose.com).
- Greenhalgh J, Gooding K, Gibbons E, et al. How do patient reported outcome measures (PROMs) support clinician-patient communication and patient care? A realist synthesis. J Patient Rep Outcomes 2018;2:42. DOI: 10.1186/s41687-018-0061-6. [PubMed: 30294712]
- 24. Salmon P, Mendick N, Young B. Integrative qualitative communication analysis of consultation and patient and practitioner perspectives: towards a theory of authentic caring in clinical relationships. Patient Educ Couns 2011;82(3):448–54. DOI: 10.1016/j.pec.2010.10.017. [PubMed: 21111558]

- Skovlund PC, Ravn S, Seibaek L, Thaysen HV, Lomborg K, Nielsen BK. The development of PROmunication: a training-tool for clinicians using patient-reported outcomes to promote patientcentred communication in clinical cancer settings. J Patient Rep Outcomes 2020;4(1):10. DOI: 10.1186/s41687-020-0174-6. [PubMed: 32048085]
- 26. Santana MJ, Haverman L, Absolom K, et al. Training clinicians in how to use patient-reported outcome measures in routine clinical practice. Quality of Life Research 2015;24(7):1707–1718. (In English). DOI: 10.1007/s11136-014-0903-5. [PubMed: 25589231]
- National Asthma E, Prevention P. Expert Panel Report 3 (EPR-3): Guidelines for the Diagnosis and Management of Asthma-Summary Report 2007. J Allergy Clin Immunol 2007;120(5 Suppl):S94– 138. DOI: 10.1016/j.jaci.2007.09.043. [PubMed: 17983880]
- Eschler J, Meas PL, Lozano P, McClure JB, Ralston JD, Pratt W. Integrating the patient portal into the health management work ecosystem: user acceptance of a novel prototype. AMIA Annu Symp Proc 2016;2016:541–550. (https://www.ncbi.nlm.nih.gov/pubmed/28269850). [PubMed: 28269850]
- Farberg AS, Lin AM, Kuhn L, Flanders SA, Kim CS. Dear Doctor: a tool to facilitate patientcentered communication. J Hosp Med 2013;8(10):553–8. DOI: 10.1002/jhm.2073. [PubMed: 24038860]
- Poowuttikul P, Seth D. New Concepts and Technological Resources in Patient Education and Asthma Self-Management. Clin Rev Allergy Immunol 2020;59(1):19–37. DOI: 10.1007/ s12016-020-08782-w. [PubMed: 32215784]
- Baldwin JL, Singh H, Sittig DF, Giardina TD. Patient portals and health apps: Pitfalls, promises, and what one might learn from the other. Healthc (Amst) 2017;5(3):81–85. DOI: 10.1016/ j.hjdsi.2016.08.004. [PubMed: 27720139]
- 32. Apter AJ, Bryant-Stephens T, Perez L, et al. Patient Portal Usage and Outcomes Among Adult Patients with Uncontrolled Asthma. J Allergy Clin Immunol Pract 2020;8(3):965–970 e4. DOI: 10.1016/j.jaip.2019.09.034. [PubMed: 31622684]
- Fiks AG, Mayne S, Karavite DJ, DeBartolo E, Grundmeier RW. A shared e-decision support portal for pediatric asthma. J Ambul Care Manage 2014;37(2):120–6. DOI: 10.1097/ JAC.00000000000025. [PubMed: 24594560]
- Lin HC, Chiang LC, Wen TN, Yeh KW, Huang JL. Development of online diary and selfmanagement system on e-Healthcare for asthmatic children in Taiwan. Comput Methods Programs Biomed 2014;116(3):299–310. DOI: 10.1016/j.cmpb.2014.05.004. [PubMed: 24947614]
- Fiks AG, Mayne SL, Karavite DJ, et al. Parent-reported outcomes of a shared decisionmaking portal in asthma: a practice-based RCT. Pediatrics 2015;135(4):e965–73. DOI: 10.1542/ peds.2014-3167. [PubMed: 25755233]

Table 1.

Participant demographic characteristics

| Demographics | n=25 (100%) | | | | | |
|-------------------------------|-------------|--|--|--|--|--|
| Gender | | | | | | |
| Female | 18 (72%) | | | | | |
| Male | 5 (20%) | | | | | |
| Not disclosed | 2 (8%) | | | | | |
| Age (years) | | | | | | |
| 20-29 | 1 (4%) | | | | | |
| 30-39 | 5 (20%) | | | | | |
| 40-49 | 17 (68%) | | | | | |
| 50-59+ | 2 (8%) | | | | | |
| Race | | | | | | |
| African American/Black | 5 (20%) | | | | | |
| Asian | 4 (16%) | | | | | |
| White | 10 (40%) | | | | | |
| Other/Mixed/Not disclosed | 6 (24%) | | | | | |
| Ethnicity | | | | | | |
| Hispanic/Latino | 7 (28%) | | | | | |
| Not Hispanic/Latino | 18 (72%) | | | | | |
| Time child at UCLA (years) | | | | | | |
| 0-2 | 2 (8%) | | | | | |
| >2-4 | 3 (12%) | | | | | |
| >4-6 | 8 (32%) | | | | | |
| 6+ | 12 (48%) | | | | | |
| City Median Income <\$59,000* | | | | | | |
| Yes | 6 (24%) | | | | | |
| No | 18 (72%) | | | | | |
| Unknown | 1 (4%) | | | | | |
| Highest education level | | | | | | |
| High school graduate/GED | 5 (20%) | | | | | |
| Associate degree | 2 (8%) | | | | | |
| College graduate (BA or BS) | 10 (40%) | | | | | |
| Graduate/Professional degree | 8 (32%) | | | | | |
| Insurance | | | | | | |
| PPO/HMO via employer | 18 (72%) | | | | | |
| Covered California exchange | 1 (4%) | | | | | |
| Government funded | 6 (24%) | | | | | |
| Specialist care for asthma | | | | | | |
| Yes | 14 (56%) | | | | | |
| No | 1 (4%) | | | | | |

| Demographics | n=25 (100%) | | | |
|---|-------------|--|--|--|
| Gender | | | | |
| Unknown | 10 (40%) | | | |
| Completed any paper questionnaires before | | | | |
| Yes | 20 (80%) | | | |
| No | 1 (4%) | | | |
| Unknown | 4 (16%) | | | |
| Completed any portal questionnaire before | | | | |
| Yes | 7 (28%) | | | |
| No | 6 (24%) | | | |
| Unknown | 12 (48%) | | | |
| Portal User | | | | |
| Yes | 20 (80%) | | | |
| No | 5 (20%) | | | |
| Reliable internet at home | | | | |
| Yes | 24 (96%) | | | |
| Unknown | 1 (4%) | | | |
| Preferred way to access MyChart (n=20) | | | | |
| Phone App | 16 (80%) | | | |
| Computer (desktop/laptop) | 4 (20%) | | | |

* Department of Housing and Urban Development (HUD) "very low-income level" for family of 4 in Los Angeles County

Table 2.

Themes, codes, and representative quotes from the interviews

| Themes | Codes | | Example Quotes | |
|---|-------------|---|----------------|--|
| Communication preferences with doctors | • | Back-and-forth discussion Information doctor needs What caregivers want included in the questionnaire | | The specialist calls me: "Do you have any questions? What's going on? How do you feel?" And for that reason alone, I will stay at UCLA because she reassures me. Pediatricians need to understand there are different types of asthma, and that it can present differently in different kids. The questions that are particularly important are how long the child's been experiencing symptoms, under what conditions, if they were environmental or related to that. |
| Current perceptions of visit check-in | • | Negative perceptions of filling out questionnaire during visit | • | When I was in the office trying to fill out the form, do the appointment and trying to talk to the doctor, I was frustrated, flustered and unhappy. |
| Caregivers' priorities during child's asthma visit | • | Information needed or wanted from doctor | • | Having the support of our doctors has been really awesome and giving us the information written out has been very helpful. Just making the parent feel like you trust them. |
| Perceived utility of asthma questionnaires | • | Don't know how questionnaire is used Caregivers' impression of the questionnaire | • | I've seen doctors not read the forms that we filled out in the waiting room. They don't really seem to have time to go through the form and it's sat there. Sometimes, as I left, it's still in the clipboard. It's more like, did they even read it? I don't find the purpose of them. I filled everything out, it was quite long. |
| Motivation for caregivers to complete questionnaires before visit | • | Effect of demonstrated use on motivation Value of doctor reviewing the questionnaire before visit Value of reviewing the questionnaire during visit | • | Communicating that this is information the doctor will need going into the consultationI think knowing what its utility is, that it's going to make the consultation more constructive and efficient would probably motivate me. I think it would be beneficial to have that before, so that the doctor does have time to read it Go through it with us - all the questions - and then if there was anything that came up in red, to get more details. |
| Anticipated facilitators to complete questionnaires in portal | • • • | Questionnaire entered directly into EHR Questionnaire ease of use Benefit of questionnaire flexibility Benefit of portal | • | Tell them they only have to do it once and then it goes into the system. It'd be nice to have a very specific form as it pertains to asthma, where you can actually pull that up and get straight to that conversation of what are the issues and how we can address those things. Make it all click, like click this box. The more I have to annotate, the more I might skip. If you consider the option to fill out the form and save it and keep working later is going to be the best idea. It is helpful with Because you have all your appointments on there to remind you like, "Oh, when is my appointment." And then, you do check. That's what I do like about it. It's more convenient and then you could save the earth, cut out paper. |
| Anticipated barriers to complete questionnaires in portal | • | Questionnaire language | • | Education level is a big thing. I think computer literacy is a big thing. |

| Themes | Codes | Example Quotes | | |
|--|-------|---|--------|--|
| | • | Issues with caregivers' prioritization of questionnaire Unreliable technology | • | People are just procrastinators, and they just forget - they mean to do it, it's not on purpose. Apps crashing or connectivity or what not. I think that is a barrier and that's applicable across the board. |
| Caregiver suggestions for portal questionnaire features | • | Alert/reminder preference Questionnaire fill modality Suggestions for portal interface | • • | Text messages are ideal. People don't check email as often. And with text messages you can leave it unread, so it'll remind you. Leaving a space to put whatever comments you want for your physician - it's always helpful to have that option. A function that you could save and continue because it's going to be differult to sit and focus for lower questionnaires |
| | | Support for patient information tracking | • | If there's something on My Chart that can say you've used it less this quarter, or we're back to using it on a weekly basis, or something that could help us diagnose, is the child's condition getting better? I think that would be really helpful for us to see the results of all of those questionnaires added together. |

Author Manuscript