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Promotion Tool in Pediatric Practice

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# **Perceived Utility of Parent-Generated Family Health History as a Health Promotion Tool in Pediatric Practice**

A thesis submitted to the  
Graduate School  
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by

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## Abstract

**Introduction:** FHH is a risk factor for chronic diseases. Pediatric practice is an optimal setting to incorporate FHH because risk factors may be identified and preventive measures implemented earlier in life, resulting in sustained and improved health outcomes. My Family Health Portrait (MFHP) is a web-based tool to help families collect and share their FHH with their health care provider. To our knowledge, providers' views about the clinical utility of MFHP, or other parent-generated FHH tools, have not been assessed in a pediatric setting.

**Purpose:** The purpose of this study was to describe how pediatric providers collect and use FHH in practice and to collect data about the perceived clinical utility of MFHP as a pediatric health promotion and disease prevention tool.

**Methods:** A random sample of 148 pediatric providers was invited to participate in a semi-structured qualitative interview. All transcripts were reviewed and coded inductively by two coders, and inter-rater reliability was determined.

**Results:** 21 providers completed study interviews. Participants unanimously collected FHH at new patient visits and when patients present with a symptom or complaint. Most providers believed that collecting FHH of chronic disease benefits the pediatric population. The most commonly cited barrier to FHH collection was the short visit time, and the most frequently suggested idea for improving FHH was collecting it prior to the office visit. Providers believed that the use of MFHP would improve FHH collection and allow for targeted education and preventive recommendations. Respondents also identified logistical and patient characteristic issues that must be resolved to integrate MFHP into clinical practice.

**Conclusions:** Our research suggests that pediatric primary care presents many opportunities to collect and discuss FHH with patients, and that providers are optimistic about the clinical use

of a parent-generated FHH collection tool. Future research should assess parent perspectives about the use of MFHP.



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## Table of Contents

Introduction.....	1
Methods.....	2
Results.....	4
Discussion.....	16
References.....	21
Appendix.....	24

## Figures and Tables

Appendix 1: Interview guide.....	24
Table1: Participant Demographics.....	28
Table 2: Inter-rater Reliability for Each Theme.....	29
Table 3: Utilization of FHH Information.....	30
Figure 1: Conditions of Importance to Pediatric Providers.....	31



## Introduction

Family health history (FHH) is an established risk factor for common chronic disease and is incorporated into health care provider screening and management guidelines for diabetes, cancer and cardiovascular disease.<sup>1</sup> Potential uses for FHH as a public health tool include targeted risk assessment, tailored intervention and patient education.<sup>2-5</sup> Physicians consider FHH intake to be standard-of-care in primary care practice<sup>6</sup>. However, sufficient data are rarely collected to be able to assess risk to prevent chronic disease.<sup>7-10</sup> Barriers to thorough FHH collection in clinical practice include time, inadequate FHH collection methods, uncertainty about how to assess risk, uncertainty about when referral to a specialist or geneticist is warranted and lack of outcomes research.<sup>4,6,8,9,11-13</sup> One way to alleviate barriers to FHH collection may be the use of patient-generated FHH collection tools. A questionnaire survey showed that adult providers are optimistic about the use of patient-generated FHH in clinic and believe it would increase their ability to assess risk.<sup>6</sup>

A public, web-based FHH tool, My Family Health Portrait (MFHP), was developed to aid families in the collection, documentation and sharing of FHH.<sup>14</sup> MFHP data is displayed in a two-sheet pedigree and chart. The tool was updated in January 2009 to include a drop-down menu with more conditions and an electronic medical record (EMR)-ready platform among other things.<sup>14</sup> However, the clinical utility of MFHP has not been systematically assessed.

There are many reasons that the pediatric primary care practice may be an optimal setting to collect FHH data for health promotion and disease prevention purposes. First, children go to the doctor more often than adults.<sup>15</sup> Second, parents often accompany children and can therefore be informed of their child's risks as well as their own risks. Third, children and adolescents with a FHH of some conditions may show preclinical signs or risk factors of disease, which might allow patients and healthcare providers to address the condition if screening identifies these changes at an early stage.<sup>16,17</sup> Fourth, healthy behaviors are best

learned at a young age.<sup>18</sup> Fifth, parents may be more likely to make lifestyle changes and follow screening recommendations for their children than themselves.<sup>19-21</sup>

The purpose of this study was to describe how pediatric providers collect and use FHH in clinical practice and to collect data about the perceived clinical utility of parent-generated FHH as a health promotion and disease prevention tool in a pediatric setting. This preliminary data will help guide clinicians and researchers as they consider the possible role of parent-generated FHH in pediatric clinical settings.

### **Methods**

Because this research is novel and exploratory, primarily qualitative techniques were used in this study. A phenomenological approach guided the design and analysis of this project. A phenomenological perspective was chosen for its emphasis on understanding phenomena from the participants' point of view and identifying the shared meaning of a group's experience. Methodologically, phenomenological research involves obtaining in-depth information from a small number of subjects and developing patterns and relationships of meaning.<sup>22</sup> Utilizing a phenomenological approach in both the semi-structured interviews and inductive content analysis allowed for exploration of this novel topic without predetermined hypotheses. Institutional Review Board approval was obtained from Cincinnati Children's Hospital Medical Center and the University of Cincinnati.

#### *Participants & Recruitment*

A sample of 148 pediatric providers (74 Advanced Practice Nurses [APNs]; 74 pediatricians) was randomly selected from a list of providers at a major medical center, community pediatricians with privileges at the medical center who participate in a practice-based research group affiliated with the medical center and community APNs. The lists were furnished by the medical staff office. Participants for whom email addresses were included (n = 81) were recruited by email; all others were invited by mail. A follow-up invitation was sent to all

non-responders one month after the initial contact. Recruitment was discontinued once no additional themes emerged from the interviews.

### *Protocol*

Semi-structured interviews were conducted by the P.I. by phone or in-person (Appendix 1). The interview guide was informed by previous studies.<sup>6,13,19</sup> Before beginning data collection, the interview guide was reviewed for face validity by research team members with expertise in public health, advanced practice nursing, pediatrics, health communications and genetic counseling and was also pilot tested with a convenience sample of two pediatricians. Written consent was obtained from all participants who were interviewed in-person, and verbal consent was obtained from those who interviewed by phone. During the interviews, participants were first asked about their current FHH collection practices and how they value the collection of FHH of chronic disease. Next, participants were asked if they were familiar with MFHP and guided through standardized data input of a hypothetical patient's family history<sup>a</sup>, then given a few minutes to explore the tool. Lastly, participants were asked their impressions of MFHP. During one interview, a technological error prohibited the participant from viewing the pedigree and chart, so it was described to her verbatim from the interview guide. After the interview, participants were asked to fill out a questionnaire which was used to characterize the participant population, and included questions about years in practice, location, patient age group, patient load and FHH education. Demographic data was collected by email from telephone participants. Interviews lasted between 17 and 40 minutes (mean = 27 minutes) and were audiotaped and transcribed by the P.I.

### *Data Analysis*

The transcripts were analyzed inductively for common themes within and across transcripts. Data organization and quantification were performed with the use of the qualitative

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<sup>a</sup> John Doe is a 40 year old male who has colon cancer diagnosed between ages 30-39 and high cholesterol diagnosed between ages 20-29. He has a sister and brother, and each of his parents have a brother and a sister. His daughter, Jane Doe, is 10 years old and has asthma diagnosed in childhood.

software analysis program Atlas.ti. Themes and subthemes were developed using a combination of deductive codes based on the interview questions as well as inductive codes based on participant responses and emerging themes. The themes and subthemes were agreed upon by the P.I. and research team members. A random sample of transcripts was coded by two independent coders, and the codes were assessed for inter-rater reliability.<sup>23</sup> All transcripts were coded by the P.I. The final set of applied codes was reviewed by an independent coder, and discrepancies were resolved through consensus. Once coding was complete, data frequencies were computed. Questionnaire data was analyzed to be reported descriptively.

## **Results**

Of the 148 providers invited to participate in the study, 27 responded, for an enrollment rate of 18%. Twenty-one pediatric and adolescent primary care providers (13 pediatricians and 8 APNs) completed study interviews. Fourteen interviews were completed by phone and seven were completed in person. Participant demographic data (Table 1) was obtained from all but 2 participants, who did not return the questionnaire. Sixty-three percent reported receiving some education about FHH. Sources of FHH education cited by more than one provider included medical school, residency, graduate school and continuing medical education.

In the qualitative data analysis, inter-rater reliability was high (Table 2). Twenty-two categories (69%) showed perfect or almost perfect agreement ( $\kappa > .81$ ). Nine categories showed substantial agreement ( $\kappa \geq .60$ ), and one category showed moderate agreement ( $\kappa = .57$ ).

Themes that emerged from the interviews are divided into four categories: FHH Collection Practices, Utilization of FHH Information, Perceived Challenges, Benefits and Importance of Collecting FHH and Perceptions of MFHP as a FHH Collection Tool.

## **1. FHH Collection Practices**

Several themes and sub-themes emerged when participants were asked when they collect FHH, methods of FHH collection and information collected. These themes and sub-themes are described below.

***When FHH is collected:*** Two main themes emerged when participants were asked when they collect FHH. These included inconsistent collection of FHH at new and annual visits and specific symptoms or complaints as a reason to collect FHH.

*Inconsistent collection of FHH:* Although all participants reported collecting FHH at a new patient visit, some indicated this did not happen consistently. Several providers indicated that a new patient (n = 2) or newborn visit (n = 2) is sometimes too busy to collect FHH, and therefore FHH collection may be postponed to a follow-up visit.

Most providers reported that they update FHH annually (n = 12), although five did not update FHH after the initial patient visit. Of the providers who did not update annually, three acknowledged that FHH should be updated, but admitted that this does not happen in reality. Two providers reported that they update the initial FHH when the patient reaches an age at which they would expect symptoms to present.

*Presenting symptoms as a reason to collect FHH:* All participants reported that they collect FHH when a patient presented with a specific complaint or symptom. One provider explained the rationale: “A symptom that is often considered trivial or non-concerning may take on greater importance with the right FHH” (P5). Other scenarios in which providers collected FHH included when a parent voices a concern about a family member’s diagnosis (n = 5), an annual visit in adolescence (n = 2), a targeted visit such as a sports physical or developmental assessment (n = 2) or when prescribing new medications such as oral contraceptives or those

that might produce an allergic reaction (n = 2). Providers reported that in all of these instances, the FHH is targeted to relevant conditions.

***Lack of standardization in FHH collection practices:*** When asked about methods of FHH collection, the major theme that emerged was the lack of standardization in FHH collection practices. Methods of FHH collection included parent or patient interview (n = 9), patient information form (n = 4) or both (n = 8). No providers referenced any practice guidelines for FHH collection or use of FHH collection tools, and no providers reported documenting FHH in pedigree format. Most providers who used interview techniques reported asking a broad, open-ended question, followed by subjective disease-specific prompts if needed (n = 5). One physician explained, *“I usually just ask kind of a general, ‘Are there any illness that run in the family’, and then I’ll kind of throw out specifics like diabetes, heart disease, just kind of like major kinds of illnesses”* (P16). Others used the patient form (n = 1) or EMR prompts (n = 3) to guide the interview. Three providers reported relying on the patient information forms in instances where the FHH does not get obtained during the visit: *“I think especially towards the end of the visit, if I forgot...I can quickly glance at the sheet, and if the sheet is filled out and it’s all negative, I can move on and kind of know that at least I’ve screened for most things”* (P14).

***Inconsistent FHH information collected:*** Again, the major theme identified when asked about information collected was inconsistency. Some providers noted that family members routinely included in FHH collection were parents (n =12), siblings (n =10) and grandparents (n = 10), while collecting information about aunts and uncles (n = 5) and great-grandparents (n = 1) was less common. Medical conditions included in verbal FHH intake or patient information form by more than one provider included diabetes, heart disease, cancer, asthma, high cholesterol, hypertension, stroke and psychiatric conditions. Six participants volunteered that they also included social information, such as who lives at home and custody

status, and environmental information, such as nutritional information and whether the family lives in an apartment or house.

The frequencies at which participants volunteered that a FHH of a condition might be important in past or potential clinical scenarios are displayed in Figure 1. Though some providers used cancer and later-onset diseases to exemplify FHH use in practice, two providers stated that FHH of cancer was not important in their practice, and two others stated that FHH of “diseases of old age” was not important.

## **2. Utilization of FHH Information**

Providers reported that FHH informs their clinical decision-making and also increases their understanding of a patient’s risks and social situation (Table 3). At least two providers equated FHH collection with existing goals of education and prevention in pediatric practice. As one provider noted, *“We really do talk a lot about diet and exercise and healthy lifestyle, all of which are going to decrease your risk factors for pretty much all of these illnesses. So I think we do that on a regular basis anyway”* (P9).

## **3. Perceived Challenges, Benefits, and Importance of Collecting FHH**

Three additional themes emerged from the interviews that were relevant to current FHH collection practices. These include perceived challenges, perceived benefits and perceived importance of collecting FHH information.

***Perceived challenges to current FHH collection practices:*** Throughout the interviews participants identified many challenges associated with current FHH collection practices, which had to do with time, logistics and family characteristics.

*Time:* The most frequently cited challenge to FHH collection was the short visit time to accomplish many things (n = 11). One provider explains, “*There are just so many other things to review for the child. There is just not always enough time to go through every grandmother and every aunt and every uncle. So you just do the best you can with the time that is allowed*” (A9). However, when asked how obtaining FHH impacts the time spent with a new patient, most providers said the time was either not significant or allotted in the schedule (n = 12).

*Logistics:* Three providers who utilized patient information forms felt that sometimes the FHH got lost in the other paperwork. Providers said that occasionally they neglect to collect FHH entirely (n = 3) or ask questions not specific enough to produce valuable answers (n = 4). Two providers suggested that the lack of standardization in FHH collection methods is a barrier.

*Family characteristics:* Barriers attributable to family characteristics included a lack of FHH information for children who are adopted or in foster care (n = 6) and families’ minimal knowledge of FHH (n = 6), which providers hypothesized to be caused by separation of family members, lack of communication about medical information or inability to produce that information on the spot. Some providers believed that information about FHH is under-reported (n = 2), and some suggested that a family’s knowledge of and ability to share FHH information was mediated by factors such as SES and literacy (n = 3).

***Perceived benefits:*** All but one provider thought that collecting FHH of chronic disease benefits the pediatric population. Four providers voiced that a benefit of FHH collection in pediatric care was the earlier age of onset they are seeing for certain diseases. One physician argued, “*It’s becoming more and more important because we’re unfortunately dealing with more and more obesity in our older kids... I mean obviously we don’t see heart attacks, but we do see hypertension...we see hypercholesterolemia, we see type 2 diabetes, which we didn’t used to see a whole lot of. So I think those adult diseases are starting to creep into our world*” (P10).



Others explained that a benefit of FHH could be parent and patient education and preventive measures (n = 7). An APN recalled, *“I just had a kid this week who you could label the great grandmother and the grandmother and the mother all had type 2 diabetes and his sister now has it, and I’m like, ‘Do you know how to prevent that?’ and he’s like, ‘You can prevent it?’ So you can open up this whole conversation about yeah, that’s your genetic and family heritage, but that doesn’t mean that has to be you. Which is true in lot of situations for these kids, having that conversation of this doesn’t have to be you. So it’s a great tool to have that conversation”* (A3). Three providers suggested that FHH of chronic disease has greater importance in adult practice.

**Perceived Importance:** When asked to rank the importance of FHH collection against the other components of a new patient visit on a scale of one to ten (1 = least important; 10 = most important), the mean rank was six (range 1 - 9.75; median = 6). One participant did not provide a ranking because, *“I think the FHH is important for the big picture, just as what medications are they on is important for the big picture, the family’s social situation is important for the big picture, so I struggle with giving it a number because there is an implied value judgment”* (A6). Of the thirteen providers who provided a reason behind their ranking, eight said that other components of the visit, such as the child’s past medical history, physical exam, current complaints, social history and developmental history, took precedence over the FHH. The importance may be impacted by family characteristics: *“Our families have so many other medical problems and social problems that have to be addressed in that time frame”* (P12). One provider suggested that the family’s agenda dictates what was accomplished in the visit.

#### **4. Perceptions of My Family Health Portrait as a FHH Collection Tool**

When providers were shown and asked their impression of MFHP, five major themes arose. These included a lack of awareness about MFHP, perceived benefits and barriers to

integration of MFHP into practice, uncertainty about how MFHP would affect time spent on FHH, ambiguity about feasibility of incorporation into practice and strategies for implementing the tool into practice.

***Lack of awareness of MFHP:*** When asked if they were familiar with MFHP, only one participant had heard of MFHP. No providers had previously seen or used the website.

***Potential benefits to use of MFHP in practice:*** After using the tool, providers cited many positive aspects of the potential use of MFHP in clinical practice, including improved FHH collection practices, comprehensive information, patient-centeredness, portability and collection of FHH prior to the visit.

***Improved FHH collection practices:*** Benefits to MFHP included a belief that the information would be more extensive than current methods (n = 7). Five felt MFHP would improve collection practices by allowing them to review the FHH instead of collecting it, and two felt it would facilitate more targeted questions based on FHH information. Four providers believed that the tool would be easily updated; two felt it could standardize FHH intake. One provider suggested that a parent-generated FHH, *“Might serve as a reminder, it might make the doctor feel a little obligated, so if the parent took the time to do this, then I should really do something with it”* (P13).

***“Comprehensive information in a nutshell”:*** Providers liked the final pedigree and chart (n = 16), stating that they were organized and easy to read and that the pedigree provided a clear display of inheritance patterns. As one APN summarized: *“I think its comprehensive information kind of in a nutshell presentation with the chart or the pedigree”* (A2).

*Patient-centered:* Two providers felt that generating their own FHH would empower families to participate in their health care: *“Having something that is on paper that they generated themselves is helpful from a public health mindset of getting people to take charge of their own health information”* (P15). One provider suggested that a computer-generated FHH may be conducive to single-parent families by making the sharing of important health information between estranged family members less personal.

*Portability:* Three viewed this tool as a portable document that could be brought to future visits with various specialists, as well as shared with family members. The importance of portability in the current healthcare system was highlighted by one APN: *“Patients change doctors because of the insurance company, they change specialists because of the insurance company, they change hospitals...so patients have to be responsible for their own health care information and carry it from doctor to doctor”* (A6).

*Collection of FHH prior to the visit:* Even prior to using MFHP, providers suggested that FHH could be improved by collecting prior to the office visit (n = 6). Likewise, providers perceived collecting FHH prior to the patient visit as a benefit to using MFHP (n = 2). They suggested that a form completed prior to the visit would be less likely to be lost among the other forms that the patient completes during the visit. Respondents also felt that prior completion of the FHH would make physicians more likely to remember to address FHH, and would give the parent or patient the opportunity to speak with family members and obtain more accurate information. Two providers who conducted verbal FHH intakes felt MFHP would help eliminate the added time it takes families to respond to FHH questions, although a verbal review of MFHP would still be important because, *“I always find when people have a checklist that they don’t pay that much attention to it. It has a tendency to have the straight line down the middle for ‘no’...speaking to somebody can’t be replaced by a piece of paper”* (A1).

**Potential barriers to use of MFHP in practice:** Providers voiced several concerns about the potential use of MFHP in practice and voiced a concern that not all parents would be able to complete MFHP (n = 14). Reasons that parents might not complete MFHP could be categorized into anticipated parent challenges, anticipated office integration challenges and privacy issues.

*Anticipated parent challenges:* Two metropolitan/central city physicians expressed that families whose basic needs are not met may be less likely to be concerned with filling out requested forms prior to a doctor's office. *"Our families are all indigent patients, 95% plus Medicaid, so there are a lot of barriers to care that this [MFHP] is not high priority to them at all. Higher priority is - if they even made it to the doctor - higher priority is getting their bus fares, higher priority getting the food to eat that day and something warm to wear, is higher priority than filling this out. I can imagine a different patient population than ours could fill this out quite easily"* (P12). Nine providers suggested that families' limited computer or internet access would be a barrier.

Two suggested that limited literacy skills might hinder families' abilities to complete MFHP. Others suggested the medical terminology incorporated into MFHP would be a barrier (n=5), as families may not be able to specify disease type or understand the grouping of conditions: *"You have the broad categories and if people don't know about a certain diagnosis and what that may fit into, it may take them a little while to find out...it'd be interesting to have sort of a non-medical person play with it to see, you know, is it easy to find the diagnoses?"* (P10). Another provider suggested that providers might overcome this barrier by verifying information contained in the FHH: *"As long as the physician recognizes that it might not be totally reliable and verifies with the patient anything that is really important, I think it really only adds to the encounter rather than causing problems or taking away from it"* (P15).

*Anticipated office integration challenges:* Office integration barriers to MFHP use included a perceived difficulty to changing standard office procedures and forms, especially in clinics with a large number of providers and patient volume (n = 3). One provider explains, *“It’s always pretty difficult when you make changes in the forms, and once everybody became aware that that’s what you’re doing - like if you had 100,000 families in your practice, and all of a sudden you’re going to change a Family Health Portrait form and you have to do it one at a time, I don’t know how long that would take before everybody is on the same format”* (A5). Six providers were concerned about the tool’s ability to link to their current EMR, and two were concerned about the logistics of scanning the tool into all paper charts. Two providers stated that it would be difficult for parents to complete a FHH tool with a child in the room.

*Privacy concerns:* Three providers wanted reassurance that the privacy of the information entered into MFHP would be protected. One provider questions, *“If they are entering FHH on to a public website like this, is there some way that that information is going to be used, you know, if their names are on it, is there some way that that’s going to be used that might be harmful to them”* (P16).

***Uncertainty about how MFHP would affect time spent on FHH:*** Providers’ beliefs about how MFHP would affect the overall time spent on the collection and discussion of FHH were varied. Four providers thought that the use of MFHP would decrease the time spent on FHH collection, three others supposed that it would increase discussion time, and five were unsure if it would add or save time. One provider explained, *“I don’t think it would necessarily impact time wise because I don’t think it’s a substitution to ask some of the questions. If somebody brings it to you, I think you still have to go through it with the patient to be sure that what they think some of these diseases are really the diseases...So I don’t necessarily think it*

would be a time saver, but I do think that it would certainly help ensure that you get good information” (P4). Three providers said that MFHP would make the time spent on FHH more “productive” or “efficient”.

**Ambiguity about feasibility of incorporating MFHP into practice:** Seven providers believed that it would be feasible to incorporate MFHP into their practices, three stated that it would be difficult and eight gave indefinite answers. Those who said it would be difficult or gave indefinite answers cited challenges associated with office logistics and practice patterns, such as large office size, integration into records system, changing practice routines and the challenge of providing computers for family use. They also cited characteristics of the patient population such as limited access to computers and the internet and a low likelihood of completing the tool.

**Strategies for implementation:** Providers offered suggestions to help incorporate MFHP into their practice. Strategies focused on integration of MFHP into the records system, promoting patient awareness and access to MFHP, getting providers on board to use the tool, making the final chart have a pediatric focus and making the tool easily updatable.

**Ease of integration into records system:** Many providers wanted the tool to be compatible and able to be incorporated into their current records system (n = 10). Suggestions included, “Having some kind of an interface between the scan and our EMR” (P16), and, “Whether parents couldn’t send this by email somehow to the electronic medical record, so it’d be automatically in the EMR” (P3), and, “If somehow they could integrate this with our EMR or other people’s EMR, that’d be great if they could just send it to ours” (P14).

*Promoting awareness of and access to MFHP:* To help incorporate MFHP into practice, providers suggested increasing family awareness of the tool itself and the importance of FHH (n = 6), perhaps by an educational pamphlet, reminder phone calls or office posters. One provider reasoned, *“If they have something they can take home with this website on it, sort of explaining the importance of doing it, that may encourage them to actually do it”* (P10). Four providers suggested putting a link to MFHP on their practice website for parents to access at home. Two providers identified a need for financial and logistical assistance with installing computers in clinic.

*“Getting providers on board”:* Two providers voiced that provider education might help improve FHH collection practices or use. Others suggested that FHH might be better collected if there was evidence that the questions asked produce optimal answers (n = 1) or better utilized if there were evidence-based guidelines for the management of patients with a FHH of a condition (n = 2).

*Pediatric focus:* Four providers volunteered that the final FHH chart produced after data input could be tailored to pediatric practice by substituting or adding conditions that usually have a pediatric onset, such as asthma, developmental disability, ADHD, SIDS, congenital heart disease and seizures.

*Ease of updating:* Two providers suggested making the FHH “more visible” in the chart or EMR. One provider explained, *“We’d have to make sure that we put it in a place that people know that it’s information that’s acceptable and that they should you know glance at it and periodically update it. Cause otherwise it’s just like any other part of the chart, if it’s not updated, it’s not as useful over time”* (P4). To facilitate the process of updating information obtained from MFHP, one provider suggested that, *“It would be helpful to have it highlight*

*anything that is new or different when we get the report, rather than looking through the same information that you look through every year” (P15).*

## **Discussion**

Our study was the first to assess pediatric providers’ impressions about the use of a parent-generated FHH in clinic. This is a timely issue because the recent NIH State-of-the-Science Conference: Family History and Improving Health and the subsequent AHRQ report support the need for evidence about how to collect FHH systematically, best methods and tools to obtain and use family history, and use of technology in FHH collection.<sup>24,25</sup> Additionally, the Centers for Disease Control and Prevention workgroup meeting on the use of family history information in pediatric primary care and public health highlighted the need for research on the applicability of available FHH collection tools in pediatric settings, as well as current needs and barriers to the use of FHH in pediatric primary care.<sup>26</sup> Our study showed that providers were favorable towards the idea of collecting FHH prior to the office visit, and identified many benefits implementing a parent-generated FHH collection tool in practice. Our study also identified logistical and family characteristic issues that must be resolved so that MFHP can be more easily integrated into clinical practice.

Our research suggests that pediatric primary care presents many opportunities to collect and discuss FHH with families, including annual well-child visits and sick visits. All respondents collected FHH at a new patient or well-child visit, and more targeted histories when patients presented with other indications. Many reported collecting FHH beyond first-degree relatives and updating FHH, which is important in a pediatric population whose younger parents might not have shown disease yet.<sup>26</sup> Participants used FHH not only for risk assessment, management and education purposes, but also to assess a family’s ability to care for the child. Providers believed that the collection of FHH of chronic disease is important, but importance varied. Valdez et al. (2010) suggests that pediatric providers may give higher priority to FHH if



more guidance for use of FHH information was available or if there were evidence-based benefits to the patient. Some providers in our study suggested that FHH collection of chronic disease may have more benefit to adult patients, but others acknowledged the need for early education and prevention in pediatric primary care. Given the potential for sustained health promotion behaviors, our data suggest that pediatrics may be an optimal setting to use FHH for disease prevention.

Like adult providers, pediatric providers were optimistic about the potential use of MFHP in practice.<sup>6</sup> Some envisioned parents or patients completing the tool at home, while others suggested providing kiosks or laptops in the waiting room. In either scenario, the use of a FHH collection tool may lessen current barriers to FHH collection. Consistent with prior reports, our participants thought that collecting FHH prior to the visit might save time during the visit or might make FHH collection and discussion more efficient.<sup>4,6</sup> Providers suggested that the use of MFHP would extend the scope of information collected. The portability of MFHP might promote sharing FHH information with other providers and family members. Additionally, MFHP may serve as a reminder to review specific FHH information and standardize the information that is collected.

One perceived barrier to MFHP is the providers' concerns about internet privacy; however, it was unclear if these concerns regarded the actual entering of the data online or a misconception about storing data on the internet. It is important to note that respondents were not explicitly told that MFHP could only be saved on a hard drive which would eliminate the concern about storing information on the internet. Women who were previously interviewed about their interest in recording their family history via the internet also voiced privacy concerns,<sup>27</sup> though providers in another study never volunteered any concerns about the privacy of information on the internet.<sup>20</sup> In future studies, concerns or misconceptions about the privacy of information related to MFHP may be mediated by directing providers and families to the "Learn more about MFHP" link

(<https://familyhistory.hhs.gov/fhhweb/popup/getHelp/helpDetailsLearnMore.action>).

Interestingly, no providers in our study voiced privacy concerns about incorporating FHH in the EMR.

Although seven participants thought it would be feasible to incorporate MFHP into practice, many were unclear about feasibility and identified logistical and family characteristic challenges to integrating MFHP into practice. From an office practice standpoint, one such challenge would be integrating MFHP into the current records system. Even if a family completes and brings in a copy of their FHH, it still has to be included in a paper chart or somehow scanned in or linked to the EMR. An update made to MFHP in January 2009 which makes it EMR-ready seeks to address issues of integration into the EMR. Another challenge would be changing the existing practice, including training of all persons involved in collecting and updating patient records. If providers were to place computers in their offices, funding for the computers could be an issue, as would having children near the expensive equipment. Additionally, incorporating family-completed forms into an office visit assumes that the family will complete the forms, which does not always occur. If families do not complete the forms, then backup processes, such as provider collection of information or resources for families to complete the form at the office must be in place. Completion of MFHP on paper could be a backup for families with limited computer access or literacy. However, when we previously worked with a low literacy population, we found that differences in FHH information obtained by an electronic tool versus a paper chart were noted.<sup>21</sup>

Participants' questions and concerns about MFHP identified ways in which it might be improved for use in clinical practice. First, as more practices move toward EMR, having MFHP easily integrated into an EMR is very important to providers. Second, clearly defining how the information is or is not stored on the internet may give answers to providers who have concerns about the confidentiality of patients' personal information. Third, better information may be gained if the terminology and disease groupings are easily understood by lay people. Because

there is a tradeoff between specificity of disease and the consumer's ability to navigate MFHP, perhaps establishing links between the disease name and a description or picture will increase understanding of medical terminology. Since some providers associated social and environmental information with FHH, adding those components to MFHP might improve the scope of information collected. A chart that includes the most common conditions of pediatric practice might make the final printout more useful to pediatric providers.

Our findings indicate that providers perceive that family characteristics such as SES and education may influence parents' ability to collect and record their FHH. However, previous studies suggest that underserved women can complete their FHH using a paper or electronic tool.<sup>20,21</sup> Since the use of a parent-generated FHH requires the participation of both the family and the provider, families' perspectives about the use of a parent-generated FHH tool such as MFHP in pediatric practice need to be explored before MFHP can be integrated into practice.

#### *Limitations of study*

The study population is confined to one geographic area and respondents' views may not be representative of all areas. Although a small sample size is typical of phenomenological research, it limits external generalization. A response bias might be present if those who feel strongly about FHH were more likely to respond to our invitation to participate. In addition, since it is considered standard-of-care to collect FHH in pediatric primary care, and the interviewer was in the field of genetic counseling which values FHH collection, a social desirability bias might have been present. Though participants were guided through data input for a hypothetical patient, there was not sufficient time to thoroughly explain MFHP to the participants, and they were not given adequate time to explore all aspects of the tool, so misconceptions, specifically regarding the storage of data and ability to link to EMR, may have influenced their answers. Assessment of providers' impressions were typically asked in terms of "a collection tool like MFHP", so answers may not be specific to MFHP but instead apply to a larger category of parent-completed computer-generated tools.

Another limitation of our study lies within the fundamentals of phenomenology. Codes are subjectively developed by the researchers, and it is possible that some do not accurately represent the true meaning of the respondent. To address this potential bias, inter-rater reliability was determined for a random sample of three transcripts, and, after coding, all transcripts were reviewed by an independent research team member. Any differences in coding were discussed and agreements were reached by consensus.

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## Appendix

### Appendix 1: Interview Guide

Thank you for agreeing to meet with me today. As you know, the topic of this interview has to do with the use of family health history (FHH) in pediatric primary care. FHH is a known risk factor for many hereditary and chronic diseases. FHH can be used to assess people's risk for disease and to develop more effective strategies for early detection and prevention. We would like to learn more from you about your experiences and preferences regarding the collection and use of FHH in your practice. Let me begin by asking about your current FHH collection practices.

#### Current Practice and use of FHH

1. Please describe the process you use to obtain a FHH for a new patient in your practice.

*If not addressed, probe:*

- a. Who typically collects family history information?
  - b. In what format do you typically collect family history information? (*Prompt if necessary: notes, narrative, pedigree, etc*)
  - c. What type of information do you collect when you record FHH?
  - d. How do you decide what FHH questions to ask? (*Prompt if necessary: standard list, EMR list, memory, etc*)
  - e. Describe which members of a family that you routinely ask about during FHH collection.
2. Please describe any situations other than a new patient visit when you collect FHH information from your patients.

- a. *If not addressed, probe:* In what situations do you update FHH information?

3. What are some reasons you collect FHH information about your patients?

*If not addressed, probe:*

- a. In general, how has FH influenced your clinical management?
  - b. What guidelines, if any, does your practice have regarding collection of FHH?
  - c. How often do you return to ask about FHH during a patient visit?
  - d. How often do you ask about FHH in subsequent visits?
4. How does obtaining FHH impact the time you spend with a new patient?
  5. How does obtaining FHH impact the time you spend during an annual well-child visit?



6. On a scale of 1 to 10 (1 = no importance; 10 = most important), how do you rank the importance of FHH against all other ways you need to spend your time during a new patient visit?
  - a. *If 5 or lower, probe:* What needs to happen to improve your ranking?
7. What are your thoughts about collecting FHH information about chronic disease in relatives of your pediatric patients?
8. In your opinion, does/would collecting FHH about chronic disease benefit your pediatric population?
9. Have you experienced any barriers to collecting FHH in your practice?
10. Do you have any suggestions for how FHH data could be better collected in routine clinical practice?

#### Patient-generated FH

11. In the past year, how many parents or patients have brought you a FHH that they generated themselves outside of your office? *If “zero”, skip to next section.*
12. *If not “zero”, probe:* How was this history presented? (*Prompt if necessary: handwritten or computer-generated; text, chart, or pedigree* )
13. *If not “zero”, probe:* How did you use the FHH information provided by the patient?

#### My Family Health Portrait

Because family health history is a powerful screening tool, the Surgeon General created a computerized tool to help individuals collect their family health history called *My Family Health Portrait*. The web-based tool allows individuals to organize information about their family history and present it to their PCP. Are you familiar with *My Family Health Portrait*?

If yes, ask interviewee how s/he is familiar with it and if s/he has ever completed *My Family Health Portrait*. Say: I want to make sure we are talking about the same tool.” Show participant *My Family Health Portrait* and then ask them their impressions about the tool based on their previous use of it.

If no or not completed, say: I’d like you to spend a few minutes using *My Family Health Portrait* to get your impressions of how this online tool works. Please go to the website <http://familyhistory.hhs.gov/>. We are going to create a Family History, but notice the option to open a saved history file.

The first information you fill in is personal information. Let’s say that your name is John Doe and that your birth date is 12/12/1970. You are not a twin, and your height is 6 ft 2 in. Your weight is 220.

The next section asks about health information. Notice the scope of conditions available, and the option to add a new condition. You have colon cancer, diagnosed 30-39 years and high cholesterol, diagnosed in your 20s. You are white and not Hispanic or Latino.

For simplicity purposes, let's say that you have one of each of the listed relatives.

From this table, you can add the same health information that you added about yourself about each of your relatives. If you do not have any information, that is okay too. There is also the option to add other family members that were not previously asked about, such as nieces and nephews and step children. Let's add information about your daughter.

Her name is Jane; She is living; She is 10 years old; Has asthma, diagnosed in childhood.

Please take 2 minutes to explore the tool. When you have filled out all information you want to include, click view diagram and chart.

Scroll down, notice the 3-generation pedigree and key. Age of diagnosis is displayed in the chart below. Presence or absence of common chronic disease is also listed. This page can be printed or saved.

Just for your information, there is also a paper-based version of the tool.

I will be happy to answer further questions about the tool to the best of my ability in a few minutes. First, I'd like to ask you a final set of questions about your impressions of the tool.

14. Have you ever had a patient or patient's family bring you his/her FHH using *My Family Health Portrait*?

a. *If yes, probe:* What was your reaction?

#### Impressions and perceived value of *My Family Health Portrait*

15. Now that you have spent a little time working with *My Family Health Portrait*, what are your general impressions of this tool?

*If not addressed, probe:*

a. What are your thoughts about the ease or difficulty of completion?

b. What are your thoughts about the time needed to complete the tool?

c. Tell me your thoughts about the scope of information collected.

d. Tell me your thoughts about the final presentation of the information.

16. How might *My Family Health Portrait* be used in pediatric practice? Please explain.

17. What concerns do you have about the potential use of *My Family Health Portrait* in practice?

18. If a patient were to bring you a FHH using *My Family Health Portrait*, how do you think it might impact your current practice?

*If not addressed, probe:*

- a. How might it impact your collection of FHH?
  - b. How might it impact your discussion of FHH?
  - c. How might it impact your clinical decision-making?
  - d. How might it impact your time spent on FHH?
  - e. How might it impact the total time spent with a patient?
19. How feasible do you think it would be to incorporate a FHH collection tool like *My Family Health Portrait* into practice?
20. What would be most helpful to you to incorporate a FHH collection tool like *My Family Health Portrait* into practice?

**Table 1:** Participant Characteristics

Characteristic		N (%)
Gender	Male	5 (24)
	Female	16 (76)
Race	Caucasian	17 (89)
	Asian	1 (5)
	African-American	1 (5)
Time spent taking FHH, assessing risk and discussing findings at new patient visit	1-5 minutes	11 (61)
	> 5 minutes	7 (39)
Practice setting	Major medical center	4 (19)
	Community practice	17 (81)
Years from medical/graduate school graduation	≤ 15	9 (50)
	> 15	9 (50)
Primary care specialty	Pediatrics	16 (84)
	Adolescent Medicine	3 (16)
Practice location	Urban	7 (7)
	Suburban	11 (58)
	Rural	1 (5)

**Table 2:** Inter-rater Reliability for each Theme

1. CollnProcess	1
2. CollnWho	1
3. Documt	1
4. CollnInfo	1
5. CollnDecide	1
6. CollnMem	0.84
7. CollnScen	0.6
8. CollnUpdate	0.78
9. CollnReason	0.57
10. Influmgmt	0.61
11. CollnBarr	0.65
12. CollnTimeNew	1
13. CollnTimeAnn	0.71
14. ImpScale	1
15. ImpScaleReas	1
16. CollnChron	1
17. CollnChronBen	0.77
18. CollnSugg	1
19. PastYr	1
20. Familiar	1
21. ToolImpress	1
22. ToolEase	1
23. ToolComp	1
24. ToolScope	1
25. ToolFinal	1
26. ToolUse	0.67
27. ToolBarr	0.86
28. ToolImp	0.6
29. ToolTime	1
30. ToolFeas	1
31. ToolIncorp	1
32. ToolBen	0.6

**Table 3:** Utilization of FHH Information

	<b>Reasons for Collecting FHH</b>  (n = number of providers identifying theme)	<b>How FHH Influences Clinical Management</b>  (n = number of providers identifying theme)
Appreciate patients' risks	16	0
Recommend screening practices	6	16
Provide patient and family education	5	5
Prevention	5	0
Aid in diagnosis	4	6
Target surveillance	4	3
See the overall picture	2	0
Find out if a parent has experience providing care for a condition	2	0
Find out if a parent's history of chronic illness might inhibit their ability to care for a child	1	0
Refer to genetics and other specialists	0	7
Decide which guidelines the patient should follow	0	3
Prompt further questions or physical examination during the office visit	0	3

**Figure 1:** Conditions of Importance to Pediatric Providers

