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I, Kelly A Berger , hereby submit this original work as part of the requirements for the degree of Master of Science in Genetic Counseling.

It is entitled:

Mothers' Perceptions Of Family Health History And An Online Parent-Generated Family Health History Tool

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Mothers' Perceptions of Family Health History And An Online Parent-Generated Family Health History Tool

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by

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Abstract:

Purpose: To learn about parents' 1) perceptions of the meaning of family health history (FHH) 2) prior experience with FHH, and 3) impressions of and willingness to complete the Surgeon General's FHH tool called My Family Health Portrait (MFHP). *Methods:* Qualitative in-depth interviews were conducted with parents recruited through a newsletter and advertisements at Cincinnati Children's Hospital Medical Center. Themes were developed using deductive codes based on pre-determined interview questions and inductive codes based on interviewee responses. Interviews were transcribed and then coded by two coders. Inter-rater reliability was determined using Cohen's Kappa. *Results:* Twenty-five respondents were interviewed. Nineteen (76%) mothers described FHH as being aware of the diseases that run in families. When asked about value of FHH six mothers (24%) discussed prevention of disease or diagnosing at an early stage. Sixteen (64%) mothers reported talking to their pediatrician about health problems that run in their family. All participants had positive impressions of MFHP after being shown the tool. Most participants felt MFHP was user-friendly and an easy program that facilitated FHH collection (n=17; 68%). The most commonly expressed challenge to completing MFHP was a lack of knowledge about health conditions within the family. Most respondents (n=23; 92%) stated they would be able to complete MFHP prior to their child's medical appointment. *Conclusion:* These findings suggest parents are interested in FHH and may be motivated to complete a parent-generated FHH outside of a pediatric appointment. Future research should focus on implementation and usability of parent-generated FHH in clinical practice.

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Table of Contents

Introduction.....	1
Methods.....	2
Results.....	4
Discussion.....	18
References.....	25
Appendix.....	27

Figures and Tables

Table 1: Health Concerns for Children	5
Figure 1: Positive Views on MFHP.....	12
Appendix 1: Disease/Conditions Included in MFHP	27
Appendix 2: Interview Guide	28

Introduction:

Family health history (FHH) is a cost-effective and simple tool used by health care providers to identify families and individuals who are at an increased risk for developing disease. It is able to capture shared genetic, environmental, and lifestyle factors that contribute to one's overall health. Data show that having a first-degree relative with a common chronic disease can increase one's risk of developing that disease anywhere from two to five fold [1]. From a clinical standpoint, collection of FHH can benefit patients through targeted risk analysis, education, and interventions [1-3].

Recognizing that FHH is one of best current predictors of chronic conditions including obesity, diabetes and cardiovascular disease, the Surgeon General initiated a FHH campaign in 2004 in which families were encouraged to collect their FHH and share it with their provider [4]. To facilitate the collection, documentation and sharing of FHH, a public web-based tool called *My Family Health Portrait* (MFHP) was designed [4]. MFHP allows users to complete their FHH in a step-wise process and presents the entered information in both a pedigree and a chart format. The pedigree shows every health condition entered into the tool. The chart has individual columns for six common diseases (stroke, diabetes, heart disease, ovarian cancer, breast cancer and colon cancer) and another column for any additional health information entered. The most recent version includes a drop-down menu with an extensive list of health conditions grouped into 17 broad categories that are further divided into subcategories (See Appendix 1). It is also compatible with some electronic-medical record (EMR) programs [5]. At least one study suggests that patient-completed MFHP information for diabetes, breast, ovarian and colon cancers is highly accurate [6].

The pediatric setting may be an ideal place to collect a detailed parent-generated FHH to promote health and to aid in disease prevention [7-13]. First, children visit the physician's office more frequently than adults, allowing for more opportunities to collect FHH data [10, 12]. Second, parents' routinely accompany their child to the pediatric appointment, which can allow pediatricians to ask questions to produce a more detailed FHH to provide information to the parents about health risks for themselves and their children [10]. Third, healthy habits and behaviors are best learned at young ages, therefore if a child is at risk for developing a common chronic disease, risk-reduction interventions can begin during the pediatric period [3, 9-11]. Fourth, parents are more likely to make positive lifestyle choices for their children than themselves, possibly reinforcing the recommendations proposed by the pediatric providers [7, 8, 10, 13].

While there are many potential benefits to collecting FHH in the pediatric setting, to our knowledge, the feasibility of parents' completing this type of information prior to a pediatric visit has not been assessed. Pediatric providers' perspectives of parent-generated FHH have been studied previously [10], but the current study is the first to focus on parents' perceptions of the significance of FHH as well as feasibility of completion of MFHP. The preliminary data gathered from our research will help to determine the parents' perspectives of MFHP.

Methods:

Due to its novel and exploratory nature, this study utilized a phenomenological approach to gain knowledge from the participant's point of view. Utilizing a phenomenological approach best guided the qualitative research in a way that accurately reflected the thoughts and experiences of those being interviewed [14]. Unlike many other types of research, a

phenomenological approach does not have a predetermined hypothesis and will allow for in-depth information to be gathered from a relatively small sample size and for analysis to be conducted on the developing patterns and relationships [14, 15]. Institutional Review Board approval was obtained from Cincinnati Children's Hospital Medical Center (CCHMC) and the University of Cincinnati.

Participants and Recruitment

Study participants were recruited through the Clinical Trials Office at CCHMC by posting flyers on a research board. Information about the study was also included in mailers sent to over 1,500 people who previously expressed interest in participating in research studies at CCHMC. Interested participants contacted Kelly Berger (KB) by phone and were given the option of participating in an in-depth interview at CCHMC or by phone. Although our recruitment materials targeted "parents" of children under the age of 18, only mothers responded and agreed to participate in the study. Interviews were scheduled with any interested parent that met our inclusion criteria. Inclusion criteria included having at least one child under the age of 18. For the phone interviews, parents were required to have access to a computer with an internet connection for the duration of the interview. A computer with internet access was available onsite for interviews conducted at CCHMC. Only one parent of a child was eligible to participate.

Protocol

All interviews were conducted, audiotaped and transcribed by KB. Informed consent was collected prior to all interviews. The interview guide was piloted on a convenience sample of three parents for face validity and comprehension (Appendix 2). The first section focused on assessing parents' current perceptions, understanding and prior use of FHH within a pediatric

setting. Respondents were then introduced to the online tool, MFHP, and asked to spend about 15 minutes inputting FHH information for one of their children and respective family members. At the conclusion of the interview, participants were asked about their impressions of MFHP in pediatric practice. As a thank-you for taking part in the interview, mothers received a CD-ROM containing the FHH completed by the parent as well as a folder of information regarding FHH. After the interview participants were asked to complete a brief demographic questionnaire. For telephone interviews, the demographic information was collected over the phone. Interviews lasted between 20 and 60 minutes.

Data Analysis

A codebook was created to keep track of emergent themes and sub-themes. The themes were developed using deductive codes based on pre-determined interview questions and inductive codes based on interviewee responses. All transcripts were coded by KB. A second coder independently coded 20% of randomly selected transcripts and inter-rater reliability was determined between coders. Any discrepancies were resolved through consensus. The second coder reviewed all remaining transcripts for consistency. Coded data was organized and quantified using ATLAS.ti, a qualitative analysis software program [16]. No new themes emerged after 25 interviews and recruitment was stopped.

Results:

Demographics

Of the 46 participants who initially showed interest in the study, 25 interviews were completed; 24 were in-person and one was by telephone. Among the remaining 21 participants who initially showed interest in the study, nine “no-showed” for the appointment or called to

cancel without rescheduling, eight didn't return follow-up phone calls, three declined participation after learning more about the study, and one didn't have a child within the age limits. All participants were female. Twelve were African American, nine Caucasian, two Asian Indian, and two Hispanic. The majority of the women were married (n=14). Of the 22 women who provided their education level, half received a four year college education or higher (n=11), five had some college, five had a high school diploma or GED, and one was currently in high school. Mothers were asked if their children had any special health care needs or were followed for any chronic health conditions. Only six participants did not report any health concerns for their children; the health concerns listed by the remaining 19 participants are listed in Table 1 below.

Table 1: Health Concerns for Children	
Participant ID	Health Concerns ¹
1	Hypotonia, Allergies
3	Asthma, Allergies
4	MRDD, Asthma, Allergies, Seizures
5	Asthma, Allergies
6	CMD, Athrogryposis, Club Foot
7	MRDD, Asthma, Lung Disease, Obesity, Depression, ADHD, ODD, FTT, Hearing Loss
9	Eosinophilic Gastritis
11	Asthma, Allergies
12	Chronic Ear Infections
14	Asthma
16	Brain Injury, Cerebral Palsy
17	Eczema, Allergies
18	Prolapse
19	Asthma, Allergies, Depression, ADHD, PTS
20	ADD
21	Tracheomalacia, premature
22	Speech Delay
24	Shwachman-Diamond Syndrome, Migraines, IBS, Small for Gestational Age, ADD, ADHD, Cerebral Palsy
25	Asthma, Eczema

¹ CMD = Congenital Muscular Dystrophy; MRDD = Mental Retardation, Developmental Delay; ADHD = Attention Deficit Hyperactivity Disorder; ODD = Oppositional Defiant Disorder; FTT = Failure to Thrive; PTS = Post Traumatic Stress; ADD = Attention Deficit Disorder; IBS = Irritable Bowel Syndrome

Cohen's Kappa was used to calculate agreement between coders. A κ -value above 0.60 was targeted as this signifies substantial agreement between coders [15]. After the second reviewer coded 20% of the transcripts, 18 categories (62.1%) showed near perfect agreement ($\kappa > 0.81$), and six categories had κ -values above 0.60. Three categories had κ -values between 0.55 and 0.58 and were considered acceptable by the research team. The two remaining codes required KB to retrain the independent coder and two additional transcripts were analyzed. After retraining, the κ -values were above 0.60, meeting substantial agreement.

Emergent themes were grouped into six different categories: *mothers' understanding of FHH*, *mothers' previous experience of FHH*, *positive views of MFHP*, *challenges encountered with MFHP*, *future use of MFHP* and, *recommended improvements for MFHP*.

Mothers' Understanding of FHH

Mothers' understanding of FHH was divided into two main sub-themes; *awareness and prevention*, and *FHH interpretation*.

Awareness and Prevention: The interviews began by asking all 25 mothers to describe what FHH meant to them. Nineteen mothers (76%) described FHH as being aware of the diseases that run in families. Three of the participants (12%) described FHH as "*things in the families past*," but did not specifically relate it to medical conditions or disease. Instead they spoke in generalities like, "*information*," "*everyday life*," and "*social things*."

Nine respondents (46%) related FHH to health risks for themselves or their children based on the diseases that run in their respective families but did not seem to always make the connection to prevention. In other words, they compared it to being aware of their *vulnerabilities* or *susceptibilities* to specific diseases without talking about how knowing that information could lead to prevention or lifestyle changes. For example, one of the nine

participants stated that the importance of knowing the FHH was that *“if you know about it then you have a better chance of...not necessarily controlling it, but being more informed about it”* (T25). However, when asked about the *value* of FHH, six mothers mentioned prevention and felt that FHH information could be used to prevent the disease or diagnose the condition at an early stage. For example, one parent noted,

“[FHH] helps you because it can help you prevent stuff...depending on what disease or whatever is that trigger’s your family health history you can avoid going through some things that another family member went through by finding out earlier than waiting till your symptoms get worse or your health fail.” T15

Others felt that FHH was valuable because talking about FHH with family could help them learn more about the past (n=3; 13%) and sharing FHH with medical professionals could allow for better healthcare in the future (n=2; 9%). Participants were also asked about the value of FHH for their children. The most common response was prevention (n=7; 41%) as a result of changes in lifestyle or medical management.

FHH Interpretation: Participants frequently had questions about what diseases/conditions were relevant to FHH, particularly if a condition was not listed in the drop down menu of MFHP. Conditions mothers asked about included: allergies, anemia, clotting/vein problems, club foot, ear infections, eczema, foot problems, impacted tooth, kidney stones, menopause, migraines, miscarriages, needing glasses, obesity, prematurity, seizures, spider bites, substance abuse, and un-descended testicles. Of these, only one, clotting/vein problems, was listed on MFHP. Occasionally mothers would not see a specific condition or disease, such as allergies, listed in MFHP and assumes the condition was not of interest to pediatricians. One participant wanted to know if both present and past health concerns qualified as FHH and should be included in

MFHP. Another mother asked if MFHP was similar to ancestry.com. Ancestry.com allows the user to search for family members using historical records. The main page of the website states it is the world's largest online resource for family history documents and family trees. Of interest, the mother who asked about ancestry.com described the meaning of FHH to be "*your families past and things that have happened...gatherings, just social things and everyday life*" (T14); including all social determinants of health in her description of FHH.

Mothers' Previous Experience with FHH

Respondents were asked several questions about their previous experience with FHH collection and pediatric visits including *pediatric experience, benefits of sharing FHH, pediatric recommendations and concerns about sharing FHH*.

Pediatric Experience: Sixteen mothers reported talking to their pediatrician about health problems that run in their family (64%). These 16 were then asked to share an experience where they discussed FHH information with the pediatrician. The most frequent experience shared was discussing a specific disease that runs in the family; one participant discussed sharing a family history of heart disease and high blood pressure with the family pediatrician. Three participants discussed a personal or family diagnosis with their child's pediatrician in hopes of using the information for prevention for their child. One mother discussed a situation where she felt the physician took her child's symptoms of depression more seriously after revealing a family history of depression

"...I had to reveal that I suffered from depression a long time ago, and my mother had it too. So that really helped them to...make a decision that is something we need to address and helped the doctors realize, ok, this isn't just a passing thing." T19

Benefits of Sharing FHH: All mothers (n=25) felt there were benefits to sharing FHH with their child's pediatrician. The most commonly perceived benefit (n=12) was to keep the pediatrician informed of FHH because knowledge could lead to preventive screenings (n=10), lifestyle recommendations or change of care (n=4) for the child. Another stated benefit included parent education (n=3) about what may happen or to learn about a specific condition.

Pediatric Recommendations: Participants were asked if their pediatrician had ever provided any health recommendations to the family or child based on FHH. Only nine mothers (36%) responded yes. They reported recommendations for basic medical management, such as recommending a physical therapy evaluation for a young girl with joint laxity and a strong FHH of joint problems, but also included pediatricians discussing early warning signs or symptoms of a specific disease noted in FHH.

Concerns about Sharing FHH: Mothers were also asked if they had any concerns about sharing FHH information with their child's pediatrician. The majority, 88% (n=22), stated they had no concerns about sharing FHH. Two mothers previously changed pediatricians in order to find a better fit and a more positive rapport. Prior to the change, both mothers stated they would not have felt comfortable sharing FHH or stated they did not feel the physician was receptive to that information. Another participant stated, *"I think we have a great pediatrician. So I think that they listen, but I also know it's hard to remember everything and how well it gets documented..."* (T1). One mother was concerned with insurance companies learning about their FHH. Respondents were asked if they thought other parents might have concerns about sharing FHH. The most common response (n=5; 29%) was a concern about social stigma surrounding some diagnoses, such as psychological problems or cancer. One mother stated, *"I think there is a certain stigma that goes along with depression and anxiety, and I know that there are a lot of*

people and maybe even doctors at times that don't quite maybe accept that as a medical issue" (T11). Additional concerns that respondents identified as potential issues for other parents were poor rapport with the pediatrician leading to lack of sharing information (n=4; 24%), concerns about insurance discrimination (n=3; 18%), resistance to admit to the health problem being in family (n=3; 18%), lack of parent understanding the importance of FHH information (n=1; 6%), and physicians over-reacting to FHH and 'over-screening' (n=1; 6%). However six participants (36%) did not feel parents should have any concerns discussing FHH with pediatrician.

Positive Views of MFHP

None of the twenty-five participants had previously seen or heard about MFHP. All participants, (n=25) had positive input about using MFHP. (See Figure 1 below)

Increased Awareness: Four (16%) felt that filling out MFHP was beneficial because it made them more aware of the health conditions and ages of onset/diagnosis in the family. One *"was impressed that it just made [me] feel more in control over our diagnosis and our history and it makes me feel good knowing that I have this information for the doctors, but it also makes [me] feel like [I] don't know enough"* (T23).

User-friendly: Most felt it was user-friendly (n=17; 68%), *"an easy program"* (T2), *"a nice way to go through your family history"* (T21), and *"easier to put stuff together than [they] thought it would be"* (T24).

Convenience: Eleven participants commented on the convenience of MFHP being electronic and paperless (40%). Three mothers specifically commented on how *"it's saved on a disc where you can use it and put in more information that you find as you know any other follow-up information that is given to you, you can put that on there"* (T3).

Visual Output: There were several positive comments about the “*tree-view*” (T12) and chart (n=8; 32%). Some really liked the chart at the end “*cause [they] can see that just being printed off and handed to a physician at that point. Meet the family, at a glance kind of thing*” (T22). Others thought the “*pedigree is a really nice visual of your current family’s health*” (T13). Overall, MFHP’s output is “*more graphic, you see everything at a glance*” (T20).

Pre-set Conditions: To speed up MFHP completion, three mothers appreciated “*it had diseases already in there*” (T15) and “*walks you through it and it has a lot of the symptoms right there for you where you can look at, like if you had lung, it goes straight into the different categories of asthma, then when you went into heart disease, hypertension. And it had several listings under that it makes it easier for you to select one*” (T23).

Age Groupings: One mother liked the ten-year age span for age of diagnosis and stated, “*they made that easy*” (T1). Another thought the “*estimated age*” in ten year ranges was “*nice for just a quick filling out to realize what you don’t know and then going back and you can ask people to fill in the rest of it more accurately*” (T6).

“Add New” Option: While several mothers liked the pre-set conditions and diseases, two participants also liked that they could add new conditions not listed. Mothers also appreciated that MFHP had the capability to retain the newly added diagnoses and previously entered ages and were available while inputting other family members because it “*made entering a little bit easier and faster*” (T17).

Challenges Encountered with MFHP

Several challenges of using MFHP emerged while interviewing participants, including *incomplete FHH information, challenges with preset conditions, technical challenges and perceived barriers.*

Incomplete FHH Information: The most frequent challenge that came up while using MFHP was the lack of FHH information about other family members, often due to strained or limited relationships with family members. Twenty different participants (80%) mentioned at some point in the interview that they did not know “*exactly everything about everyone, but...just know the basics*” (T15). Some participants stated that the family was not open to discussing

² **User-friendly** - MFHP was an easy program to use. **Convenience** – MFHP was available on the computer **Visual Output** – Output at the end including pedigree and chart. **Increased Awareness** – Completing MFHP made parent think about similarities of diseases or ages of diagnosis in family. **Pre-Set Conditions** – Diseases and Conditions already programmed into MFHP. **Age –Groupings** – 10 year age spans for age at diagnosis. **“Add New” Option** – MFHP allows users to free-text in diseases or conditions not programmed in.

health issues. One participant said, *“I’m not sure what they all have cause I don’t communicate with them”* (T4). Due to the limited communication, one mother stated *“I would use [MFHP] if I knew more about my family”* (T5). In four interviews (16%), the issue of identifying pertinent health information in blended families was raised. For mothers who had children from several different relationships, limited information may have been available from the child’s father’s side of the family. For example, some mothers were not sure about the relationship between a previous partner and his siblings—for example, if they were full, half or step siblings—and were not sure what health conditions those siblings might have had. In a few cases, participants skipped filling out their child’s father’s side of the family on MFHP, limiting the potential benefits of collecting FHH.

Challenges with Preset Conditions: Eight different mothers had challenges with the medical terminology used in MFHP: *“Some people might know them by different terms than what the medical terminology might require”* (T15). Some participants did not know that hypertension was the same as high blood pressure (n=6). Other mothers had difficulty identifying a specific disease within the disease groupings (n=5): Mothers looking for asthma didn’t know to look under “lung disease,” and mothers looking for ADHD didn’t know to look under “psychological disorders.” Some mothers felt MFHP was lacking diseases they considered to be important, including obesity, cervical cancer, thyroid problems, and women’s health problems (miscarriages, endometriosis, HPV, etc) (n=4). One mother wanted to see diseases and health conditions grouped by systems or body part (skin, reproductive, hearing, etc.). Another thought the ten year spans should continue until 80 and above (n=1). Four mothers had questions about which ages qualify as newborn, infancy, childhood, and adolescence, which are the four age groupings prior to the start of the ten year spans.

Technical Challenges: Challenges were also identified with the technical set-up of MFHP. For example, entering in the birth date required a specific format (mm/dd/yyyy) which was challenging for mothers, often requiring them to go back and fix the formatting. Several mothers had difficulties adding half-siblings or knowing that half-siblings were not supposed to be added at the “Add Immediate Family Members” page which asks “How many (brothers, sisters, etc.) do you have?” For some mothers it was challenging for them to think of their child as the proband while filling out how many siblings, aunts and uncles their child had because “you” is the child. Mothers instinctively answered this question for themselves instead of their child: One participant said she desired “*a way that it could be worded so that if the parent of the child was doing it, so you’re not constantly like, you know I have to think of who*” (T6). Also, the process to change the proband presented a challenge (n=1). One mother thought the saving process was challenging. She completed the interview over the phone and was the only mother who had to save the health information herself. Another mother identified the lack of interpretation of FHH as a technical challenge, and would only use the tool if it was able to provide personalized risks. Lastly, the website itself was slow in responding for three of the mothers during the interviews.

Perceived Barriers: Participants were also asked if they felt other parents would have any barriers to completing MFHP. Besides the concerns of not having access to the internet (n=5; 22%) and not knowing how to use MFHP (ie, drop-downs, navigation, etc.) or a computer (n=8; 34%), other barriers included parents not knowing the health information of family members (n=7; 30%), being too busy (n=4; 17%), and parents not realizing the importance of FHH information (n=1; 4%). It was also suggested that the tool be available in the pediatrician’s office so MFHP could be completed as a part of the medical visit or while in the waiting room.

Two mothers mentioned that thinking about FHH was upsetting to them because “*it’s kind of scary when you look at the pattern of the similarities of ...deaths*” (T23).

Use of MFHP

Participants were asked about how they thought they would use MFHP. Their responses were divided into three different sub-themes; *future plans for MFHP*, *potential health benefits of MFHP*, and *parent completion of MFHP*.

Future Plans for MFHP: When asked how they might use MFHP in the future, the most common response (n=10; 62%) was that mothers would take MFHP to a physician’s appointment (not all specified pediatric appointment). One mother specifically stated, “*It could be really good for families that do have to move a lot, like military families or something like that*” (T11). Others stated they would keep it up-to-date (n=9; 56%), give it to their child when they got older (n=5, 31%), have it available in case of emergency (n=4; 25%), and use it to educate their children to make healthier lifestyle choices (n=1; 6%).

Potential Health Benefits of MFHP: Mothers were asked if they thought collecting FHH information would be helpful in improving their own health. Fifteen mothers (71%) thought it would make them more informed of their own health risks because they would “*know what’s coming down the line*” (T8). Six mothers (29%) specifically stated that the information may make it easier for them to use preventive care, including screening and lifestyle recommendations. Two mothers (9%) stated they didn’t think FHH would have an impact on their health; of these, one stated it would be more beneficial for their children. When asked if they thought collecting FHH information would be helpful in improving their child’s health, sixteen mothers (76%) stated they would use it to make their child more informed about his/her own health risks. Five mothers (24%) stated they would use the information to make themselves

(the mothers) more aware of the child's health risks. Four mothers (19%) stated they hoped collecting FHH would increase pediatric awareness making it easier to take advantage of preventive medicine/lifestyle and potential follow-up for the child.

Parent Completion of MFHP: Mothers were specifically asked if they would complete MFHP if their child's pediatrician asked them to complete it prior to their child's next visit. A majority (n=23; 92%) stated they would complete the information and bring it to the medical appointment. One mother stated it would only get completed if it was mandatory and another stated she would only complete MFHP if it were available on a computer at the pediatrician's office prior to being seen.

Recommended Improvements to MFHP

Twelve mothers' had suggestions for improving MFHP, some of which directly relate to the already identified challenges, including *disease groupings, medical terminology, technical enhancements, and a template for contacting relatives.*

Disease Groupings: Organization of diseases had been identified as a challenge, and mothers offered multiple suggestions for reorganizing the list of diseases. Suggestions were made to include more pediatric conditions such as allergies or recurrent ear infections (n=2), more diseases on the "disease or condition" list and less under headings (n=3), more headings for other body systems (n=2), and to put the list in alphabetical order under the "more options" tab to make it "*more intuitive from a user perspective*" (T1) (n=1). A specific suggestion was to have a group with "*womens' health issues and mens' health issues*" (T16) including gender specific concerns (miscarriages, endometriosis, etc.) and STDs (n=2). One mother explains her reasoning for wanting a larger list:

"I think it may have had some really good categories, but I guess it would help, for me, to have a bigger list, like oh yeah that's right, that

person does have that so that it would kind of trigger my memory. Because just kind of sitting here thinking about, ok, what does this person have? I'm sure I'm missing things..." T10

Medical Terminology: Mothers also had challenges with and suggestions for addressing the medical terminology. Two participants suggested it may be helpful to have non-medical terminology next to the medical word or to have a pop-up with a short explanation of the disease when they scroll over it.

"I guess it would be good to kind of be more descriptive, like you know, I didn't know all these diseases and other than the names or whatever, should have had a little bit more information saying what it was, like if you move the mouse on it...Saying ok, these are the symptoms or this is the disorder..." T18

Technical Enhancements: Mothers experienced technical challenges with MFHP and provided suggestions for improvement. Suggestions for the tool included 'auto-fill' for race for other family members if the child is not bi-racial (n=1) and more follow-up questions if certain conditions are entered. For example, if lung cancer is listed as a disease, the program should ask the user about smoking or if diabetes is entered, the program should ask the user about obesity (n=1). Three mothers wanted MFHP to go back more than three generations. One felt it should be easier to change the proband from one family member to another. Two mothers wanted a spot to include dates for common childhood illnesses, vaccines, surgeries, etc., so their child's health information could be kept in one place. Three mothers mentioned they would like MFHP to be more interpretive and provide personalized disease risks, including to "*know what's genetic and what isn't*" (T16).

"I was hoping that somewhere in there, I don't know if it's even possible to say that, ok that this is in the family and this is the percentage of chance that somebody, it could be passed down...because what it is, it's just giving you basically a table of what's what, it's not giving it, it's the information you put in. You're not getting anything out of it." T18

Template for Contacting Relatives: To address the challenge of not knowing about the health of other family members, one mother thought “*if you could have some kind of set text that you could send to your family. I know it was like pulling teeth to get my mother and father-in-law. They don’t want to tell their families, they don’t want to think that anything is wrong with them. So maybe if you said, hey I’m doing this for my [child], trying to get a good history, give them a reason, they’d be more likely to tell them that.*” (T12).

Discussion:

To our knowledge, this study is the first to focus on parents perceptions of FHH and utilization of FHH in a pediatric setting. In general, mothers responded positively to the idea of recording their FHH prior to a pediatric appointment. Participants suggested several ways they felt collecting FHH information could benefit them or their children; including being more informed about potential health risks and receiving pediatric recommendations for preventive care with screening and lifestyle recommendations. Previous research also suggests that parents are interested in FHH for the benefit of their children [13]. Participants in the current study also provided different ways they planned to use FHH in the future; including bringing MFHP to a physician’s appointment, and giving the FHH information to their child when s/he got older. Since participants worked with MFHP during the interviews, they also provided feedback regarding the online tool and provided several suggestions for overcoming the challenges they encountered.

When asked broadly about the value of FHH, only six mothers mentioned prevention. However, when more specifically asked about the benefits of sharing FHH with their child’s pediatrician, 10 mentioned prevention. The reason for this difference is unclear. It is possible that in the former scenario parents were considering the value of FHH for themselves, whereas in

the latter scenario they were thinking specifically about benefits for their children. Both Cree et al and Wallace et al. found that women perceived a major benefit of FHH to be utilizing the information to protect their children and keep them healthy [8, 13]. This consistent theme about benefits to children reinforces the potential to improve pediatric outcomes by introducing FHH in pediatric settings. If parents are more likely to make changes for their children, FHH may be most actionable in a pediatric setting and changes made in childhood could potentially have longer lasting health benefits than those made as adults.

The benefits of introducing parent-generated FHHs in pediatric settings can only be realized if providers also perceive benefits to parent-generated FHHs. We were therefore interested in comparing the findings of our study which assessed mothers perceptions of FHH and MFHP, to that of the study by Kanetzke et al, which evaluated 21 pediatric providers' responses to MFHP and providers' perceptions of parents recording FHH prior to a pediatric visit [10]. Similar and different findings between the two populations (parents and pediatric providers) are noted below.

Similar Findings

Lack of Knowledge: Both providers and mothers identified lack of knowledge about FHH as being a barrier to parent-generated FHHs [10]. Providers hypothesized that family dynamics and limited discussion of medical information between family members could limit the completeness of FHH [10]. Eighty percent of mothers expressed limited knowledge about a family member's health conditions at least once during the interview.

Potential Health Benefits: Nine percent of providers in the study by Kanetzke et al. thought collection of FHH could empower families to participate in their own healthcare [10]. Sixteen percent of mothers specifically stated that they liked how MFHP made them more aware

of health conditions and the ages of onset of health conditions in their family. Forty percent of mothers stated they would bring MFHP to a future physician's appointment. Both mothers and providers felt bringing parent-generated FHHs to pediatric appointments could lead to health recommendations based on FHH and positive lifestyle changes. One parent and one provider made very similar suggestions regarding patient education, the parent explained:

"Maybe it would be great, if the doctors could take this information and talk to the child as they get older, you don't want to worry them too much, but you do want to educate. So there is a difference. Somehow, like for example, say... you know heart disease does run in your family, and you're healthy and you probably will be healthy, you just have to remember, you know, for example, your diet and exercise" T19

The pediatric provider from Kanetzke et al's study thought MFHP:

"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[10]."

Easy to Update: Nineteen percent of pediatric providers from Kanetzke et al's study and 36% of mothers believed MFHP could be easily updated [10]. The electronic nature of the tool increased the ease of updating for many mothers.

Visual Output: Seventy-six percent of pediatric providers and 32% mothers liked the pedigree and chart created by MFHP[10]. Providers thought the pedigree and chart "were organized and easy to read and that the pedigree provided a clear display of inheritance patterns,[10]" and mothers described it as a "meet the family at a glance" (T22). Both mothers and providers thought MFHP could increase portability of FHH information.

Different Findings

Perceived Barriers: One of providers' main concerns addressed computer access and literacy issues, and Kanetzke et al identified this concern as an area for future research [10]. While mothers did not identify computer access and literacy issues as a concern for themselves, they suggested computer access and literacy might be a concern for other parents trying to fill out MFHP prior to an appointment. It is unknown if some of the mothers actually identified computer access and literacy issues as potential problems for themselves but spoke hypothetically because they were uncomfortable revealing they faced access and literacy problems. A recent survey evaluating demographics of internet users surveyed 2,252 American adults and found that 71% of African Americans, 80% of Caucasians and 82% of English-speaking Hispanics use the internet [17]. While ethnicity does not seem to significantly affect internet use; educational attainment may. Only 52% of adults surveyed with less than a high school education and 67% of adults who have a high school education use the internet, compared to 90% and 96% of those who completed some college or completed college, respectively [17]. Of the 25 mothers in our study, six did not have any college education, but they all stated they would be able to complete MFHP outside the physician's office and bring to an upcoming appointment. In our study, 16 mothers (64%) reported at least some college education and yet nine struggled with either the pre-set categories or with discerning the type of information that was important in FHH. A previous study by Wallace et al (2009) found that even after a FHH education session only 67% of women (n=100) with less than a four-year college degree felt they would be able to find MFHP on the internet and 50% felt they could teach a family member how to use MFHP on the internet [13]; suggesting access to the internet might be an issue for parent-generated FHH.

Completion of FHH Prior to Pediatric Appointment: Only 38% of providers from the study by Kanetzke et al were optimistic that parents would complete MFHP prior to the office visit [10], compared to 92% of the mothers interviewed. While most providers hypothesized limited computer or internet access would be the biggest barrier to parent-generated FHHs [10], parents cited lack of knowledge about FHH as the biggest barrier. The reasons for the lack of knowledge included not being in contact with family members, not understanding the family relationships of children's fathers, and viewing FHH as a private matter not to be shared. Similar challenges were found in a previous study about parents barriers to FHH collection; in both studies the most frequent barrier identified was lack of knowledge [13].

Pew Research Center's Internet & American Life Project in partnership with the California HealthCare Foundation conducted a national phone survey of 2,253 American adults and found 61% search the internet for health information, information on doctors and ways to stay healthy [18]. Although we didn't ask mothers if they routinely search the internet, of the twenty-five participants interviewed, none of them had previously heard of MFHP, suggesting FHH is not a topic frequently searched. In addition only one provider from Kanetzke et al's study had heard of MFHP suggesting parents aren't coming to providers with the tool. [10]. Although not limited to a pediatric setting, a study by Fuller et al (2009) evaluated physicians responses to patient-generated FHH and found that only 3% of physicians reported receiving computer-generated pedigrees [19]. However, physicians were receptive to receiving patient-generated FHHs.

Participants made several suggestions for improvement of MFHP. As anticipated by providers interviewed by Kanetzke et al, some mothers had difficulties with the medical terminology and the broad groupings in the drop-down menu of MFHP [10]. The suggestions

for pop-ups with brief descriptions using non-medical terminology would be small changes to MFHP that could have a large positive impact. Participants wanted it to be easier to add other family members to the FHH and one respondent suggested MFHP could be modified so the user could click on an individual and choose a relative to add in relation to the highlighted individual (e.g. child, sibling, parent, etc). Future revisions to MFHP should consider some of the recommendations presented by mothers in this study.

Limitations: The smaller sample size limits the generalization of our findings. Although we did not specifically target mothers, no fathers participated in the study. It is unknown if or how information from fathers might change our findings. Recruitment was limited to parents who showed an interest in the study which may have created a response bias. While the interviewer tried to remain neutral, participants may have felt obligated by social stigmas to respond in a positive manner when asked about future use of MFHP. All participants who had a four-year college degree or higher were also married and all our single participants were African American so we were unable to examine potential connections between these demographic factors and responses. Participants were not asked about their experience with computers or current internet usage which may have been useful in evaluating their future plans for MFHP.

In conclusion, our findings suggest that mothers are receptive to collecting FHH information for use in a pediatric setting. They also perceive a benefit of sharing FHH with their child's pediatrician to increase awareness and take measures to prevent disease. Previous studies suggest pediatric providers are receptive to parent-generated FHHs. Therefore intervention studies where MFHP is incorporated into pediatric practice are needed. Such intervention studies will need to address barriers to completing FHH information such as lack of knowledge about FHH, and challenges with MFHP. Future intervention studies will also need to determine

feasibility, logistics, compatibility with EMR, how pediatricians use FHH information from MFHP (e.g. screening, medical management, etc), and whether parents make any recommended changes (or make changes on their own) to improve pediatric outcomes.

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APPENDIX 1

Disease/Conditions Included in MFHP

Diseases/Conditions listed in **bold** are headers and will prompt the user to “please specify” from the list of disease options included in that category.

Cancer (more options),

Bone, Brain, Breast, Colon, Esophageal, Gastric, Kidney, Leukemia, Liver, Lung, Muscle, Other cancer, Ovarian, Pancreatic, Prostate, Rectal, Skin, Thyroid, Unknown cancer, and Uterine cancer.

Clotting Disorder (more options),

Clotting Disorder, Deep Vein Thrombosis (DVT), Pulmonary Embolism, Unknown Clotting Disorder

Dementia/Alzheimer’s,

Diabetes (more options),

Diabetes, Gestational Diabetes, Type 1 Diabetes, Type 2 Diabetes, Unknown Diabetes

Gastrointestinal Disorder (more options),

Colon Polyp, Crohn’s Disease, Familial Adenomatous Polyposis, Gastrointestinal Disorder, Irritable Bowel Syndrome, Lynch Syndrome/Hereditary Nonpolyposis Colon Cancer, Ulcerative Colitis, Unknown Gastrointestinal Disorder

Heart Disease (more options),

Angina, Coronary Artery Disease, Heart Attack, Heart Disease, Unknown Heart Disease

High Cholesterol

Hypertension

Kidney Disease (more options),

Cystic Kidney Disease, Diabetic Kidney Disease, Kidney Disease Present from Birth, Kidney Nephrosis, Nephritis, Nephrotic Syndrome, Other Kidney Disease, Unknown Kidney Disease

Lung Disease (more options),

Asthma, COPD, Chronic Bronchitis, Chronic Lower Respiratory Disease, Emphysema, Influenza Pneumonia, Unknown Lung Disease

Osteoporosis

Psychological Disorder (more options),

Anxiety, Attention Deficient Disorder- Hyperactivity, Autism, Bipolar Disorder, Dementia, Depression, Eating Disorder, Mental Disorder, Obsessive Compulsive Disorder, Panic Disorder, Personality Disorder, Post Traumatic Stress Disorder, Schizophrenia, Social Phobia, Unknown Psychological Disorder

Septicemia,

Stroke/Brain Attack,

Sudden Infant Death Syndrome,

Unknown Disease,

Other – Add New

This option allows for free-text to be entered into MFHP

APPENDIX 2

Parent Interview Guide

Thank you for agreeing to talk with me today. As you know, the topic of this interview has to do with your views on FHH. Let me begin by asking:

Meaning and perceived value of FHH

1. What does family health history mean to you?
2. What value does family health history have to you? *(note – participants may find this question ambiguous and may have to modify depending on pretest)*
3. What value do you think that FHH has for your children? *(If respondent says no value, probe on why not).*

Experience with FHH

4. Have you ever recorded your family health history? *(If yes, probe on when collected FHH, format of FHH and how/if interviewee used their FHH information)*
5. Have you ever talked to your pediatrician about health problems that run in your family?
 - a. If yes, say “tell me about that experience” (if more than one, ask them to focus on one particular experience)
 - b. If no, say “can you think of a situation when you talk to a pediatrician about health problems that run in your family?”
6. Do you feel there are or would be any benefits to discussing your family health history with your child’s pediatrician *(if yes, probe on what benefits; if no, probe on why not)*
7. Do you have any concerns about discussing your family health history with your child’s pediatrician? *(if yes, probe on what they are. Probe on whether concerns are specific to their child’s pediatrician or ANY pediatrician. If no, probe on whether they think other parents might have concerns discussing FHH with a pediatrician)*
8. Has a provider ever made recommendations to improve your child’s health based on your family history?
 - a. If yes, say “tell me about that experience” (if more than one, ask them to focus on one particular experience)
9. Do you worry about health problems that run in your family?

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 us to spend 15-30 minutes using *My Family Health Portrait* to get your impressions of how this online tool works. Together we will complete your child's FHH. Please go to the website <http://www.hhs.gov/familyhistory/> and click on the English version of the web-based tool. Allow interviewee 15-30 minutes to complete then ask them to display the tool in pedigree/chart format.

Impressions and perceived value of *My Family Health Portrait*

10. Now that you have spent a little time working with *My Family Health Portrait*, what are your general impressions of this tool? (*Probe on ease/difficulty of completion, time to complete, information collected, presentation of information*).
11. What did you like about using this tool?
12. What didn't you like about using this tool?
13. Did you encounter any challenges when using this tool? (*Probe on what they were*)
14. How much of your FHH do you feel you were able to complete during the time you spent on it?
15. How might you use *My Family Health Portrait* in the future?
16. Do you think collecting FHH information would be helpful to improve your health? (*Probe on how might be helpful/not helpful*)
17. Your child's health? (*Probe on how might be helpful/not helpful*)
18. On a scale of 1 to 5 with one being very easy and 5 being impossible, how difficult would it be for you to complete *My Family Health Portrait* on your own prior to your child's medical visit? (*Probe on why they answered this way*).
19. Would you complete *My Family Health Portrait* prior to your child's medical visit if your provider asked you to complete it? (*Probe on why/why not*)
20. Is there any additional information you would need to be able to complete *My Family Health Portrait*?

Additional Time to Complete FHH:

21. Is there anything else you would like to add to your child's FHH?
 - a. If yes, any additional comments about *My Family Health Portrait*?

Demographics

22. How old are you?

23. How many children do you have?

24. What is your gender?

25. How would you describe your race?

26. What is your marital status? (circle)

Married

Single

Divorced

Widowed

27. What is your highest level of education? (circle)

Some High School

Some College

High School or G.E.D.

4 year College Degree

28. On average, how many times a year do you take your child/children to visit a pediatric provider?

29. What type of pediatric provider do you generally see for well-child visits? (*For example, a pediatrician, APN, etc.*)

30. Does your child/children have any special health care needs or chronic health conditions? (*If yes, please list conditions*)

-

31. How did you hear about this research study?:

Thank you for taking the time to talk with me about family health history. I value your input and will keep your responses confidential.