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ORIGINAL RESEARCH

# Primary Care Providers' Responses to Patient-Generated Family History

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**Abstract** Family health history is one of the best predictors of an individual's risk for common disease, yet it is underutilized in routine care. Although the Surgeon General has recommended consumers record their family health history and share it with their health care provider, providers' perceptions of patient-generated family histories are unknown. To learn more about providers' experience with and perceptions about patient-generated family histories, we mailed surveys to 301 providers and had a response rate of 24% ($n$=68). Seventy-three percent felt a patient-generated computer pedigree would improve their ability to assess risk as compared to their current methods. Seventy percent felt a patient-generated computer pedigree would either have no effect on or would increase the number of patients that could be seen in a day. Results suggest that providers appreciate the potential benefits of patient-generated family histories. Genetic counselors and nurses are in a prime position to promote and facilitate the use of patient-generated family health histories in routine care.

**Keywords** Primary care providers · Family health history · Computer-generated tools · Risk assessment

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## Introduction

Taking a family health history (from here on referred to as FHH) is a key component of routine patient care in a primary care setting because it is currently one of the best predictors of an individual's risk for common disease and is the primary tool for initial genetic assessment for single gene and transmittable chromosome disorder (Acheson et al. 2000; Walter and Emery 2006). While single gene and chromosome disorders may be considered rare, it is estimated that 43% of "healthy" individuals are at an increased risk for common, chronic disease, such as coronary artery disease, cancer, and diabetes, based on their FHH (Scheuner et al. 1997). Despite the importance of FHH, it is inconsistently and ineffectively utilized in routine care and treatment. While it appears FHH is discussed with most patients, primary care providers are failing to get the relevant information necessary to assess risk and make appropriate recommendations (Murff et al. 2004; Sifri et al. 2002; Summerton and Garrood 1997).

Without an adequate FHH review, a significant number of individuals at increased risk for common disease may not be identified or properly managed. Inaccurate risk assessment leads to both the underestimation and overestimation of disease risk. Underestimation of patient risk may result in missing important screening and diagnostic opportunities whereas overestimation of risk may result in the over-utilization of medical services and prophylactic treatment (Murff et al. 2004). Both of these inaccurate risk assessments can lead to misdiagnosis, improper management of patients, and excess cost in the management of patient health.

According to Wolpert and Speer (2005), a complete FHH includes a minimum of a three-generation FHH in pedigree form, pertinent health information about each closely related relative including both maternal and paternal aunts, uncles, and grandparents, age of onset for diseases, and ancestry. However, current studies suggest that the majority of this information is rarely obtained (Murff et al. 2004; Sifri et al. 2002; Summerton and Garrood 1997). In a retrospective chart review by Tyler and Snyder (2006), 97.8% of charts had some record of FHH. However, in 69.5% of these charts, there was not adequate information to apply risk to the individual.

The lack of FHH information in patients' charts stems from several barriers including the lack of a standard format for collection that clearly indicates biological relationships, and limited time for patient visits (Bennett et al. 1995; Yoon et al. 2003). In a study which compared self-reported patient health histories recorded on computer programs to patient medical records, Sweet et al. (2002) reported that of 363 computer entries, 101 patients were considered at high risk based on their pedigree information. However, only 69 of these 101 patients had information indicating this high risk in their medical record. This study indicates that patients know their FHH information but are not sharing it with their providers. Additionally, Wolpert and Speer (2005) argue that the method of and format for collection can create a barrier to the consistent collection of adequate information for risk assessment. Provider-generated narrative and patient-questionnaire formats are frequently inadequate to capture the significance of familial risk factors. They often neglect to distinguish between maternal and paternal FHH and do not always facilitate recognition of patterns of inheritance (Wolpert and Speer 2005). And finally, time is a primary barrier to the adequate collection of FHH. In order to obtain a complete 3-generation pedigree, most healthcare providers need at least 15 to 20 min (Rich et al. 2004). For primary care visits that average 16 min total in length, obtaining a full 3-generation FHH simply is not possible (Menasha et al. 2000; Murff et al. 2004; Wolpert and Speer 2005).

In 2004, the U.S. Surgeon General launched a new healthcare campaign called the Family History Initiative to encourage individuals to collect their family health information. This initiative includes a "Family History Day" that coincides with Thanksgiving Day to facilitate the collection of family health information and a web-based tool for the general public to use to collect their family history (https://familyhistory.hhs.gov/fhh-web/home.action, updated 09/21/09). Patients can utilize this tool to record their family history and generate a pedigree that can later be taken to their medical visit. In theory, the utilization of this and other patient-generated FHH tools would solve many of the problems that are associated with inadequate FHH such as inadequate time for a complete FHH interview, ineffective methods for eliciting the proper information, and lack of a standard format that clearly identifies relationships and patterns.

Since the Family History Initiative's announcement in 2004, three projects have been implemented by the National Human Genome Research Institute to educate Americans about the importance of FHH, including the Brigham and Women's Hospital Family History Project, the Appalachian Family History Demonstration Project (Wallace et al. 2009), and the Alaska Native Family Demonstration Project (U.S. Department of Health and Human Services 2005; U.S. Department of Health and Human Services 2006). Through the implementation of these projects, data is being collected on the reactions to the tool by consumers. There is not, however, any existing published data regarding the provider's perspective on patient-generated FHHs—including their acceptance and use of such tools. An extensive search of literature was performed on PubMed and Medline Plus as well as individual major medical organization websites such as the American Academy of Pediatrics (AAP), the American Academy of Family Physicians (AAFP), and the American Medical Association (AMA). The search resulted in no study, article, or position statement that assesses or expresses the reactions of providers to a FHH generated by patients who use a FHH collection tool. Therefore, while considerable time and money are being spent to promote this tool, it is unclear whether primary care providers believe the implementation of patient-generated FHHs will be beneficial in clinical practice The investigators perceived this as a critical gap in determining the feasibility of the Surgeon General's Family History Initiative. This study begins to address this identified gap in knowledge and identifies where future research efforts need to be made to effectively incorporate the use of patient-generated FHH in primary care.

## Methods

### Study Design

We performed a quantitative cross-sectional descriptive study of primary care providers in a Midwest metropolitan

area of about two million people. A convenience sample of primary care providers administering routine or preventive care to patients of all ages, ethnicities, and health statuses were targeted for this study. Each participant was mailed a survey along with a $5.00 incentive and a postage paid return envelope.

### Subjects

Since this was the first known survey of primary care provider attitudes toward FHH tools, we used a convenience sample of 301 providers in the Cincinnati area. Providers were identified from community clinics and private offices in the Cincinnati area. Providers were first sought from clinics. Clinics providing primary care service in the Cincinnati area were listed on *The Bureau of Primary Health Care* (bphc.hrsa.gov) and the *Cover the Uninsured* website (www.covercincy.org). We also included five clinics whose providers may have been impacted by a previous Family History Demonstration Project (FHDP) for urban Appalachian women (Wallace et al. 2009). Phone calls to these different clinics ascertained the names, provider type, and the number of providers practicing at these clinics. All primary care providers identified at these clinics who also matched our criteria were asked to participate in the study. The remaining participants needed for our convenience sample of 300 were found using a search for primary care providers on a private practice referral web site, *United Healthcare* (www.uhc.com). The search selected for pediatric, family medicine, and internal medicine physicians and advance practice nurses (APNs) within a 25 mile radius of Cincinnati, OH, 45202. The website generated a list of providers ordered from nearest to furthest clinic from the zip code entered. A portion of these identified providers (the first providers on the list that matched our criteria and that were needed to satisfy our convenience sample size) were asked to participate in the study.

LPNs, RNs who are not APNs, providers in practice less than one year, and providers outside of a 25 mile radius of Cincinnati were excluded from this study.

### Survey

The survey was developed by the principal investigator and co-investigators who have targeted expertise in FHH implementation, genetics education of providers, and primary care clinical settings. The survey was designed to assess the following: demographics, primary care providers' current utilization and perceived value of current methods of FHH collection, and primary care providers' perceived value of three different defined patient-generated FHH formats (hand-written narrative, hand-drawn pedigree, and computer-generated pedigree). The instrument was reviewed for face validity by 5 members of the target audience and for content validity by 10 experts in FHH and genetics. The complete survey can be viewed in the "Appendix".

### Data Analysis

Frequencies and relative frequencies were computed on all categorical variables including demographics, FHH use at the clinic and provider level, provider-perceived value of current FHH methods, and provider-perceived value of patient-generated FHHs. Participant responses to patient-generated FHHs in patient-written narrative format were compared to their responses for hand-drawn pedigree format and computer-generated pedigree format using a weighted kappa statistic evaluated at an alpha level of 0.05. The weighted kappa statistic was used to give a measure of how well an individual's response regarding one patient-generated FHH format agreed with their answer on another format. Perfect agreement is indicated by a value of 1 and chance agreement is indicated by a value of 0 (Cohen 1968). All analyses were conducted using SAS version 9.1 (SAS Institute Inc, Cary NC).

The study was approved by both the University of Cincinnati's (UC) and Cincinnati Children's Hospital Medical Center's (CCHMC) IRB.

## Results

### Subjects

Using the methods described above, 38 primary care providers were identified at community clinics and 17 of these were at clinics previously targeted by the AFDP. In addition, 296 provider names were selected from the list generated by the private practice referral website for a total of 334 provider names. Of the provider names identified through the methods described above, 301 providers were selected as eligible participants and mailed surveys. Twenty-one of these mailed surveys were undeliverable for 280 remaining surveys. Sixty-eight of 280 surveys were completed and returned by the cutoff date for a response rate of 24.3%.

*Demographics* Ninety-four percent ($n$=63) of respondents were physicians; 63% ($n$=42) were male and 37% ($n$=25) were female. The average age of respondents was 48.6 years old. The largest percentage of respondents reported working in pediatrics (36%, $n$=24), followed by internal medicine (33%, $n$=22). Twenty-one percent ($n$=14) of respondents worked in family practice, and 9% ($n$=6) worked in other areas. While 70% ($n$=46) of respondents

indicated receiving genetics education in medical/graduate school, only 27% ($n$=18) of total respondents had pursued continuing medical education in genetics since medical/graduate school. A complete list of respondent characteristics can be seen in Table 1.

## FHH Results

*Current Utilization and Perceived Value of FHH* Ninety-six percent ($n$=64) of participants indicated it is standard-of-care to collect a FHH at an initial patient visit, and 70% ($n$=46) said it is standard-of-care to review and update FHH at an established patient visit. To collect FHH, most respondents stated there is a standard form they use to collect FHH and indicated that collecting the FHH is the sole responsibility of the primary care provider performing the medical evaluation. Additionally, the majority of participants reported collecting FHH in a face-to-face manner with the patient and using a narrative format to record the FHH (Table 2).

Most primary care providers (68%, $n$=46) felt FHH was either very important or important to the routine care of patients in a primary care setting (Table 2). However, 87% ($n$=59) of respondents indicated that they spend only 1–5 min during the initial visit obtaining FHH. Additionally, most providers indicated spending only 1–5 min discussing FHH with a patient (Table 3). At established patient visits, 34% ($n$=23) of providers indicated spending 0 min reviewing the charted FHH, and 33% ($n$=22) indicated spending 0 min updating FHH (Table 3).

Based on current FHH collection practices, one third of providers stated that it was difficult or somewhat difficult to identify diseases/conditions for which a patient is at risk and requires additional management and/or screening. The most common reason cited for difficulty assessing risk was "not confident in accuracy of information provided by patient". "Not enough information in FHH," and "biological relationships in FHH are not clear" were the second and third most frequently cited response. Only 10% of respondents indicated a lack of confidence in their own genetics knowledge as the reason for difficulty assessing risk (Table 3).

*Patient-generated FHH in a Primary Care Setting* Of the 33 providers who reported that a patient had brought in a FHH, 8 of these providers had a patient bring a hand-drawn pedigree and 3 of these providers had a patient bring a computer-generated pedigree.

Regardless of respondents' personal experiences with patient-generated FHH, all respondents were asked to answer questions comparing patient-generated FHH for-

**Table 1** Characteristics of Respondents

| | |
|---|---|
| Age | |
| Range | 26–80 |
| Mean | 48.6 |
| Median | 49 |
| Sex | |
| Male | 62.7%, $n$=42 |
| Female | 37.3%, $n$=25 |
| Provider Type | |
| Physician | 94%, $n$=63 |
| Advanced Practice Nurse | 4.5%, $n$=3 |
| Other[a] | 1.5%, $n$=1 |
| Y'ear of Graduation from Medical School/Graduate School | |
| Range | 1953–2007 |
| Mean | 1985 |
| Median | 1986 |
| Genetics Education | |
| Medical or Graduate School | |
| Yes | 69.7%, $n$=46 |
| No | 30.3%, $n$=20 |
| Continuing Education | |
| Yes | 27.3%, $n$=18 |
| No | 72.7%, $n$=48 |
| Area of Practice | |
| Pediatric | 36%, $n$=24 |
| Internal Medicine | 33%, $n$=22 |
| Family Practice | 21%, $n$=14 |
| Other[b] | 9%, $n$=6 |
| Number of providers in practice | |
| Range | 1–110 |
| Mean | 15.1 |
| Median | 8 |
| Patients seen in 1 week | |
| Range | 4–250 |
| Mean | 83.8 |
| Median | 80 |
| Percent of patients ≥ 18 | |
| Range | 0–100% |
| Mean | 64.6% |
| Median | 80%, 90% |
| Percent of patients ≤ 18 | |
| Range | 0–100% |
| Mean | 39.6% |
| Median | 10% |
| Setting of Practice | |
| Specialty Group Practice | 59.7%, $n$=40 |
| Academic Medical Setting | 14.9%, $n$=10 |
| Federally Funded Community Health Center | 10.5%, $n$=7 |
| Hospital | 9%, $n$=10 |
| Public Health Agency | 4.5%, $n$=3 |
| Urban Clinic | 1.5%, $n$=1 |

[a] intern

[b] cardiology ($n$=2), geriatrics ($n$=1), pulmonary ($n$=1), reproductive health ($n$=1), urban medicine ($n$=1)

**Table 2** Primary Care Provider Standard Method of FHH Collection

| | |
|---|---|
| Standard of care to collect | |
| Yes | 96%, $n$=64 |
| No | 4%, $n$=3 |
| Standard procedure | |
| Yes | 59%, $n$=40 |
| No | 41%, $n$=28 |
| Standard form | |
| Yes | 63%, $n$=42 |
| No | 37%, $n$=25 |

mats with their current methods of FHH collection. Although not all providers answered questions about each patient-generated format, most felt patient-generated FHHs would contain more information than FHH obtained using their current methods (Fig. 1). However, this does not mean that each respondent felt all patient-generated methods (hand-written narrative, hand-drawn pedigree, and computer-generated) would contain more information than a FHH obtained using their current methods. In fact, we found that some respondents answered differently for hand-written narratives as compared to computer-generated pedigrees. For instance, when comparing a single respondent's answer regarding a patient-written narrative to their own answer for a computer-generated pedigree, we found that the respondent tended not to answer similarly ($\kappa$=0.3, $p$<0.001). Therefore, if a respondent felt a computer-generated pedigree would have more information than what they collected using their standard methods, they did not necessarily feel a patient-written narrative would have more information. This was the opposite when comparing a respondent's answer for a computer-generated pedigree to a hand-drawn pedigree. When comparing these two methods, we found that respondents tended to answer similarly ($\kappa$=0.7, $p$<0.0001). Therefore, if a respondent answered that a computer-generated pedigree would have more information than typically collected using their standard methods, that respondent also tended to answer that a hand-drawn pedigree would have more information (Table 4).

The majority of respondents felt patient-generated family histories would be relatively easy to use and to identify conditions for which a patient is at risk. Sixty-two percent

**Table 3** Current Methods of Family Health History Collection

| Initial Visit[a] | | Established Visit[b] | |
|---|---|---|---|
| Who collects and records | | Standard of Care | |
| Physician/nurse practitioner | 66%, $n$=40 | Yes | 70%, $n$=46 |
| physician + others[c] | 30%, $n$=18 | No | 30%, $n$=20 |
| Method of Collection | | Time Spent Studying | |
| Patient questionnaire | 8%, $n$=5 | 0 | 34%, $n$=23 |
| Over the phone interview | 1.6%, $n$=1 | 1–5 min | 63%, $n$=42 |
| Face-to-face | 90%, $n$=55 | 6–10 min | 3%, $n$=2 |
| Patient questionnaire + face-to-face | 10%, $n$=6 | 11–15 min | 0%, $n$=0 |
| Time Spent Obtaining | | More than 15 min | 0%, $n$=0 |
| 0 min | 4%, $n$=3 | Time Spent Updating | |
| 1–5 min | 87%, n-59 | 0 min | 33%, $n$=22 |
| 6–10 min | 7%, $n$=5 | 1–5 min | 64%, $n$=43 |
| 11–15 min | 1.5%, $n$=1 | 6–10 min | 3%, $n$=2 |
| More than 15 min. | 0%, $n$=0 | 11–15 min | 0%, $n$=0 |
| Time Spent Studying | | More than 15 min | 0%, $n$=0 |
| 0 min | 24%, $n$=16 | | |
| 1–5 min | 73%, $n$=49 | | |
| 6–10 min | 1.5%, $n$=1 | | |
| 11–15 min | 1.5%, $n$=1 | | |
| More than 15 min. | 1.5%, $n$=1 | | |
| Time Spent Discussing | | | |
| 0 min | 9%, $n$=6 | | |
| 1–5 min | 84%, $n$=56 | | |
| 6–10 min | 6%, $n$=4 | | |
| 11–15 min | 1.5%, $n$=1 | | |
| More than 15 min. | 0%, $n$=0 | | |

[a] the first visit with the primary care provider for routine or preventive care

[b] an annual or biennial scheduled visited by an established patient for routine or preventive care

[c] physician plus others (including nurse, medical assistant, or medical secretary) collect family history

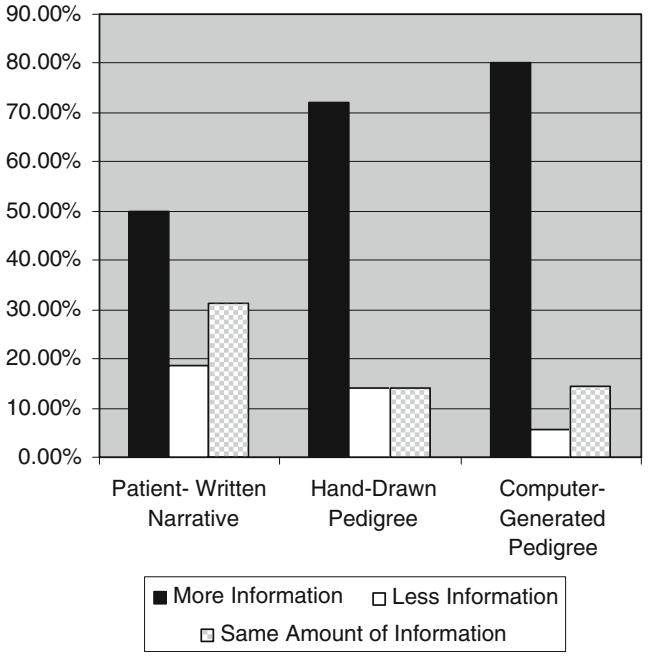


**Fig. 1** Information in Patient-Generated Compared to Provider-Generated Family Histories. Providers were Asked if Family Histories in Each of the Three Formats (Patient-written Narrative ($n$=64), Hand-drawn Pedigree ($n$=57), and Computer-generated Pedigree ($n$=55)) Contain More, Less, or the Same Amount of Information as Compared to Family Histories Generated Using Providers' Current Methods of Family History Collection.

($n$=40) of providers felt a patient-generated FHH in a narrative form would be either easy or somewhat easy to identify conditions for which a patient is at risk. When considering a hand-drawn pedigree format, 76% ($n$=44) of providers felt a patient-generated FHH would be easy or somewhat easy to use to identify risk. When considering a computer-generated pedigree format, 78% ($n$=47) of providers felt a patient-generated FHH would be easy or somewhat easy to use to identify risk.

As indicated by the percentages listed above, each respondent did not feel all patient-generated methods would be easy or somewhat easy to identify conditions for which a patient is at risk. When comparing a respondent's answer for a computer-generated pedigree to their answer for a patient-written narrative, we found that respondents did not answer similarly. For instance, a respondent who thought computer-generated pedigrees would be easy or somewhat easy to use to identify risk tended to answer differently with regard to a patient-generated FHH in patient written narrative format ($\kappa$=0.4, $p$<0.0001). When comparing a respondent's answer for a hand-drawn pedigree to their answer for computer-generated pedigree, we found that respondents tended to answer similarly ($\kappa$=0.8, $p$<0.0001).

When comparing patient-generated FHH to current methods of FHH collection, respondents felt patient-generated FHH would improve their ability to assess a patient's risk for health conditions and diseases. Fifty-eight percent ($n$=38) of respondents felt a patient-written narrative family history would improve their ability to assess risk as compared to their current method of FHH collection. Sixty-three percent ($n$=38) of providers felt a hand-drawn pedigree would improve their ability to assess risk compared to their current method of FHH collection. Seventy-three percent ($n$=44) of providers felt a computer-generated pedigree would improve their ability to assess risk compared to their current method of FHH collection (Fig. 2).

Seventy-two percent ($n$=47) of providers felt a patient-written narrative would either have no effect on or would increase the number of patients seen in a day. Seventy-three percent ($n$=44) of providers felt a hand-drawn pedigree would either have no effect on or would increase the number of patients seen in a day. And 70% ($n$=42) of providers felt a computer-generated pedigree would either have no effect on or would increase the number of patients seen in a day.

## Discussion

To our knowledge, this is the first study to suggest that providers are open to receiving patient-generated family

**Table 4** Perceptions of Current Family Health History Collection

| | |
|---|---|
| Importance of Family Health History | |
| Very important | 37%, $n$=25 |
| Important | 31%, $n$=21 |
| Somewhat important | 31%, $n$=21 |
| Not important | 1.5%, $n$=1 |
| Difficulty to Assess Risk | |
| Easy | 21%, $n$=14 |
| Somewhat easy | 43%, $n$=29 |
| Somewhat difficult | 32%, $n$=22 |
| Difficult | 4%, $n$=3 |
| Reason for Difficulty[a] | |
| Not confident in accuracy | 32%, $n$=36 |
| Not Enough Info | 25%, $n$=29 |
| Relationships not clear | 16%, $n$=18 |
| No guidelines for calculating / interpreting risk | 10%, $n$=11 |
| Other | 9%, $n$=10 |
| Not confident in own knowledge | 6%, $n$=7 |
| Never Experience Difficulty | 3%, $n$=3 |

[a] Participants were asked to check as many reasons they experienced. All participants were encouraged to answer this question regardless of whether they indicated in the previous answer that they typically do not encounter difficulties

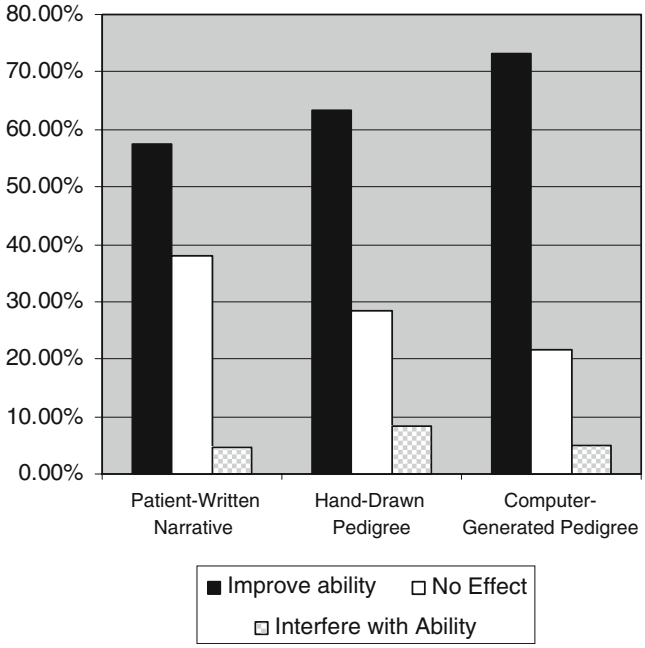


**Fig. 2** Assessing Risk Using Patient-Generated Family Histories. Providers were Asked if Patient-generated Family Histories in Each of the Three Formats (Patient-written Narrative ($n$=66), Hand-drawn Pedigree ($n$=60), and Computer-generated Pedigree, ($n$=60)) would Improve Their Ability to Assess Risk, Interfere with Their Ability to Assess Risk, or Have No Effect on Their Ability to Assess Risk for Diseases/Conditions Based on Their Family History.

histories. This finding is critical to the success of the Surgeon General's message that consumers should share their family histories with their health care providers. Most providers in this study felt patient-generated FHHs would contain more information than FHH obtained using their current methods. Additionally, they felt this information could improve their abilities to identify family members at risk for chronic health conditions and diseases. This study also suggests that primary care providers favor receiving computer-generated or hand-drawn pedigrees from their patients as compared to patient-written narratives. While most patients do not have the knowledge necessary to hand-draw pedigrees representing their FHH, the Surgeon General tool is available to all who have internet access and are able to follow and answer the tool's prompts. While we did not ask providers why they might prefer graphical representation to patient-written narratives, it can be hypothesized that primary care providers recognize that a graphical representation of FHH allows for a quick assessment of FHH red flags and enables quick identification of areas that need further investigation during a time-limited routine visit. Additionally, as further discussed below, providers may feel more confident in the information in graph form because it suggests a higher level of understanding of family health history information by the patient. Also important, most primary care providers indicated that receiving patient-generated family histories would not decrease the number of patients they could see in a day, which is critical to the success of the Surgeon General's Family History Initiative.

Similar to other studies, we found that the majority of primary care providers value FHH and consider it standard practice to collect FHH at an initial patient visit (Acheson et al. 2000; Murff et al. 2004; Sifri et al. 2002). While nearly all providers reported collecting family histories, one third indicated they are not confident in the accuracy of the information presented by patients regarding their FHH. Presumably, this lack of confidence reduces the value of FHH for modifying a patient's management. In a comment section on our survey, a pediatrician described the difficulty he or she encountered when eliciting a patient's FHH through the patient's mother:

> "Families do not volunteer important information [because they] do not understand [the] significance. For example, a parent was interviewed by a nurse and doctor regarding diseases in family history and disclosed no changes. She [the parent] was overheard in the waiting room speaking on her cell phone regarding her recent hospitalization for a pulmonary embolus and coumadin therapy. She had not mentioned this to anyone. I think patients do not know what 'family history' means."

In this case, the parent's significant medical history could have potentially affected the patient's management and thus, was relevant to her child's (the patient) FHH. However, the relevant information was not shared during the patient's FHH interview. The pediatrician's observation may provide insight to previous studies that show that patients know more FHH information than is being documented in medical records (Sweet et al. 2002). The feelings expressed by providers in this study (such as the example stated above) in combination with findings from previous studies, suggest that current methods used to collect FHH are not sufficient to and may be interfering with the ability to obtain information that primary care providers feel is both valuable and reliable. This provides support that primary care providers would be open to receiving patient-generated family histories created on tools such as My Family Health Portrait as it would likely be more complete than what they could obtain in a routine clinic or office visit. These results also suggest that providers would have confidence in the information in these patient-generated FHHs. This confidence in the information could stem from providers' understanding that FHH collection tools like My Family Portrait, provide instructions and prompts that

help patients provide the type and level of family history data that can be useful for assessing disease risk. This is important because as this study has illustrated and past studies have shown, patients do tend to know their FHH but do not share it with their providers. Therefore, our data suggests that providers will feel more confident about the family histories provided by patients who utilized these FHH collection tools because patients are guided to provide accurate and complete FHH information.

There are several limitations to this study. The 24% response rate is comparable with other physician surveys but is a relatively low response rate (Friedman et al. 1997; Menasha et al. 2000). The results regarding the amount of time devoted to collecting and using FHH suggests that our population is similar in this regard to primary care providers in other geographic regions (Menasha et al. 2000; Fairfield et al. 2004; Murff et al. 2004; Wolpert and Speer 2005). However, we do not have data for non-responders to rule out the possibility of a response bias. Furthermore, as indicated by the relatively high percentage of participants that have obtained CMEs in genetics, it is possible that those choosing to take the time to fill out the survey are those that have an interest in genetics and FHH that is not typical of the general provider population. Additionally, the sample size was small, and subjects were from a limited geographical region, thus the respondents may not be representative of the national population of primary care providers.

Responses were based on providers' perceptions of patient-generated FHHs rather than actual experience with these formats. This type of assessment could provide an inaccurate impression of how these tools would actually be perceived if the providers had experience with the different formats. Additionally, the information each provider imagined would be present in each format could significantly differ from one respondent to another. We did not assess provider knowledge of FHH interpretation as part of the survey. Additional studies of the clinical utility of patient-generated FHHs, particularly computer-generated FHHs, need to occur in clinical practice.

## Practice Recommendations

Data from this study suggest that providers would be receptive to patient-generated FHH, but that they have little exposure to these tools or methods of collection. If the implementation of patient-generated FHHs is going to be successful, additional efforts are needed to promote patient-generated FHH tools to primary care providers.

Genetic counselors and nurses can develop and evaluate strategies to increase knowledge and utilization of patient-generated FHH tools by primary care providers. Educational strategies might include: practice sessions with available patient-generated FHH data collection tools so that primary care providers can select those most appropriate for their patient population; teaching primary care providers' to recognize patterns consistent with single gene disorders as well as findings that indicate an increased risk for common chronic diseases; encouraging them to use evidence-based guidelines to reduce the risk of common chronic diseases in identified at-risk family members; and discussing the roles of various genetic specialists and when to consider making a genetics referral.

Genetic counselors and genetic nurses can partner with primary care providers and members of their communities to investigate strategies to integrate patient-generated FHH into routine care and measure the resulting clinical outcomes. By working with primary care providers, we can directly address education gaps, identify barriers and facilitators for integrating family history into routine care, develop unique procedures to partner with primary care providers, and collect the much needed data on the clinical utility of FHH as a health promotion and disease prevention tool.

## Summary

This is the first study to suggest that providers are open to receiving patient-generated family histories. This finding is critical to the success of the Surgeon General's message that consumers should share their family histories with their health care providers. While providers in this study value FHH, they underutilize it because of concerns for accuracy and time. In our convenience sample of primary care providers, we found a trend suggesting that primary care providers believe patient-generated FHHs could provide more useful FHH information than what they currently collect and would not decrease the number of patients they are able to see in a day. Genetic counselors and nurses should facilitate the effective integration of family healthy history into the primary care setting by partnering with primary care providers to address educational and research gaps related to the clinical utility of FHH.

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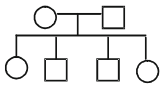
## Appendix

**Definition:**
The following definitions may be helpful while completing the survey.

**Pedigree**- in medicine, a family health history diagram with symbols to indicate the individuals in the family, their relationships to one another, those with a disease, etc.



**Annually scheduled established patient visit** – an annual or biennial scheduled visited by an established patient for routine or preventive care

### Demographic Information

**1) Age:**_____

**2) Sex**
- ☐ **Male**
- ☐ **Female**

**3) Provider Type:**
- ☐ **Physician**
- ☐ **Advanced Practice Nurse**
- ☐ **Physician s Assistant**
- ☐ **Other:**_____

**4) At what school did you complete your medical training?** _____
_____

**5) What year did you graduate from medical / graduate / nursing school:**_____

**6) Did you take 1 or more classes in genetics in medical school / graduate / nursing school?**
- ☐ **Yes**
- ☐ **No**

**7) What is your current area of practice?** _____
_____

**8) How many physicians and advanced practice nurses are in your practice?** _____
_____

**9) How many patients do you personally see in a week?**_____
_____

**10) What percentage of your patients are adults (18 years and older)?** _____

**11) What percentage of your patients are children (17 years and younger)?** _____

**12) Which best describes the setting in which you practice?** ***(Please check only one.)***
- ☐ **Solo Practice**
- ☐ **Single specialty group practice**
- ☐ **Multi-specialty group practice**
- ☐ **Staff Model Health Maintenance Organization (HMO)**
- ☐ **Managed Care Organization (MCO)**
- ☐ **Other model HMO**
- ☐ **Hospital**
- ☐ **Academic Medical Center**
- ☐ **Public Health Agency**
- ☐ **Federally funded community health center**
- ☐ **Urban clinic**
- ☐ **Rural clinic**
- ☐ **Other:**_____

**13) Have you ever obtained continuing medical / nursing education (CME / CEU) credits in genetics?**
- ☐ **Yes**
- ☐ **No**

**14) If so, how were these CMEs / CEUs obtained? (check all that apply)**
- ☐ **Classroom module/course**
- ☐ **Conference(s)**
- ☐ **Grand Rounds**
- ☐ **Web-based module/course**
- ☐ **Other:**_____

## Family History in the Routine Care of Patients

**Part I:** For questions 1-5, please check the answer choice that best describes the practices ***at your office***. Please check only one answer unless specified otherwise in the question.

**1) In your office/clinic, is it considered standard of care *to collect family health history at initial patient visits*?**
☐ Yes
☐ No

**2) In your office/clinic is it considered standard of care to *review and update family health history at annually scheduled established patient visits*?**
☐ Yes
☐ No

**3) Is there a standard *procedure* that your office uses to collect family history?**
☐ Yes
☐ No

**4) Is there a standard *form* that your office uses to collect family history?**
☐ Yes (*please include a copy of this form with your returned questionnaire*)
☐ No

**5) Who in your office collects and records family health history? (Please check all that apply)**
☐ The physician or nurse practitioner doing the medical evaluation
☐ Clinic / office nurse
☐ Medical assistant
☐ Medical secretary
☐ Patient
☐ Other:_____

**Part II:** For the questions 6-15, please check the answer choice that best describes ***your personal practice***. Please check only one answer unless specified otherwise in the question.

**6) What method do you most often use to collect family health history?**
☐ Self-administered patient questionnaire
☐ Over the phone interview
☐ Face-to-face interview
☐ Other:_____

**7) How do you typically record family health history in a patient's chart?**
☐ Insert patient questionnaire in chart
☐ Write / type / dictate narrative
☐ Construct pedigree
☐ Don t record because this is responsibility of others
☐ Other:_____

**8) At an *INITIAL PATIENT VISIT*, on average, how much time do you spend *obtaining family history from the patient*?**
☐ 0 minutes
☐ 1-5 minutes
☐ 6-10 minutes
☐ 11-15 minutes
☐ more than 15 minutes

**9) At an *INITIAL PATIENT VISIT*, on average, how much time do you spend *studying the charted family history for the patient*?**
☐ 0 minutes
☐ 1-5 minutes
☐ 6-10 minutes
☐ 11-15 minutes
☐ more than 15 minutes

**10) At an *INITIAL PATIENT VISIT*, on average, how much time do you spend *discussing family history with the patient*?**
☐ 0 minutes
☐ 1-5 minutes
☐ 6-10 minutes
☐ 11-15 minutes
☐ more than 15 minutes

## Family History in the Routine Care of Patients

**11) At *ANNUALLY SCHEDULED ESTABLISHED* patient visits, on average, how much time do you spend *studying the charted family history for a patient*?**

☐ 0 minutes
☐ 1-5 minutes
☐ 6-10 minutes
☐ 11-15 minutes
☐ more than 15 minutes

**12) At *ANNUALLY SCHEDULED ESTABLISHED* patient visits, on average, how much time do you spend *updating family history with the patient*?**

☐ 0 minutes
☐ 1-5 minutes
☐ 6-10 minutes
☐ 11-15 minutes
☐ more than 15 minutes

**13) Based on your current family history collection practices, on average, how difficult is it to identify diseases/conditions for which the patients are at risk and need additional management and/or screening?**

☐ Easy
☐ Somewhat easy
☐ Somewhat difficult
☐ Difficult

**14) When you experience difficulty identifying diseases/conditions for which the patient is at risk and requires additional management and/or screening, why do you feel it is difficult? (please check all that apply)**

☐ Never experience difficulty
☐ Not enough information in family health history
☐ Biological relationships in family health history are not clear
☐ Not confident in accuracy of information provided by patient
☐ Not confident in genetics knowledge
☐ No evidence-based guidelines for identifying patients at risk who require additional management and/or screening
☐ Other:_____

**15) How important do you feel a patient s family history is in the routine management and care of patients?**

☐ Very Important
☐ Important
☐ Somewhat Important
☐ Not important

**A) Please explain the reason(s) for your answer.**

_____

_____

_____

**Part III:** Given the information available to the general public regarding family history, it is possible that your patients may bring their family health history into their visits in different formats. Patients may collect their family history and record it in narrative or paragraph format *(**Patient Written Narrative- Column A**)*. Patients may draw a pedigree or receive a hand drawn pedigree from a health care professional such as a geneticist or a genetic counselor *(**Hand Drawn Pedigree- Column B**)*. And finally, it is possible that a patient will bring a family history in pedigree form generated by a computer program *(**Computer Generated Pedigree- Column C**)*. The following table contains questions 16-22 A,B, and C regarding these three types of patient generated family histories. Please answer the questions for each column, A, B, and C.

| | Patient Written Narrative (A) | Hand Drawn Pedigree (B) | Computer Generated Pedigree (C) |
|---|---|---|---|
| **16) Has a patient ever brought in a family health history in this format?** | ☐ Yes<br>☐ No (Please skip to #18A) | ☐ Yes<br>☐ No (Please skip to #18B) | ☐ Yes<br>☐ No (Please skip to #18C) |
| **17) How often do different patients bring in a family health this format?** | ☐ Less than once a year<br>☐ Less than once a month<br>☐ Monthly<br>☐ Weekly | ☐ Less than once a year<br>☐ Less than once a month<br>☐ Monthly<br>☐ Weekly | ☐ Less than once a year<br>☐ Less than once a month<br>☐ Monthly<br>☐ Weekly |

***(please continue on back page →)***

| | Patient Written Narrative (A) | Hand Drawn Pedigree (B) | Computer Generated Pedigree (C) |
|---|---|---|---|
| **18) On average, do/would health histories in this format contain more or less information than you/your office generally collect in a family health history?** | ☐ More<br>☐ Less<br>☐ Same | ☐ More<br>☐ Less<br>☐ Same | ☐ More<br>☐ Less<br>☐ Same |
| **19) How difficult was it/would it be to identify diseases/ conditions for which the patients are at risk and require additional management or screening?** | ☐ Easy<br>☐ Somewhat Easy<br>☐ Somewhat Difficult<br>☐ Difficult | ☐ Easy<br>☐ Somewhat Easy<br>☐ Somewhat Difficult<br>☐ Difficult | ☐ Easy<br>☐ Somewhat Easy<br>☐ Somewhat Difficult<br>☐ Difficult |
| **20) Why do/might you feel it is/could be difficult to identify diseases/ conditions for which patients are at risk and require additional management or screening? (please check all that apply)** | ☐ Never / don't expect to experience difficulty<br>☐ Not enough information in family health history<br>☐ Not confident in accuracy of information provided by patient<br>☐ Biological relationships in health history are not clear<br>☐ Other:_____ | ☐ Never / don't expect to experience difficulty<br>☐ Not enough information in family health history<br>☐ Not confident in accuracy of information provided by patient<br>☐ Biological relationships in health history are not clear<br>☐ Other:_____ | ☐ Never / don't expect to experience difficulty<br>☐ Not enough information in family health history<br>☐ Not confident in accuracy of information provided by patient<br>☐ Biological relationships in health history are not clear<br>☐ Other:_____ |
| **21) Compared to you current method of obtaining and documenting family history, how do you feel family health histories in this format would affect your ability to identify patients at risk who require additional management /screening?** | ☐ It would improve my ability<br>☐ It would interfere with my ability<br>☐ It would have no effect on my ability | ☐ It would improve my ability<br>☐ It would interfere with my ability<br>☐ It would have no effect on my ability | ☐ It would improve my ability<br>☐ It would interfere with my ability<br>☐ It would have no effect on my ability |
| **22) How do you feel family health histories in this format would affect the number of patients seen in a day?** | ☐ Increase patients seen<br>☐ Decrease patients seen<br>☐ No effect on patients seen | ☐ Increase patients seen<br>☐ Decrease patients seen<br>☐ No effect on patients seen | ☐ Increase patients seen<br>☐ Decrease patients seen<br>☐ No effect on patients seen |

**23) Have you heard of the Family History Demonstration Project designed to increase community awareness of the importance of family history in preventing disease and improving health?**

☐ **Yes**
☐ **No**

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