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Primary Care Providers Believe Patient-Generated Family History Will Increase Ability to Assess Patient Risk

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Primary Care Providers Believe Patient-Generated Family History Will Increase Ability to Assess Patient Risk

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Abstract

Family history is the best predictor of an individuals risk for common disease, yet it is inaccurately used in routine care. We hypothesized that patient-generated family history can improve a primary care provider's ability to asses risk without decreasing the number of patients seen. We mailed surveys to 301 providers and had a response rate of 24% (n=68). Seventy-three percent felt a computer-generated pedigree would improve their ability to assess risk as compared to their current methods. Seventy percent felt a computer-generated pedigree would either have no effect on or increase the number of patients seen in a day. Results suggest that providers feel optimistic about the potential benefits of patient-generated family history and are open to the implementation of patient-generated family history into routine care.

Acknowledgments

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Table of Contents

Taking a family history is a key component in the routine care of patients in a primary care setting because it is currently the best predictor of an individual's risk for many common diseases (Walter & Emery, 2006). It is estimated that 43% of "healthy" individuals are at an increased risk for common disease based on their family history (Scheuner, Wang, Raffel, Larabell, & Rotter, 1997). Despite the importance of family history, it is inconsistently and ineffectively utilized in routine care and treatment. While it appears family history is discussed with most patients, primary care providers are failing to get the relevant information necessary to assess risk and make appropriate recommendations (Summerton and Garrood, 1997; Sifri, Wender, & Paynter, 2002; Murff et al, 2004).

Without an adequate family history 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 risk for disease. 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 a (Murff et al, 2004). Both of these inaccurate risk assessments can lead to misdiagnosis, improper care of patients, and excess cost in the management of patient health.

According to Wolpert and Speer, a complete family health history includes a minimum of a three generation family history 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 (Wolpert & Speer, 2005). However, current studies suggest that the majority of this information is rarely obtained (Summerton and Garrood, 1997; Sifri et al, 2002; Murff et al, 2004). In a retrospective chart review by Tyler et al, 97.8% of charts had

some record of family history. However in 69.5% of these charts, there was not adequate information to apply risk to the individual (Tyler & Snyder, 2006).

The lack of family history information in patients' charts stems from several barriers: the providers' lack of knowledge regarding the information to elicit from patients, the lack of a standard format for collection that clearly indicates biological relationships, and limited time for patient visits. (Bennett, Steinhaus, & Ulrich, 1995; Family History Working Group, 2003). In a study which compared self-reported patient health histories recorded on computer programs to patient medical records, Sweet, Bradley, and Westman (2002) reported that of 363 computer entries, 101 patients were considered at high risk based on their pedigree information. However, only 69 of these patients had information indicating this high risk in their medical record. This study indicates that patients know their family history 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. Text and patient questionnaire formats are frequently inadequate to capture the significance of familial risk factors. They often neglect to distinguish between maternal and paternal family history and do not always facilitate recognition of patterns of inheritance (Wolpert & Speer, 2005). And finally, time is a primary barrier to the adequate collection of family history. In order to obtain a complete 3-generation pedigree, most healthcare providers need approximately 15 to 20 minutes (Rich et al, 2005). For primary care visits that average 16 minutes total in length, obtaining a full 3-generation family history simply is not possible (Menasha, Schechter, & Willner, 2000; Fairfield, Chen, Colditz, Emmons, & Fletcher, 2004; Murff et al, 2004; Wolpert & Speer, 2005).

Because of the recognition of the importance of family history, as well as the barriers of obtaining family history in a primary care setting, there has been growing interest in the development of family history tools. Two tools that are being developed to address the problem of incomplete family history are the Surgeon General's family history tool, My Family Health Portrait (familyhistory.hhs.gov), and the Center for Disease Control and Prevention's family history tool, Family Healthware (http://www.cdc.gov/genomics/). These are web-based family history programs that result in a computer-generated pedigree. Patients can utilize these tools prior to doctors' visits to generate a family history they can bring to their medical visit. In theory, the utilization of these tools would solve many of the problems that are associated with inadequate family history such as inadequate time for a complete family history interview, ineffective methods for eliciting the proper information, and lack of a standard format that clearly identifies relationships and patterns.

Unfortunately, there is limited data on the benefits and limitations of any of these patient administered methods of collection in the clinical setting. An extensive search of literature using search engines such as PubMed, Medline Plus, and Google, as well as searching individual major medical organization websites such as the American Academy of Pediatricians (AAP), the American Academy of Family Physician (AAFP), and the American Medical Association (AMA) resulted in no study that assesses or expresses the reactions of providers to a family history generated by patients' utilization of a family history collection tool. Therefore, while large amounts of money and time are being spent to promote the use of these family history tools to the general public, it is still unknown whether primary care providers will benefit from the implementation of a patient-generated family history. Therefore, this study begins to address

this discrepancy in data and determine where future research efforts need to be made to effectively incorporate the use of family history in primary care.

Methods

Study Design

We performed a quantitative cross-sectional study of primary care providers in the Cincinnati area. 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

Primary care providers were identified by calling community clinics listed on *The Bureau of Primary Health Care* (bphc.hrsa.gov) and *Cover the Uninsured* (www.covercincy.org) websites and asking for a list of providers practicing at each clinic. Additionally, a search for primary care providers was performed 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 within a 25 mile radius of Cincinnati, OH, 45202. 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. Names for 334 primary care providers were identified by the combination of the methods described above. After eliminating duplicate names, 301 providers were selected as eligible participants and were mailed a survey.

Survey

The questionnaire was developed by the principal investigator and co-investigators who have targeted expertise in family history implementation, genetics education of providers, and primary care clinical settings. The survey was designed to assess the current utilization and

perceived value of family history by primary care providers and to compare the perceived value by primary care providers of family history generated by providers versus patients. The complete survey can be viewed in the appendix. The study was approved by both the University of Cincinnati (UC) and Cincinnati Children's Hospital Medical Center (CCHMC) IRB and was piloted for face validity by primary care physicians, genetic counselors, and genetic counseling students at UC or CCHMC.

Demographics. The survey was designed to evaluate demographic and descriptive characteristics of participants such as age, years in practice, type of practice, specialty, location of office, average age of patients seen, number of patients seen, and exposure to genetics in medical school and continuing education courses.

Current utilization and perceived value of family history. The survey contained a series of both opened- and closed-ended questions that address current utilization of provider-generated family history such as the following: In your office/clinic, is it considered standard-of-care to collect family health history at initial patient visits? In your office/clinic is it considered standard-of-care to review and update family health history at routine established patient visits? And, is there a standard procedure that your office uses to collect family history? Additionally, the survey evaluated the perceived difficulty interpreting provider-generated family histories through questions such as the following: Based on your current family history collection practices, on average, how difficult is it to identify diseases/conditions for which patients are at risk and need additional management and/or screening? And, when you experience difficulty identifying diseases/conditions for which a patient is at risk and requires additional management and/or screening, why do you feel it is difficult?

Patient-generated family history in a primary care setting. The last set of questions of the survey assessed the perceived value of patient-generated family histories. Three different formats of patient-generated family histories were evaluated including patient-written narrative, hand-drawn pedigree, and computer-generated pedigree through questions such as the following: On average, do health histories in these formats contain more or less information than you/your office generally collect in a family health history? Based on the information in health histories in this format, on average, how difficult was it to identify diseases/conditions for which the patients are at risk and require additional management or screening? And, compared to your 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?

Data Analysis

Frequencies and relative frequencies were computed on all categorical variables including demographics, family history use at the clinic and provider level, and provider perceived value of patient-generated family histories. Family history use, perceived importance by the provider, and difficulty assessing risk were compared with the following variables: population served (pediatric versus adult), genetics background of the provider, age of the provider, specialty of the provider, and average number of patients seen in one week. These proportions were compared using chi-square tests and Fisher's exact test. Statistical significance was evaluated at an alpha level of 0.05. Participant responses to patient-generated family histories 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. All analyses were conducted using SAS version 9.1 (SAS Institute Inc, Cary NC).

Results

Subjects

Of the 301 providers mailed surveys, 21 surveys were undeliverable. Of the 280 remaining surveys, 68 surveys were completed and returned before the cutoff date (4 additional surveys were received after the cutoff for inclusion) for a response rate of 24.3%.

Demographics. Ninety-four percent of respondents (n=63) were physicians with 63% (n=42) male and 37% (n=25) female. The average age of respondents was 48.6 years old. The largest percentage of respondents work in pediatrics (36%, n=24). Internal medicine respondents were second at 33% (n=22). Twenty-one percent (n=14) of respondents work in family practice, and 9% (n=6) work in other areas. While 70% (n=46) of respondents indicated receiving genetics education in medical/graduate school, only 27% (n=18) of total respondents have pursued continuing medical education in genetics since medical/graduate school. A complete list of respondent characteristics can be seen in Table 1.

Current utilization and perceived value of family history. We assessed the current utilization of family history in routine practice. Ninety-six percent (n=64) of participants indicated it is standard-of-care to collect a family history at an initial patient visit, and 70% (n=46) said it is standard-of-care to review and update family history at an established patient visit. To collect family history, 63% (n=42) of respondents stated there is a standard form they use to collect family history, and 60% (n=40) indicated that collecting the family history is solely the job of the primary care provider performing the medical evaluation. Eighty-one percent

(n=55) of participants reported collecting family history in a face-to-face manner with the patient, and 68% (n=46) said they then write/type/dictate a narrative to record the family history.

Most primary care providers (68%, n=46)) feel family history is either very important or important to the routine care of patients in a primary care setting. Yet, 87% (n=59) of respondents indicated that they spend only 1-5 minutes during the initial visit obtaining family history. Only one individual spent 11-15 minutes collecting family history. No providers reported spending more than 15 minutes collecting the family history. Additionally, 84% (n=56) of providers indicated spending only 1-5 minutes discussing family history with a patient. At established patient visits, 34% (n=23) of providers indicated spending 0 minutes reviewing the charted family history, and 33% (n=22) indicated spending 0 minutes updating family history.

Based on current family history collection practices, 36% (n=25) 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 sited for difficulty assessing risk was "not confident in accuracy of information provided by patient" at 54% (n=37). "Not enough information in family history," and "biological relationships in family health history are not clear" were the second and third most frequently sited response at 42% (n=28) and 26% (n=18) respectively. Only 10% of respondents indicated a lack of confidence in their own genetics knowledge as the reason for difficulty assessing risk.

Patient-generated Family History in a Primary Care Setting. Most primary care providers (52%, n=35) have not had a patient bring in a family history in any format to a visit. Of the providers that have had a patient bring in a family history (n=33), all have received at least one patient-written narrative. Only 24% (n=8) of these providers have had a patient bring a hand-drawn pedigree and 9% (n=3) of these providers have had a patient bring a computer-

generated pedigree. Of those providers that have had a patient bring in a hand-written narrative, 39% (n=13) report it occurs less than once a year, 52% (n=17) report it occurs less than once a month, 3% (n=1) report it occurs monthly, and 6% (n=2) report it occurs weekly. Sixty-three percent (n=5) of those that report having a patient bring in a hand-drawn pedigree report it occurs less than once a year, 15% (n=2) report it occurs less than once a month, and 12.5% (n=1) report it occurs monthly. Sixty-seven percent (n=2) of providers that have had a patient bring in a computer-generated pedigree report that it occur less than once a year and 39% (n=1) report it occurs less than once a month.

Regardless of respondents' personal experiences with patient-generated family history, all respondents were asked to answers questions comparing patient-generated family history formats with their current methods of family history collection. However, all respondents did not answer questions about each patient-generated format.

Primary care providers felt patient-generated family histories would contain more information than family histories obtained using their current methods. Fifty percent (n=32) of primary care providers felt a patient-written narrative, 71% (n=41) felt a hand-drawn pedigree, and 80% (n=44) felt a computer-generate pedigree would contain more information than a provider-generated family history (Figure 1). We found a significant difference in respondents' answers to this question depending on which format was being considered ($\kappa = 0.3$, $p<0.001$).

The majority of respondents felt patient-generated family histories would be relatively easy to use to identify conditions for which a patient is at risk. Sixty-two percent (n=40) of providers felt a patient-generated family history in a narrative form would be either easy or somewhat easy to identify diseases/conditions for which a patient is at risk. When considering a computer-generated pedigree format, 76% (n=44) of providers felt a patient-generated family

history would be easy or somewhat easy to identify risk. Again, there was a significant difference in respondents answers to this question depending on the format ($\kappa=0.4$, $p<0.0001$).

When comparing patient-generated family history to current methods of family history collection, respondents felt patient-generated family history 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 family history 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 provider-generated family history collection (Figure 2).

We also assessed whether providers feel a patient-generated family history would interfere with the number of patients seen in a day. Seventy-two percent (n=47) of providers felt a patient-written narrative would either have no effect on or 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 increase the number of patients seen in a day.

Discussion

In 2004, the U.S. Surgeon General launched a new healthcare campaign called the Family History Initiative to encourage individuals to collect 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 to facilitate the generation of a pedigree. 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 family health history including the original Brigham and Women's Hospital Family History Project (B&WFH project), the Appalachian Family Demonstration Project (AFDP), and the Alaska Native Family Demonstration Project (ANFDP) ("U.S. Surgeon General Urges," 2005; "New Family Health History Projects," 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 this new method of family history collection by the patient. Therefore, while considerable time and money are being spent to promote this tool, it is unclear whether the implementation of this tool is feasible and whether it will actually increase a provider's ability to make appropriate screening and management decisions.

In this study we found that the majority of primary care providers value family history and consider it standard-of-care to collect family history at an initial patient visit. While providers are collecting family histories, respondents indicated they are not confident in the information presented by patients regarding their family history. Presumably, this lack of confidence reduces the value of family history for modifying a patient's management. One pediatrician explains this lack of confidence as he describes the difficulty eliciting relevant family history for a patient 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 medical history was very relevant to the patient's (her child's) family history and could potentially affect the patient's management and yet it was not shared during the patient's family history interview. This feeling was echoed by several providers in the study and may provide insight to previous studies that show that patients know more family history information than is being documented in medical records (Sweet et al, 2002). The feelings expressed by providers in this study in combination with findings from previous studies suggest that current methods used to collect family history are not sufficient to and may be interfering with the ability to obtain information that primary care providers feel is both valuable and reliable.

Similar to previous studies, providers spend very little time obtaining family history (Menasha et al, 2000; Fairfield et al, 2004; Murff et al, 2004; Wolpert & Speer, 2005). The majority of providers indicated spending 1-5 minutes collecting family history and 1-5 minutes discussing family history with the patient. According to previous studies, this amount of time is not adequate to obtain and discuss a complete three-generation family history (Rich et al, 2005). Therefore, in addition to the methods utilized, time allotted to collect family history, may also be interfering with the ability of primary care providers to collect valuable and reliable family histories.

Primary care providers from this study felt optimistic about the potential benefits of patient-generated family history. They felt that patient-generated family histories may contain more information then they are able to elicit at a standard office visit. Additionally, providers felt patient-generated family histories may be easier to interpret and assess risk for disease than

the family histories they are currently utilizing to assess risk. Furthermore, respondents' answers suggest that patient-generated family history in computer-generated pedigree formats would be the most beneficial. Trends found in this study indicate that providers feel computer-generated pedigrees may be the best method for acquiring accurate and complete information and would be the easiest format to use for interpreting and assessing risk. Based on these positive responses, providers seem open to the implementation of patient-generated family histories into routine care.

In order for the implementation of patient-generated family history to be feasible, this method of collection should not infringe on the number of patients a provider is able to see in a day. Based on this study, the majority of providers feel that patient-generated family histories would either have no effect on the number of patients seen in a day or may increase the number of patients seen in a day.

While data from this study indicates that patient-generated family history may be an effective tool for primary care providers to collect family history, this study shows that providers have little exposure to these tools or methods of collection. If the implementation of patient-generated family histories is going to be successful, additional efforts need to be made to promote patient-generated family history tools to primary care providers as well as the general public. Futhermore, providers either need to be educated in interpreting risk based on family history or clear evidence-based guidelines for making referrals to genetic professionals need to be created.

There are several limitations to this study. The 24% response rate is comparable with other physician surveys. However, since we did not collect information from non-responders, we cannot tell if there is a response bias. Additionally, the our sample size was small and from a

limited region, thus it may not represent our target population of primary care providers accurately. Since responses were based on providers' perceptions of patient-generated family histories rather than actual experience with these formats, answers may not be accurate. Therefore, additional studies of providers with greater exposure to patient-generated family histories, specifically computer-generated family histories, need to occur. And finally, this study was limited because it did not assess the need for training for physicians to interpret family history.

Conclusion

There are many barriers to making proper screening and management recommendations to individuals at increased risk for common disease based on their family history in a primary care setting. First, a primary health care provider must have an accurate and complete family history to assess. Second, the provider must be able to interpret the risk accurately to follow evidence-based guidelines for screening and management recommendations. Two obstacles that interfere with a provider's ability to effectively utilize family history are the lack of a standard method to collect family history that is easy to interpret and lack of time to collect a complete family history. Theoretically, patient-generated family histories could be beneficial in routine care because they address these obstacles. Providers in this study agree with the benefits of patient-generated family histories and are open to using them in a primary care setting. Additionally, trends present in this study suggest that primary care providers feel patient-generated family histories in computer pedigree format may be the most beneficial to their practice. Before this implementation can be effective, additional efforts need to be made to educate both the general public and primary care providers regarding the use and interpretation of patient-generated family histories.

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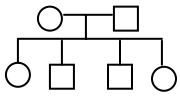
Definition:
The following definitions may be helpful while completing the survey.

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

Family History in the Routine Care of Patients

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

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.

_____

_____

_____

(please continue on back page →)

Family History in the Routine Care of Patients

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 ☐ No (Please skip to #18A)	☐ Yes ☐ No (Please skip to #18B)	☐ Yes ☐ No (Please skip to #18C)
17) How often do different patients bring in a family health this format?	☐ Less than once a year ☐ Less than once a month ☐ Monthly ☐ Weekly	☐ Less than once a year ☐ Less than once a month ☐ Monthly ☐ Weekly	☐ Less than once a year ☐ Less than once a month ☐ Monthly ☐ Weekly
	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 ☐ Less ☐ Same	☐ More ☐ Less ☐ Same	☐ More ☐ Less ☐ 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 ☐ Somewhat Easy ☐ Somewhat Difficult ☐ Difficult	☐ Easy ☐ Somewhat Easy ☐ Somewhat Difficult ☐ Difficult	☐ Easy ☐ Somewhat Easy ☐ Somewhat Difficult ☐ 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 ☐ Not enough information in family health history ☐ Not confident in accuracy of information provided by patient ☐ Biological relationships in health history are not clear ☐ Other:_____	☐ Never / don't expect to experience difficulty ☐ Not enough information in family health history ☐ Not confident in accuracy of information provided by patient ☐ Biological relationships in health history are not clear ☐ Other:_____	☐ Never / don't expect to experience difficulty ☐ Not enough information in family health history ☐ Not confident in accuracy of information provided by patient ☐ Biological relationships in health history are not clear ☐ 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 ☐ It would interfere with my ability ☐ It would have no effect on my ability	☐ It would improve my ability ☐ It would interfere with my ability ☐ It would have no effect on my ability	☐ It would improve my ability ☐ It would interfere with my ability ☐ 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 ☐ Decrease patients seen ☐ No effect on patients seen	☐ Increase patients seen ☐ Decrease patients seen ☐ No effect on patients seen	☐ Increase patients seen ☐ Decrease patients seen ☐ 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**

Table I. 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*	1.5%, n=1
Year 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**	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
Hospital	9%, n=10
Academic Medical Setting	14.9%, n=10
Public Health Agency	4.5%, n=3
Federally Funded Community Health Center	10.5%, n=7
Urban Clinic	1.5%, n=1

*intern

**cardiology (n=2), geriatrics (n=1), pulmonary (n=1), reproductive health (n=1), urban medicine (n=1)

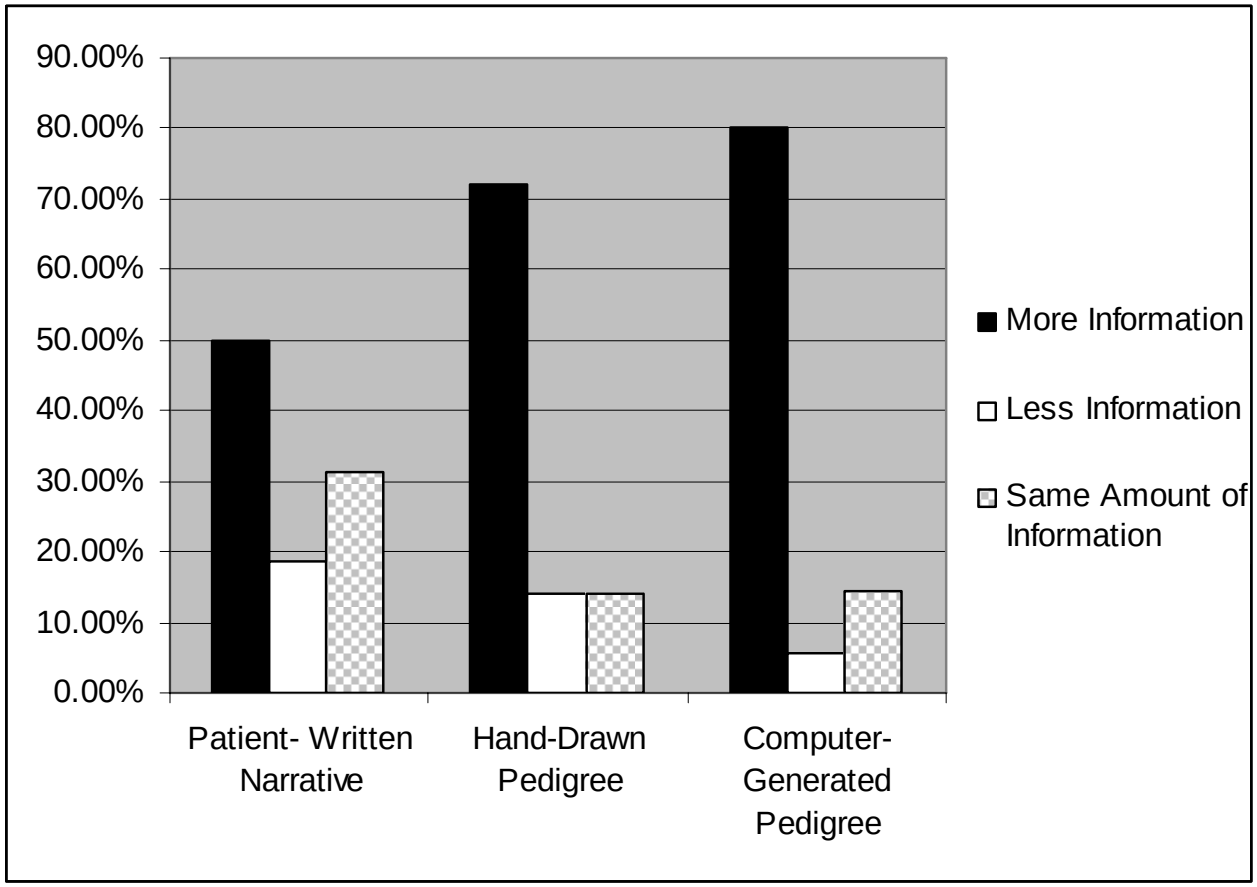


Figure 1. Information in Patient-Generated Compared to Provider-Generated Family Histories.

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.

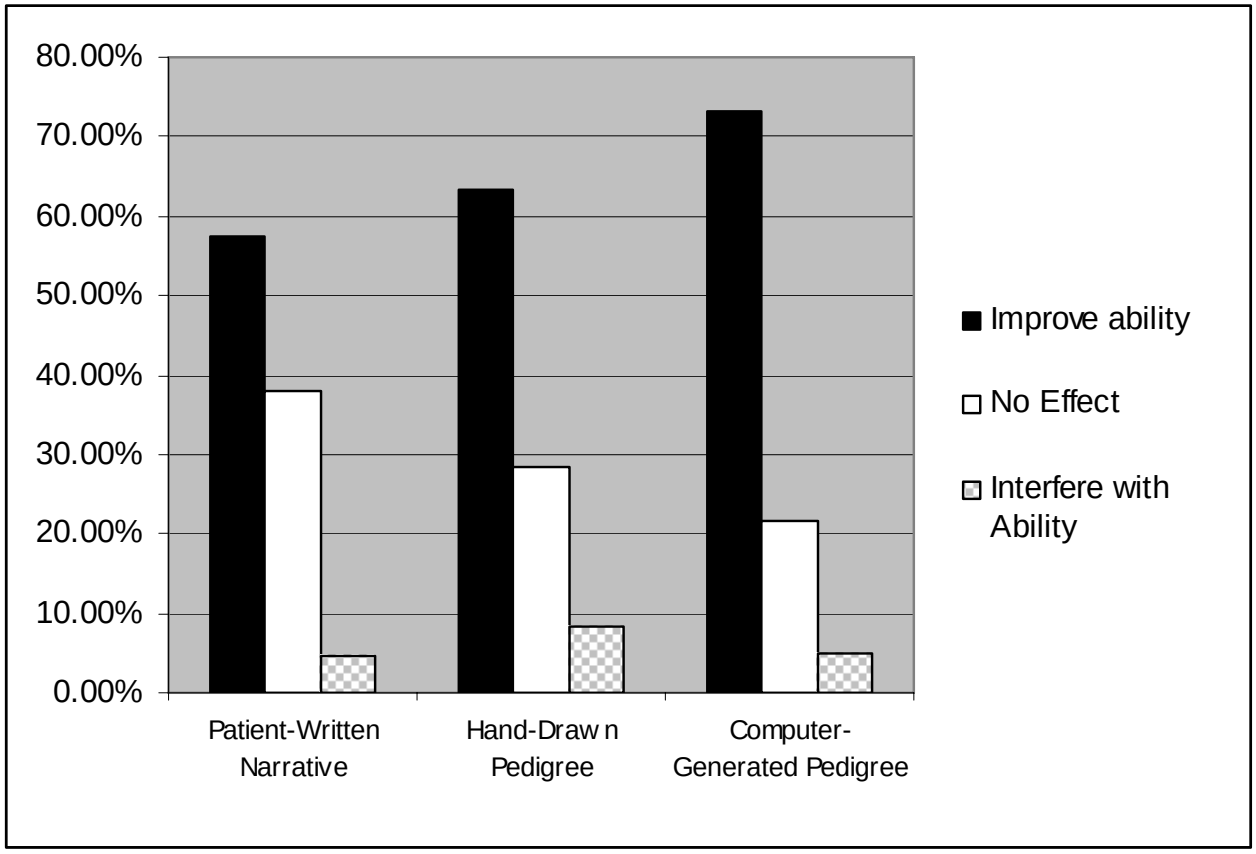


Figure 2. Assessing Risk Using Patient-Generated Family Histories. Providers were asked if patient-generated family histories in each of the three formats (patient-written narrative (n=66), hand-drawn pedigree (n=60), and computer-generated pedigree, (n=60)) would improve their ability to assess risk, 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.