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Genetic Counselors' Current Use of Personal Health Records-Based Family Histories in Genetic Clinics and Considerations for Their Future Adoption

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Abstract

Given the widespread adoption of electronic medical records and recent emergence of electronic family history tools, we examined genetic counselors' perspectives on the emerging technology of the personal health record (PHR)-based family history tool that links to an electronic medical record (EMR). Two-hundred thirty-three genetic counselors responded to an on-line survey eliciting current use of electronic family history (EFH) tools and familiarity with PHR-based family history tools. Additionally, after being shown a series of screen shots of a newly developed PHR-based family history tool based on the U.S. Surgeon General's *My Family Health Portrait* (United States Department of Health and Human Services 2009), participants were surveyed about the perceived usefulness, ease of use, and impact on current workflow that this kind of tool would have in their practices. Eighty-three percent reported that their institution has an EMR, yet only 35 % have a dedicated space for family history. Eighty-two percent reported that less than 5 % of their patients have a PHR, and only 16 % have worked with patients who have a PHR. Seventy-two percent or more agreed that a PHR-based family history tool would facilitate communication, increase accuracy of information, ensure consistency in recording information, increase focus on actual counseling, reduce repetitive questions, improve efficiency, and increase the legibility and clarity. Our findings suggest that participants were familiar with existing EFH tools, but that the majority did not use them in practice. Genetic counselors' adoption of such tools is limited due to non-existence of this kind of technology or inability to integrate it into their clinics. They are also

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strongly in favor of adopting a PHR-based family history tool in genetics clinics, but have practical concerns that must be addressed before the tool can be implemented.

Keywords

Electronic medical record; Electronic health record; Patient portal; Family history; Pedigree; Electronic family history tool

Introduction

Recording family history has long been a standard practice in genetic counseling. Currently, usual care in genetic counseling involves asking specific questions about a person's family history over the phone or via written questionnaire prior to a session, or in person during a session. Ideally, information should be collected by the patient ahead of time and diagnoses should be confirmed by medical records if possible (Bennett 2012). This information is then mapped visually onto a hand-drawn pedigree (family tree) using standard nomenclature (Bennett 2012; Bennett et al. 2008; Rich et al. 2004). This pedigree can be cumbersome to update, difficult to read and lacks portability. In addition, patients are often unaware that genetic counselors will be asking extensive questions about their family's health and come unprepared to answer questions that could have an effect on the quality of their session and their personal health. If patients are given sufficient information and the right tools, they could provide their family history electronically to a genetic counselor prior to a session, which may streamline their appointment and possibly allow counselors to save time or to focus more on other important parts of a session (Guttmacher et al. 2004; Hulse et al. 2011).

Today's healthcare is moving away from paper records towards electronic medical records (EMRs) (Martin-Sanchez et al. 2004). As a result, genetic counselors and other healthcare providers who acquire and record family history information may need to adjust their methods in order to record family history electronically (Glaser et al. 2008; Peace et al. 2012). Simply recording family history into the EHR may not be the best solution (Martin-Sanchez et al. 2004). Scheuner et al. (2009) reported that most EMRs have a space to enter family history information, but that it often consists only of unstructured, free-text space. This supports the results of studies performed by Feero and colleagues (Feero et al. 2008) and Hoffman (2007) that reported that EMRs are underdeveloped with regard to collecting family history information.

Additionally, governmental organizations have begun to address the issues surrounding the incorporation of technology into medical record systems. The Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS) (2004) identified an urgent need to develop web-based practice tools and integrate them into medical practice. A new federal proposed rule, released by the Center for Medicare and Medicaid Services in March 2012, would make building the capacity for storing family health history in the EHR one of a menu of 20 objectives that CMS would consider meaningful use of electronic health records. (Levenson 2012)

Efforts have been made to create patient and provider-friendly electronic family history (EFH) tools (Acheson et al. 2006; Cohn et al. 2010; He and Li 2007; Orlando et al. 2011; Rich et al. 2004; Wald et al. 2010; Yoon et al. 2009). One such tool was launched in 2009 by the U.S. Surgeon General in collaboration with the Centers for Disease Control called *My Family Health Portrait* (United States Department of Health and Human Services 2009). It is a free, online tool that patients may complete, print and bring to healthcare providers. This tool, as well as others, have the potential to help transition patient family history records into the digital age, provide consistent information, and provide a platform for easy updating and portability. Virginia Commonwealth University, in partnership with Cerner Corporation, is currently developing a consumer-oriented, personal health record (PHR)-based family history tool (using the *My Family Health Portrait* platform) that can be linked to a patient's EMR.

Since genetic counselors are considered the “gold standard” in family history collection (Cohn et al. 2004; Rich et al. 2004), it is important to explore genetic counselors' attitudes towards electronic family history tools and PHRs, especially the key features required for successful adoption of this technology. As of the date of submission for publication, we were not aware of any studies that had specifically examined genetic counselors' perspectives on these topics. By surveying the professionals who take and interpret detailed family history most often in their practices, we will gain valuable knowledge and insight into current and potential utilization of EFH tools, and how these tools can be refined and implemented in the most effective manner possible.

Purpose of the Present Study

In this study we explore genetic counselors' current use of EFH tools and their considerations for adopting a PHR-based family history tool in genetics clinics. We review the findings of quantitative survey data, as well as the major qualitative themes that emerged from genetic counselors' responses related to positive and negative aspects, workflow, and technical changes needed to adopt EFH tools. Finally, we explore the relationships between the quantitative and qualitative responses that genetic counselors provided regarding the adoption of PHR-based family history tools.

Methods

Study Design

This cross-sectional, parallel quantitative-qualitative study explored genetic counselors' perspectives on the emerging technology of the personal health record PHR-based family history tool through an online, anonymous survey. Genetic counselors were chosen as the study population because of their expertise in collecting and analyzing family histories. Approval for this study was obtained from the Virginia Commonwealth University institutional review board.

Recruitment

All genetic counselors from the National Society of Genetic Counselors' general and cancer group email lists (“listservs”) who had been practicing in a clinical setting within the last 5

years as of March 2011 were eligible to participate in the study. A recruitment email was sent through the listservs that described the study and eligibility requirements, and included a direct link to the electronic survey. At the time of the email, there were approximately 2,000 subscriber emails on the listservs. The survey included an informed consent document on the first webpage and the final webpage included an opportunity for participants to provide their name and an email address to enter a drawing for an iPad. A reminder email was sent 2 weeks later, and the survey was subsequently closed 1 week after the reminder.

Survey Instrument

The survey was developed by an interdisciplinary team that included two genetic counselors, a clinical geneticist and an expert in health informatics. It was reviewed by the developers prior to its launch. The survey included sixty questions and was divided into seven sections (see supplementary material). The “Demographics” section included questions about years of clinical experience, primary specialty, general computer usage and level of computer user sophistication. The “Current Use of Electronic Family History Tools” section included questions about current use of EFH tools surrounding genetic counselors’ personal and professional usage of electronic family history tools, familiarity with and usage of a PHR, and current EMR usage and capability to incorporate family history. The sections entitled “Usefulness of a PHR-based Family History Tool” and “Ease of Use of a PHR-based Family History Tool That Links With an Institutional EMR” consisted of Likert scale statements to which participants responded “agree” or “disagree.” The two sections on usefulness also included sample screenshots of Cerner Corporation’s PHR-based Family History tool (currently in development) in order to help the participants envision using it. The “Effect of a PHR-based Family History Tool on Current Workflow” section included questions about the effect of a PHR-based Family History tool on current workflow and the logistics of obtaining a copy of a patient’s family history. The “Factors Related to Genetic Counselors’ Adoption of a PHR-based Family History Tool” section included five free-response (open-ended) questions that allowed participants to elaborate on the positive and negative aspects, necessary workflow changes, technical changes, and critical features needed to adopt this type of tool. The survey was converted into an electronic form using Inquisite software (Inquisite Inc 2009) and posted to Virginia Commonwealth University’s survey website (survey.vcu.edu).

Data Analysis

Descriptive statistics were developed using JMP 8.0 software (SAS Institute Inc 2009). Likert scale questions were collapsed into binomial variables: “agree” (which included “very strongly agree,” “strongly agree” and “agree”) and “disagree” (which included “very strongly disagree,” “strongly disagree” and “disagree”). The Likert scales were collapsed into binomial variables due to small numbers of responses in some of the individual categories.

Responses to free-response (open-ended) questions were reviewed independently by the authors (HC and CW) for broad, underlying themes using an open-coding technique. The authors (HC and CW) then established a final set of thematic categories for each question. The participants’ responses were then coded by CW by hand into a single or multiple

thematic categories, and the final coding was reviewed and approved by CW and HC. Responses varied from one word to several sentences in length.

Results

Demographics

Two hundred thirty-three individuals completed the survey, for an estimated response rate of approximately 12 % (233/2000). This response rate is comparable to other studies that sent surveys to the NSGC listservs (e.g. Enns et al. 2009; Mackoff et al. 2010). Table 1 summarizes the demographic data. Two-thirds of participants reported fewer than 10 years of experience. Cancer, prenatal, and pediatric genetic counseling were the most well-represented specialties. Combined, they accounted for 93 % of the participants' primary specialties. Sixty-seven percent of participants considered themselves to be either very sophisticated or sophisticated computer users. All of the participants used a computer for email, and the vast majority of participants also used a computer for other activities such as banking or creating and storing documents.

Current Use of EFH Tools

Tables 2 and 3 summarize the data on genetic counselors' current usage of EFH tools. Eighty-eight percent of participants stated that they were familiar with EFH tools. Forty-five percent had used one to record their own family history, 71 % had used one to record a patient's family history, and 27 % estimated that their patients had used one to record their own family history.

A smaller percentage (71 %) of genetic counselors was familiar with the concept of a personal health record (PHR), and few (16 %) had worked with patients who had a PHR. When asked what their estimate was of how many of their patients had a PHR, the majority (93 %) believed that less than 25 % had one.

Eighty-three percent of genetic counselors' institutions had an EMR, but only 35 % of those EMRs had a dedicated place to enter family history that was separate from the clinic note. Of those who did have a dedicated space, less than half (44 %) of genetic counselors entered family history into that separate space. In terms of entering family history into the EMR in general, about half responded that they entered it for less than 5 %, while about half said they entered it for 75–99 %. Nine out of ten answered that they estimated fewer than 50 % of non-genetics providers entered family history into the EMR. Ten percent of genetic counselor participants stated that a PHR could link to the institution's EMR, and 2 % stated that they have accessed a patient's PHR via their institution's EMR.

Usefulness of a PHR-based Family History Tool

Table 4 summarizes the responses about the usefulness of a PHR-based Family History tool in two contexts: a patient printing and bringing the information to an appointment and having the information linked with an institutional EMR.

When a patient prints and brings family history information, the majority (60 %) of genetic counselors agreed that this would save them time documenting a visit, but 62 % believed

that this practice would not save them time preparing the patient and/or physician summary letter. Most (70 % or more) agreed that it would facilitate communication, increase accuracy of information, ensure consistency in recording information, increase focus on actual counseling, reduce repetitive questions, improve efficiency, and increase the legibility and clarity of the information. Genetic counselors were split on whether this would increase the overall safety of the patient's care. Less than one-third agreed that this would decrease the complexity of their jobs.

In comparison, within the context of information being linked with an EMR, the majority (63 %) of genetic counselors agreed that having the patient complete a PHR-based family history that links with the institutional EMR would save them time documenting a visit, and they were split (51 % agreed and 49 % disagreed) on whether this would save them time preparing the patient and/or physician summary letter. Most (72 % or more) agreed that it would facilitate communication, increase accuracy of information, ensure consistency in recording information, increase focus on actual counseling, reduce repetitive questions, improve efficiency, and increase the legibility and clarity of the information. Sixty-four percent of genetic counselors responded that this would increase the overall safety of the patient's care. Again, greater than two-thirds disagreed that this would decrease the complexity of their jobs.

Ease of Use of a PHR-based Family History Tool That Links with an Institutional EMR

Table 5 summarizes the responses about the ease of use of a PHR-based family history tool that links with an institutional EMR. Computers were available for 80 % of genetic counselors to use in the clinical space, and slightly more than half (56 %) did not believe that having computers in the room with the patient would interfere with rapport. About three-quarters of the genetic counselors believed that their patients had internet access, but slightly more than half (55 %) did not think that their patients would be comfortable using a PHR-based family history tool. Most (75 %) believed privacy would not be a concern with their patients in terms of using the PHR-based tool. The majority (64 %) of genetic counselors stated that they would have time to complete a family history during an appointment if the patient had not done so beforehand. Genetic counselors agreed that they were concerned about pedigree notation flexibility (84 %) and the ability to make changes to the pedigree (64 %).

Effect of a PHR-based Family History Tool on Current Workflow

For this section of the survey, participants were asked to respond to questions regarding the effect a PHR-based family history tool would have on current workflow. For nearly two-thirds (61 %) of genetic counselors, the patient's family history is not available before an appointment. About one-quarter (23 %) of genetic counselors responded that it would be most helpful if a patient brought in a printout of their pedigree, while about three-quarters (73 %) responded that it would be most helpful if the patient's PHR sent an electronic pedigree to the EMR prior to the visit. Only 4 % thought it would be helpful for patients to bring the electronic pedigree file with them to an appointment.

Factors Related to Genetic Counselors' Adoption of a PHR-based Family History Tool

Table 6 summarizes the responses genetic counselors gave regarding the factors related to their adoption of a PHR-based family history tool. Seventy-four percent of the participants responded to at least one open-ended question.

The authors reviewed the responses for positive aspects of adopting the tool and placed them into eight thematic categories. The same process was completed for negative aspects and responses were placed into 12 thematic categories. For positive aspects, the categories with the highest number of responses were saving time (increasing efficiency in their work), and increasing patients' ownership and preparedness for appointments. For negative aspects, the categories with the highest number of responses were a decrease in accuracy of information and the fact that it could be time-consuming to use.

The authors reviewed the responses for workflow changes that need to be made in order to support the technology in the clinic and placed them into nine thematic categories. The top four categories were no workflow changes, new responsibilities for office staff, a change in the amount of time spent on family history, and a change in the patient room set-up.

The authors reviewed the responses for technical changes that need to be made in order to support the technology in the clinic and placed them into ten categories. The top three categories all involved changes to the EMR. They included EMR upgrades with integration of existing technologies, installing or revising the EMR, and making the EMR (and other databases) compatible with this technology.

The authors reviewed the responses for critical features of this tool and placed them into 17 thematic categories. The top four categories were ability to be customizable, user-friendly, have free text space and have the ability to import or export data.

Discussion

This is the first study we are aware of to report genetic counselors' current use of EFH tools and considerations for adopting a PHR-based family history tool in their clinics. Overall, the findings about current use suggest that genetic counselors are familiar with existing EFH tools, but that the majority do not use them in practice. The findings surrounding the adoption of PHR-based technology suggest that genetic counselors are on board with the concept, but they have logistical and practical concerns that must be addressed in order to implement such a tool.

Though the vast majority of genetic counselors were familiar with EFH tools and PHRs, adoption of such tools was limited due to non-existence or inability to integrate this kind of technology into their clinics. Nearly all stated their EMR cannot link to a patient's PHR, if the technology does exist in their clinics, and that they have not accessed a PHR-based family history via a patient's EMR. These findings are supported by the fact that the top three themes in the technical changes section of the free-response questions pertain to updating EMRs to support this technology.

Responding genetic counselors were generally in favor of the idea of using a PHR-based family history tool, especially one that they receive via the EMR prior to a visit (rather than a printout that a patient brings to the appointment). They agreed that regardless of how the information was received, utilizing PHR technology would reduce the amount of time documenting a visit, facilitate communication, increase accuracy of information, ensure consistency in recording information, increase focus on actual counseling, reduce repetitive questions, improve efficiency, and increase the legibility and clarity of the information. Many of these favorable responses were supported by the responses genetic counselors gave in the free-response section that asked about the positive aspects of adopting this type of tool. Saving time (and therefore improving efficiency) was the most prevalent theme under positive aspects, which is consistent with how participants responded to the other survey questions mentioned above. Interestingly, the only task in which genetic counselors did not believe that PHR technology would decrease the amount of time spent was documenting a patient visit. This corresponds to the fact that they stated that PHR technology would not decrease the complexity of their jobs, which is expected since they must still interpret the family history and synthesize the information into a clinic note.

The second most prevalent positive aspect participants mentioned was that this tool would increase patient ownership and preparedness for clinic. This may be due to the fact that patients would complete their family history independently of a genetic counselor prior to a visit. Findings from other survey questions reflect the idea of increasing patient ownership and preparedness, including the fact that a mere 27 % of genetic counselors estimated that their patients have used EFH tools to record their family history and family history is only available to 39 % of genetic counselors prior to a patient's visit.

One potential discrepancy in the data was the fact that in the free-response section under negative aspects, the top response was that adopting the tool would *decrease* accuracy of information, while the earlier sections noted that this tool would likely *increase* the accuracy of information. This may demonstrate the participants' ambivalence about this kind of tool and the fact that nearly all participants lack true experience with this tool in practice.

Though the present sample of genetic counselors desired that patients take ownership and be more prepared, they indicated they were concerned about barriers that might prevent that from occurring. Just over half thought that most of their patients would not be technically comfortable using a PHR. This concern was echoed in the free-response section under negative aspects and critical features of this tool. Themes included concerns about the tool being time-consuming to use, patient compliance, patient computer or internet access, and patient computer or internet literacy. Ensuring the tool was user-friendly was a top critical feature given by participants. The findings from other questions in this study suggest that genetic counselors not only want the tool to be easy for patients to use, but also easy for genetic counselors to use in a clinical setting. This is especially true for situations in which genetic counselors will need to use the tool to modify a pedigree once a patient submits it.

Two other prevalent critical features were that the tool needs to be customizable and have free text space. These features correspond to concerns the sample had about the flexibility of pedigree notation. Nearly nine out of ten participants responded that they were concerned

pedigree notation would be limited and that there would be a lack of free text. A desire for flexibility reflects the fact that pedigrees are complex and that presently, no one tool is comprehensive enough to encompass all of the intricacies of collecting family history information.

Study Limitations

There are several limitations to this study. The survey instrument was novel, and although we did not directly test the instrument's validity, two genetic counselors and a physician screened the instrument prior to use. A potential limitation of using one clinic setting to pilot the survey may be resulting differences in the interpretation of the survey questions. The low estimated response rate of 12 % suggests the sample may not be a representative of the genetic counseling population and may limit the ability to generalize the results. It is important to note that not all genetic counselors who subscribe to the listserv were eligible to participate in the survey (see "Recruitment" section), so the response rate is likely higher than 12 %. Also, the listservs were discontinued shortly after our survey was distributed; therefore, an accurate number of subscribers to those listservs could not be determined and had to be estimated, which may affect the accuracy of the reported response rate. Demographic data collected on primary specialty do not necessarily reflect the true distribution of genetic counselors among specialties; specifically, the number of genetic counselors in cancer is overrepresented, while "other specialties" are underrepresented (National Society of Genetic Counselors 2010). Because cancer genetic counselors tend to utilize electronic tools (such as risk models) in their practices, their perspectives may be influenced by their current experiences with those tools. Future analysis may be helpful to determine if this impacted our results significantly. Some questions had a lower response rate than others, making the sample size for those questions smaller, which may further limit results generalization. Finally, another limitation is the fact that participants based their responses to a PHR-based family history tool on several sample screen shots of a tool that is currently in development rather than a "live" tool. Though the purpose of this study was not to gather information on implementing an actual tool in practice, it may have been challenging for genetic counselors to give realistic opinions without having tried the tool themselves.

Practice Implications

The findings of this study suggest that genetic counselors are strongly in favor of adopting a PHR-based family history tool in genetics clinics, but they have practical concerns that must be addressed before it can be implemented. Since genetic counselors are experts in family history collection and interpretation, it is encouraging that they generally support a consumer-oriented tool—a PHR in this case—to gather family history. These results suggest that implementing a PHR-based family history tool that links with an EMR could improve the task of collecting family history in genetics clinics. Specifically, this study showed that improvements could include: increasing efficiency in certain tasks, decreasing the amount of time spent on certain tasks, facilitating provider-patient communication, increasing the accuracy of information recorded, ensuring consistency of information, increasing safety of patient care, and increasing the legibility and clarity of family history information. All of these findings point to the fact that though current technology does not meet the needs

genetic counselors have for recording EFH, PHR-technology could assist in meeting that need.

It will be important for those creating and implementing this technology to take the results of this and similar studies into account as they develop EFH tools for patient and healthcare provider use. The adoption of these tools is dependent on endorsement from healthcare providers, including genetic counselors. In order to move family history collection into the EMR era, it is crucial to develop tools such as PHRs that patients will use and that providers will in turn integrate into patient care.

Conclusions and Research Recommendations

In conclusion, this study marks an important first step in assessing current use of these tools, as well as the factors and concerns that are important to genetic counselors who will be using them in their practices. The results represent an analysis of a large data set that may lead to future research questions. Subsets of these data may be used to answer some of these other research questions. It will be important for future studies to include opinions from physicians and patients in the primary care setting, which is where the majority of patients will provide family history information. Several recent studies have made an effort to determine the needs of and develop tools for primary care providers (Cohn et al. 2010; Hulse et al. 2011; Orlando et al. 2011; Yoon et al. 2009). The results of our study add new data to the increasingly complex world of developing useful health information technology.

Once this tool is launched, it will be helpful to gather patient and provider opinions at frequent intervals, ideally in the clinical setting. This will allow for a more realistic assessment of the tool. Adjustments will certainly need to be made, and those opinions will be helpful in shaping a tool that patients and providers will be willing and able to use.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1Demographics ($N=233$)^{a, b, c}

Years of clinical genetic counseling experience	Count (%)
1–4	87 (37 %)
5–9	68 (29 %)
10–14	31 (13 %)
15–19	19 (8 %)
20	28 (12 %)
Primary specialty	Count (%)
Cancer	110 (47 %)
Prenatal	62 (27 %)
Pediatrics	44 (19 %)
Other specialty	16 (7 %)
Computer usage	Count (%)
Email	233 (100 %)
Accessing media (e.g., movies, music, or news)	207 (89 %)
Banking	207 (89 %)
Creating and storing documents	208 (89 %)
Editing and storing photos	208 (89 %)
Social networking	186 (80 %)
Other	69 (30 %)
How sophisticated a computer user do you consider yourself?	Count (%)
Very sophisticated	25 (11 %)
Sophisticated	131 (56 %)
Neither sophisticated or unsophisticated	70 (30 %)
Unsophisticated	7 (3 %)
Very unsophisticated	0 (0 %)

^aCount varies due to missing data for some responses^bPercentages do not add up to 100 due to rounding^cPercentages total greater than 100 because participants could select multiple responses

Table 2Current use of electronic family history tools ($N=233$)^{a, b}

Survey question	Yes (%)	No (%)
Familiar with EFH tools?	203 (88 %)	29 (12 %)
Used an EFH tool to record my family history?	104 (45 %)	129 (55 %)
Used an EFH tool to record a patient's family history?	165 (71 %)	67 (29 %)
My patients have used an EFH to record their family history?	62 (27 %)	167 (73 %)
Familiar with the concept of a PHR?	165 (71 %)	67 (29 %)
Worked with patients who have a PHR?	36 (16 %)	194 (84 %)
My institution has an EMR	192 (83 %)	40 (17 %)
My institution's EMR has a dedicated place to enter family history separate from the clinic note	77 (35 %)	142 (65 %)
<i>If you answered "yes" to the above question:</i> Have you ever entered a patient's family history into the dedicated space in the EMR?	44 (44 %)	57 (56 %)
My institution's EMR can link to a patient's PHR	20 (10 %)	178 (90 %)
I have accessed a PHR-based family history via a patient's EMR	5 (2 %)	206 (98 %)

^aCount varies due to missing data for some responses^bPercentages do not add up to 100 due to rounding

Table 3Current use of electronic family history tools^{a, b}

Survey question	<5 % (%)	5–24 % (%)	25–50 % (%)	51–75 % (%)	>75 % (%)
Estimate of proportion of patients with a PHR?	95 (82 %)	13 (11 %)	4 (3 %)	1 (1 %)	3 (3 %)
<i>If you have a separate space for entering family history in your EMR, for what proportion of patients do you enter family history into that space?</i>	48 (48 %)	3 (3 %)	3 (3 %)	0 (0 %)	45 (45 %)
<i>If you have a separate space for entering family history in your EMR, in your opinion, for what proportion of patients do non-genetics providers enter family history into the EMR?</i>	61 (54 %)	21 (19 %)	19 (17 %)	3 (3 %)	9 (8 %)

^aCount varies due to missing data for some responses^bPercentages do not add up to 100 due to rounding

Table 4Usefulness of a PHR-based family history tool ($N=233$)^a

Survey question	Patient prints and brings		Linked to EMR	
	Agree (%)	Disagree (%)	Agree (%)	Disagree (%)
Reduce the amount of time I spend documenting a patient visit	140 (60 %)	93 (40 %)	147 (63 %)	85 (37 %)
Reduce the amount of time I spend preparing a patient and/or physician summary letter	89 (38 %)	144 (62 %)	119 (51 %)	114 (49 %)
Facilitate communication between myself and my patients.	204 (88 %)	29 (12 %)	201 (86 %)	32 (14 %)
Increase the accuracy of the information recorded	162 (70 %)	71 (30 %)	167 (72 %)	65 (28 %)
Ensure consistency in recording a family history	183 (79 %)	50 (21 %)	205 (88 %)	27 (12 %)
Increase the overall safety of patient care	118 (51 %)	115 (49 %)	147 (64 %)	84 (36 %)
Allow me to focus more on actual counseling	181 (78 %)	52 (22 %)	182 (78 %)	50 (22 %)
Reduce the number of times a patient is asked the same question	193 (83 %)	40 (17 %)	200 (86 %)	33 (14 %)
Improve the efficiency of my current work practices	184 (79 %)	49 (21 %)	187 (81 %)	44 (19 %)
Increase the legibility and clarity of family history information	191 (82 %)	41 (18 %)	206 (88 %)	27 (12 %)
Decrease the complexity of my job	74 (32 %)	159 (68 %)	72 (31 %)	168 (69 %)

^aCount varies due to missing data for some responses

Table 5

Ease of use of a PHR-based family history tool that links with an institutional EMR

Survey question	Agree (%)	Disagree (%)
Computers are available for me to use in my clinic space	187 (80 %)	46 (20 %)
Computers in the counseling room interfere with patient rapport	103 (44 %)	130 (56 %)
Most of my patients have internet access	176 (76 %)	57 (24 %)
Most of my patients would be technically comfortable using a PHR to share their family history with their healthcare providers	105 (45 %)	128 (55 %)
Regarding privacy, most of my patients would be comfortable using a PHR to share their family history with their healthcare providers	174 (75 %)	59 (25 %)
I would have time to enter a family history during the visit if my patient did not already complete one	144 (62 %)	89 (38 %)
I am concerned about the flexibility of pedigree notation would be limited (e.g. lack of free text)	196 (84 %)	37 (16 %)
I am concerned that it would be hard to make changes to the pedigree	148 (64 %)	85 (36 %)

Table 6Factors related to genetic counselors' adoption of a PHR-based family history tool^a

What would be the positive aspects of adopting such a tool in your setting?	Count (% out of 170 who responded)
Saving time/efficiency	95 (56 %)
Patient ownership/preparedness for appointments	63 (38 %)
Accessibility	33 (19 %)
Accuracy	31 (18 %)
Consistency	31 (18 %)
Clarity/legibility	22 (13 %)
Paper reduction/electronic nature of the tool	13 (8 %)
Improve communication	12 (7 %)
What would be the negative aspects of adopting such a tool in your setting?	Count (% out of 172 who responded)
Decrease in accuracy of information	63 (37 %)
Time-consuming	37 (22 %)
Patient compliance	31 (18 %)
Patient computer/internet access	30 (17 %)
Patient computer/internet literacy	28 (16 %)
Missed rapport-building opportunity	17 (10 %)
Technical issues	16 (9 %)
Privacy issues	15 (9 %)
Requiring people to use a new technology	13 (8 %)
Expense	5 (3 %)
Language barriers	5 (3 %)
Scheduling issues	4 (2 %)
What workflow changes would have to be made for you to support this technology in your clinic?	Count (% out of 147 who responded)
None	32 (22 %)
New responsibilities for office staff	29 (20 %)
Change in amount of time spent on family history	25 (17 %)
Patient room set-up	25 (17 %)
Changes to pre-appointment packets	19 (13 %)
Unsure	15 (10 %)
Scheduling issues	13 (9 %)
Registration changes	10 (7 %)
Need access to EMR	5 (3 %)
What technical changes would have to be made for you to support this technology in your clinic?	Count (% out of 142 who responded)
EMR upgrades and integration of technologies	82 (58 %)
Installation/revision of EMR	60 (42 %)
Compatibility with EMR and/or other databases	33 (23 %)
Computer access in patient rooms	29 (20 %)
Not sure	21 (15 %)
None	18 (13 %)
Information Technology (IT) support	10 (7 %)

Computers available in waiting room	8 (6 %)
Wireless access	7 (5 %)
Faster EMR access	1 (<1 %)
What features of a PHR-based Family History tool would be critical to your adoption of a tool?	Count (% out of 148 who responded)
Customizable	72 (49 %)
User-friendly	54 (36 %)
Free text	29 (20 %)
Ability to import/export data	21 (14 %)
Accurate relationship lines (e.g., half-siblings)	13 (9 %)
Sharing across specialties/availability to all health providers	8 (5 %)
Patient access at home or in clinic	6 (4 %)
Ability to print without identifiers	5 (3 %)
Confidentiality	4 (3 %)
Low cost	4 (3 %)
Language translation	3 (2 %)
Multiple diagnoses for individuals	3 (2 %)
Ability to designate validated information	2 (1 %)
Check boxes	2 (1 %)
Searchable	2 (1 %)
Access ahead of time	1 (1 %)
Track changes	1 (1 %)

^aPercentages total greater than 100 because participants gave responses that could correspond to more than one category