J Genet Counsel (2011) 20:510–525
DOI 10.1007/s10897-011-9381-x

ORIGINAL RESEARCH

Clinical Use of the Surgeon General's "My Family Health Portrait" (MFHP) Tool: Opinions of Future Health Care Providers

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Received: 18 March 2011 / Accepted: 31 May 2011 / Published online: 24 June 2011

Abstract This study examined medical students' and house officers' opinions about the Surgeon General's "My Family Health Portrait" (MFHP) tool. Participants used the tool and were surveyed about tool mechanics, potential clinical uses, and barriers. None of the 97 participants had previously used this tool. The average time to enter a family history was 15 min (range 3 to 45 min). Participants agreed or strongly agreed that the MFHP tool is understandable (98%), easy to use (93%), and suitable for general public use (84%). Sixty-seven percent would encourage their patients to use the tool; 39% would ensure staff assistance. Participants would use the tool to identify patients at increased risk for disease (86%), record family history in the medical chart (84%), recommend preventive health behaviors (80%), and refer to genetics services (72%). Concerns about use of the tool included patient access, information accuracy, technical challenges, and the need for physician education on interpreting family history information.

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Keywords "My Family Health Portrait" · Family history · Family history tools · Genetic services · "MFHP" tool

Introduction

Obtaining a family history is considered to be a cost-effective method for screening and identifying individuals at increased risk for both Mendelian disorders and more common genetically-complex chronic conditions such as heart disease, diabetes, and some types of cancer (Frezzo et al. 2003; Guttmacher et al. 2004; Reid et al. 2009; Yoon et al. 2002). The identification of at-risk individuals can facilitate individualized preventative care and surveillance, which could impact disease morbidity and mortality (Frezzo et al. 2003; Guttmacher et al. 2004; Yoon et al. 2002). Despite the importance of family history in health care, time constraints, limited knowledge, and a paucity of management guidelines prevent many health care providers from routinely taking a family history (Frezzo et al. 2003; Hayflick et al. 1998; Rich et al. 2004; Suther and Goodson 2003; Wood et al. 2008). Many providers feel they lack the knowledge necessary to take a targeted family history, determine which patients may be at increased risk, and refer them to genetics services (Frezzo et al. 2003; Hayflick et al. 1998; Rich et al. 2004; Suther and Goodson 2003; Wood et al. 2008). A 2000 study of family practice physicians found that family history was only discussed during 51% of new patient visits and 22% of established patient visits and these discussions lasted less than two-and-one-half minutes on average (Acheson et al. 2000).

Several organizations have encouraged the use of family history in health care, including the American College of Medical Genetics, American Medical Association, American Society of Human Genetics, the Centers for Disease Control

and Prevention (CDC), the Genetic Alliance, the National Coalition for Health Professional Education in Genetics, the National Society of Genetic Counselors, and the Secretary's Advisory Committee on Genetics, Health, and Society, among others (American College of Medical Genetics 2008, 2009; American Medical Association 2004, 2010; American Society of Human Genetics 2010; Burke et al. 2002; Centers for Disease Control and Prevention 2009; Genetic Alliance 2009; Johnson et al. 2005; National Coalition for Health Professional Education in Genetics 2007; National Coalition for Health Professional Education in Genetics 2010a, b, c, d; National Human Genome Research Institute 2009a; National Society of Genetic Counselors 2011; Secretary's Advisory Committee on Genetics, Health, and Society 2004, 2005; United States Department of Health and Human Services 2009). These organizational efforts have been directed at the general public and health care providers and have included explanations of the medical importance of a family history, instructions for collecting family history information, descriptions of family history tools, identification of genetic "red flags," and the development of educational initiatives for medical students and health care providers.

In November 2004, the Surgeon General launched the Family History Initiative and declared Thanksgiving as an annual Family History Day to encourage individuals to record and share their family histories (National Human Genome Research Institute 2009a). As part of the Family History Initiative, the Surgeon General, in collaboration with the CDC, launched a family history tool titled "My Family Health Portrait" (MFHP) (United States Department of Health and Human Services 2009). This free online tool is available to the public, allows individuals to record and save their family history information, and was created to facilitate the sharing of family history information with relatives and health care providers (National Human Genome Research Institute 2009a). The most recent version of the MFHP tool was launched in 2009 (Feero 2009). At the time of the present study, the MFHP tool did not contain clinical decision support (National Human Genome Research Institute 2009a).

A handful of studies to date (National Human Genome Research Institute 2009b) have examined public [e.g., hospital employees (Murray et al. 2009), veterans (Arar 2010), Appalachian women (Wallace et al. 2009)] and health care providers' opinions (Kanetzke et al. 2011) toward the MFHP tool. Research on public use of the MFHP tool suggests that the general public believes collecting family history is important (Murray et al. 2009; Wallace et al. 2009). Participants shared the pedigrees generated by the MFHP tool with their family members and health care providers (Murray et al. 2009; Wallace et al. 2009). Challenges identified included difficulty accessing the tool online (Wallace et al. 2009) and concerns for information security (Arar 2010; Murray et al. 2009). Research with health care providers (Fuller et al. 2010) suggests providers feel that electronic family history tools, including the MFHP tool (Kanetzke et al. 2011), will improve their ability to collect family history information. Providers expressed concern about the public's ability to access the MFHP tool and understand the medical terminology used in the tool (Kanetzke et al. 2011). Other research focusing on the validity of the tool suggests that pedigrees generated by the MFHP tool are similar in content to those obtained by a genetics professional (Facio et al. 2010). This study by Facio et al. (2010) found that although the MFHP tool can be used to accurately record a history of breast, colon, and ovarian cancer and diabetes, the tool was less accurate in recording a history of coronary artery disease and stroke.

Purpose of the Present Study

The 2009 National Institutes of Health (NIH) State-of-the-Science "Family History and Improving Health" conference statement put forth the recommendation that more research is needed regarding health care providers' opinions of family history tools (Berg et al. 2009). These tools will have limited impact on health care if providers neither encourage tool use by their patients nor assess and utilize this family history information in patient care. To our knowledge, this is the first study that has asked medical students and house officers to use the Surgeon General's MFHP tool and provide feedback on the tool and the potential utilization of the tool's output in clinical practice.

Methods

Study Design

This cross-sectional study explored medical students' and house officers' opinions of the Surgeon General's MFHP tool. We chose to study medical students because education obtained during medical school can impact their opinions regarding future practice habits (Autio-Gold and Tomar 2008). We chose to study house officers in relevant primary care disciplines because they have had a few years of experience providing patient care and can therefore more realistically comment on the potential clinical applications of the MFHP tool; they also are at an early enough point in their careers that they might be more open to incorporating the tool into their clinical practice. Participants were given the option to enter either their personal or a sample family history into the MFHP tool (online version 2.0). The sample family history (Fig. 1) consisted of a simple three-generation pedigree that included a sample patient, two children, two siblings, parents, and paternal and maternal grandparents. There were 11 individuals total with nine total health conditions to be entered, as two individuals did not have

Sample Family History

Click here to go to the Surgeon General's "My Family Health Portrait" tool website. Click on "create a family history." Please add the family history for the following individuals by clicking on "Add history" next to each individual. **After you add a condition you must click "add to list" in order for the information to be saved.**

Patient: Jane Smith DOB: 8/13/72, diagnosed with hypertension in her 30's
5'5" tall, 150 lbs

Jane's parents:
Father: 72 years old, diagnosed with Type II diabetes in his 40's
Mother: 66 years old, diagnosed with high cholesterol in her 50's

Jane's children:
Daughter: 6 years old, no known health concerns
Son: 11 years old, diagnosed with ADHD at the age of 8

Jane's siblings:
Brother: 32 years old, no known health concerns
Sister: 42 years old, diagnosed with breast cancer in her 30's

Jane's grandparents (father's side):
Paternal grandfather: Died from colon cancer in his 70's
Paternal grandmother: Died from breast cancer in her 70's

Jane's grandparents (mother's side):
Maternal grandfather: Died from a stroke in his 50's
Maternal grandmother: Died from a heart attack in her 60's

After entering all of the family health information, click "view diagram and chart" to see the information displayed as both a pedigree and chart. After completing the family history, please fill out the following survey starting on the next page.

Fig. 1 Participants were given the option to enter a sample family history into the Surgeon General's My Family Health Portrait tool. The structure of this family history is depicted in the above figure

any reported health conditions. After entering a family history into the MFHP tool, participants were asked to complete an online anonymous survey assessing their opinions about the tool.

Recruitment

All first- through fourth-year medical students and house officers (residents and fellows) in the family medicine, internal medicine, obstetrics/gynecology, and pediatrics programs enrolled at the University of Michigan as of January 2010 (N=1,056) were eligible to participate in this study. After obtaining permission from the directors of each program, a recruitment email was sent out through existing group email lists. This email described the study and provided a direct link to the survey, which included an informed consent document. A reminder email was sent approximately 2 weeks into this four-week study. As an incentive, participants who completed the survey were given the option to separately submit their email addresses into a drawing for one of ten $50 gift cards. This study was granted exemption status by the University of Michigan Medical Institutional Review Board.

Instrumentation

Surgeon General's MFHP tool

The Surgeon General's MFHP tool (version 2.0) is an online family history tool that is freely available to the public and allows individuals to record and share their family history

information. The tool has a series of prompts that ask for demographic information, such as age, sex, and ethnicity, along with health information. Users are given the option of selecting a health condition from a drop-down menu or adding in a condition if it is not present. The tool asks for an age range for each diagnosis. The MFHP tool automatically asks a user for information about children, siblings, parents, aunts, uncles, and grandparents to begin creating the pedigree. Users are then able to add half-siblings, nieces/nephews, grandchildren, and first cousins at a later point in the tool. After completing the family history information, users can view this information as either a table or pedigree.

Survey Instrument

The survey instrument was developed by the multidisciplinary research team, whose members have backgrounds in medical genetics, primary care, genetic counseling, and family history research. The survey was composed of 37 questions and was divided into four sections: demographics (13 questions), mechanics of using the MFHP tool (2 questions), opinions about the MFHP tool (19 questions), and helpful resources (2 questions). An additional open-ended question asked for general comments about the MFHP tool. Demographic questions included age, sex, year of training, area of specialization (completed by house officers only), and previous experience with family history tools. Mechanics questions included which family history was entered into the MFHP tool (personal versus sample) and the time required to enter a history. Opinions about the MFHP tool were assessed by a series of Likert scale statements regarding potential use of the tool and its output, along with benefits and limitations. Both positively and negatively worded questions were included to reduce potential response bias. Resource questions asked participants to choose which listed resources would be most helpful and provided an option to list additional resources. The final survey instrument was converted into an online survey using Qualtrics™ software (2010) and was piloted with five University of Michigan genetic counseling students and the Genetic Counseling Program Director. Feedback was positive, and no changes were made to the survey instrument.

Data Analysis

Descriptive and comparative statistical analyses of the data were performed using IBM SPSS Statistics 17.0 (2008). Responses were compared across the following variables: year of training, prior experience with collecting personal family history information, history entered into the MFHP tool (personal versus sample), time required to enter a history into the tool, and challenges using the MFHP tool. Comparative statistics were generated using Pearson chi-square tests, and logistic regression was used to analyze the predictive value of time. For the Pearson chi-square tests, we treated each of these tests independently and used the alpha level of 0.05 for each test. To increase the statistical power of the data analysis, for the comparative statistics only (not including logistic regression), the five categories of responses to the Likert scale questions were collapsed into binomial variables: "agree" (includes "agree" and "strongly agree") versus "not agree" (includes "strongly disagree", "disagree", and "neutral") and "disagree" (includes "disagree" and "strongly disagree") versus "not disagree" (includes "strongly agree", "agree", and "neutral").

Open-ended comments on the MFHP tool were reviewed by the authors (KO, MM, WU) for broad underlying common themes. Many of these comments were phrases or one to two sentences in length; therefore, a more in-depth qualitative analysis was not performed.

Results

Demographics

Ninety-seven individuals entered a family history into the MFHP tool and completed the survey, for a response rate of approximately 9% (97/1056) (Table 1). The mean age was 27 years (SD=2.901 years; Range 22 to 36 years), 64% were female, and 62% were medical students. An additional 22 individuals did not use the MFHP tool but did answer the demographic questions. The 22 participants who did not enter a history were asked to indicate why: seven indicated that they did not use the tool because it was too time-consuming; seven were unaware that they were required to enter a history into the MFHP tool; two were not interested; two thought the tool was too difficult to use; one did not think the MFHP tool was important; and three participants did not answer this question. Of the 97 participants who did enter a family history into the MFHP tool, 66% (n=64) had previously gathered their own family history information and 14% (n=14) had previously used either a genealogy or cancer family history tool. Of note, none of the participants had previously used the MFHP tool, and only one participant was aware of the Surgeon General's Family History Initiative.

Mechanics of Using the MFHP Tool

Sixty-three participants (65%) entered their personal family history into the MFHP tool and 34 (35%) entered the provided sample history. The average time spent entering a family history into the MFHP tool among all participants was 15 min (SD=7 min; Range 3 to 45 min). The average time spent entering a personal family history (mean=18 min, SD=7 min;

Table 1 Demographics of study participants (N=97)

Mean age in years (range)	n=27 (22–36)	
Sex		
Female	n=62 (64%)	
Male	n=35 (36%)	
	***n* (% of total respondents)**	**Total *n* eligible (%)**
Total	97	1056
Level of Education		
Medical Students[a,b]	60 (62%)	768 (73%)
Year 1	14 (14%)	173 (16%)
Year 2	15 (15%)	168 (16%)
Year 3	11 (11%)	230 (22%)
Year 4	20 (21%)	197 (19%)
House Officers[c]	37 (38%)	288 (27%)
Pediatrics	17 (18%)	57 (5%)
Internal Medicine	16 (16%)	156 (15%)
Family Medicine	2 (2%)	36 (3%)
Obstetrics/Gynecology	2 (2%)	39 (4%)

[a] Percentages of each individual year do not add up to total percentage of medical students due to rounding

[b] The total number of medical students was approximated and included students on leave at the time of recruitment

[c] Thirty-two Pediatric residents were enrolled in the joint pediatrics-internal medicine program and were included in the total number only once as Internal Medicine residents because the survey materials were distributed to the Internal Medicine resident email lists before the Pediatric resident email lists

Range 6 to 45 min) was significantly longer than the average time spent entering the provided sample family history (mean= 10 min, SD=4 min; Range 3 to 25 min), $p<.001$. The sample family history contained 11 individuals and nine health conditions. The number of family members and medical conditions entered by participants who chose to enter their personal family history information was not ascertained.

Opinions About the Surgeon General's MFHP Tool and Taking a Family History

The majority of participants agreed (n=56) or strongly agreed (n=39) that the MFHP tool is understandable (neutral n=2), easy to use (strongly agree n=29, agree n= 61, neutral n=6, disagree n=1), and suitable for general public use (strongly agree n=22, agree n=59, neutral n=11, disagree n=5). Respondents agreed (n=30) or strongly agreed (n=66) that taking a family history is an important part of patient care (neutral n=1). The majority of participants disagreed (n=39) or strongly disagreed (n= 51) that medical geneticists and/or genetic counselors are solely responsible for taking a family history (neutral n=7).

Uses for the Surgeon General's MFHP Tool in Clinical Practice

Participants were asked to respond to a series of Likert scale statements regarding potential uses for the MFHP tool in clinical practice (Table 2). Sixty-seven percent of participants agreed or strongly agreed that they would recommend their patients complete the MFHP tool prior to their appointment, and 25% were neutral about making this recommendation. Thirty-nine percent agreed or strongly agreed that they would ensure the availability of staff members to assist in patient completion of the MFHP tool, and 44% were neutral about providing assistance. Participants agreed or strongly agreed that they would use the MFHP tool output to identify individuals at increased risk for disease

Table 2 Participants' likely use of the MFHP tool (N=97)

	Strongly Agree/Agree *n* (%)	Neutral *n* (%)	Disagree/Strongly Disagree *n* (%)
Encourage patient use	64 (67)	24 (25)	8 (8)
Ensure assistance available	37 (39)	42 (44)	16 (17)
Identify patients at increased health risk[a]	83 (86)	10 (10)	3 (3)
Record history in medical chart	81 (84)	12 (12)	4 (4)
Recommend preventative behavior	77 (80)	17 (18)	2 (2)
Make referrals to genetics services	70 (72)	25 (26)	2 (2)

n's vary slightly due to missing data for some responses

[a] Percentages do not add up to 100 due to rounding

Table 3 Participants' challenges using the MFHP tool (N=97)

	n (%)
Time involved	42 (43)
Navigating the tool's options for viewing information	10 (10)
Getting started with the tool	7 (7)
Knowing how to enter information into the tool	6 (6)
Knowing where to enter information into the tool	5 (5)
Other[a]	19 (20)
No challenges	33 (34)

Percentages total greater than 100 because participants could endorse multiple responses

[a] Other challenges reported included: not knowing family history information, having to enter multiple unlisted diseases, having to click on multiple buttons and wait for the screen to refresh, saving family history to a personal computer, and being concerned about the security of the information entered

(86%), to record a patient's family history in his/her medical chart (84%), to make recommendations for preventative behaviors (80%), and to make referrals to genetics services (72%).

Logistical Barriers to Entering a Family History into the MFHP Tool

Participants were provided with a list of possible challenges faced while using the MFHP tool and asked to select all that personally applied (Table 3). Additionally, participants were given the option to describe challenges not on the list. Participants' top two challenges chosen from the list were the time required to use the MFHP tool (43%) and navigating the tool's options for viewing information (10%). Of note, 34% of respondents indicated that they did not experience any challenges while using the tool. Nineteen participants selected multiple challenges, with 14 selecting two challenges, four selecting three challenges, and one participant selecting four challenges. Twenty percent of participants indicated experiencing additional challenges not listed. Many of these challenges were technical in nature, such as having to click "add" after entering each family member's information, waiting for the screen to refresh after the addition of each family member, and having to type in several diseases that were not available in the provided drop-down menus. Multiple respondents commented on the challenge of collecting and remembering personal family history information, noting that this is a challenge for them personally and also for their patients. One participant expressed concern for the security of the information being entered.

Barriers to Using the Surgeon General's MFHP Tool in Clinical Practice

Participants were asked to respond to a series of Likert scale statements regarding barriers that would prevent them from using the output of the MFHP tool in clinical practice (Table 4). A minority of participants agreed or strongly agreed that they would not use the MFHP tool due to concerns regarding reimbursement for time spent analyzing the family history output of the tool (8%), time required to analyze the output of the tool (7%), interpretation of the family history generated (4%), the amount of information generated by the tool (4%), and a lack of benefits to patients (1%).

Suggested Resources for the Surgeon General's MFHP tool

Participants were provided with a list of resources and asked to select the top two resources that would be most helpful in using the MFHP tool (Table 5). The top two resources selected were: (1) a list of common "red flags" in a family history that indicate increased risk for disease and (2) information about common genetic and familial conditions (including support groups, information sheets, and treatment options). Twelve participants described additional resources they would find helpful in open-ended responses. These included resources for both providers and patients. Suggestions for provider resources included tools to help interpret family history information, such as risk algorithms and recommendations for screening, genetic testing, and

Table 4 Participants' perceived barriers to using the MFHP tool in clinical practice (N=97)

"I would NOT use the MFHP tool because…"	Strongly Agree/Agree n (%)	Neutral n (%)	Disagree/Strongly Disagree n (%)
No benefit to patients	1 (1)	15 (16)	79 (83)
Uncomfortable interpreting tool	4 (4)	15 (16)	77 (80)
Too much information	4 (4)	16 (17)	76 (79)
Too time-consuming	7 (7)	22 (23)	68 (70)
Might not be reimbursed for time	8 (8)	25 (26)	64 (66)

n's vary slightly due to missing data for some responses. Seventeen individual participants endorsed at least one of these statements regarding barriers. Of these, five endorsed two of the barrier statements

Table 5 Participants' rankings of the two most helpful resources for using the MFHP tool (N=97)

Resources	1st choice (n=94) n (%)	2nd choice (n=92) n (%)
List of common "red flags" indicating increased risk for disease	72 (77)	16 (17)
Information about common genetic and familial conditions	13 (14)	47 (51)
Evidence-based proof of utility of family history in patient care	6 (6)	22 (24)
Additional educational training on family history	3 (3)	7 (8)

treatment options. Suggestions for patient resources included additional information about the importance of knowing and recording a family history and how it can be used in a health care setting and simple explanations of the medical terminology used in the MFHP tool.

Comparative Analysis of Responses

Responses to the Likert statements regarding opinions towards the MFHP tool were compared across the variables listed previously in the Data analysis section of this paper. We found that participants with more clinical experience (defined as third- and fourth-year medical students and house officers) were more likely than those without experience (defined as first- and second-year medical students) to agree with or feel neutral towards the statement that the MFHP tool generates too much information (Pearson χ^2, α=0.05, p=.006). Comparative analysis revealed that participants without prior experience collecting their personal family history information were more likely than those with experience to agree with or feel neutral towards the statement that they would feel uncomfortable interpreting the MFHP tool output (Pearson χ^2, α=0.05, p=.003) and to agree that they would use the MFHP tool output to make referrals to genetics services (Pearson χ^2, α=0.05, p=.045). Furthermore, participants who experienced challenges with the MFHP tool were less likely than those who did not experience any challenges to agree that the tool is suitable for public use (Pearson χ^2, α=0.05, p=.047). Binary logistic regression revealed that participants who spent more time entering a family history were more likely to agree they would not use the MFHP tool due to concerns about reimbursement for their time spent interpreting the tool's output (α=0.05, p=.03). The remainder of the comparative analyses and logistic regression equations were not statistically significant.

Open-Ended Comments on the MFHP Tool

Forty-four participants (45%) provided open-ended comments about the MFHP tool. Multiple participants commented positively about the tool and its ease of use, while some found the tool to be cumbersome and time-consuming. The open-ended comments were reviewed for broad underlying themes. Major themes were identified in five areas: 1) accessibility of the MFHP tool, 2) accuracy of the tool's output, 3) technical barriers, 4) clinical applications of the tool's output, and 5) provider education regarding interpreting and utilizing family history information.

Participants were concerned that the online format of the MFHP tool would prevent use by individuals who either lack access to a computer or have limited computer skills. Participants were especially concerned that older and lower-income patients may not be able to access the MFHP tool. Suggestions for increasing accessibility included providing computer access in the clinic when checking in for an appointment and providing staff assistance for patients who have difficulty using the tool.

Participants expressed concern for the accuracy of the family history information generated by the MFHP tool. Respondents noted that their patients often either do not know their family history or have incorrect health information. One participant commented that cultural differences in discussing health concerns may prevent some individuals from openly discussing medical information with their health care provider. Additional comments focused on how the language used in the MFHP tool may be too advanced for patients and therefore contribute to inaccuracies:

> "…the form uses the word 'hypertension' instead of high blood pressure, which we learned NOT to do as first year medical students!…and therefore, many questions remain about the accuracy of the form when it is completed by patients…would the accuracy differ if completed by a physician asking the patient verbal questions? Who should complete the form for the entire family? Which medical personnel, if any should help them?"
>
> ~4th year medical student

Suggestions were provided to improve patient accuracy (Table 6). These included providing a glossary of medical terminology used in the tool and having health care providers review the information with patients

Table 6 Participants' suggestions for improving the MFHP tool

Introduction to the Tool
Include more detailed information about the importance of family history and its ability to influence health care
Provide clear directions for how to use the tool and fill in the information
Using the Tool
Include medical terms that are easily understood by a broad audience
Provide a glossary of complex medical terminology
Expand the list of pre-selected conditions to encompass more medical conditions
Include obesity and substance abuse
Reformat the process of entering information into the tool to eliminate extra clicking and refreshing of the screen
Include precise ages of family members instead of ranges
Utilizing and Interpreting the Information Generated by the Tool
Format the pedigrees to contain full medical information and avoid confusing abbreviations
Provide links to websites or tools that use risk algorithms to interpret family history information
Provide links to information regarding screening recommendations based on family history risk

Thirteen participants provided 16 suggestions for improving the tool

during their appointments. Several respondents felt that the list of health conditions provided for patients to choose from was limited and not well-categorized. Suggestions for improvement included adding more diseases and other health conditions such as obesity and substance abuse.

Participants commented on technical aspects of the MFHP tool. A few participants expressed a desire to include the actual ages of individuals on the pedigree, instead of the pre-selected age brackets, which combine all individuals older than 60 years of age into one group. Other individuals did not like how the screen returned to the top of the page after the addition of each new family member, requiring users to scroll down and click on multiple buttons to add family history information. One participant commented that the generated pedigrees were hard to read because the format contained unclear abbreviations. Respondents expressed concern that patients may have difficulty navigating the tool's prompts for information. One individual suggested that the front page of the MFHP tool include simple, clear instructions for using the tool as well as an explanation of the importance of recording family history and sharing it with health care providers. Another respondent expressed concern for the security of the information entered into the MFHP tool.

Participants described how they would incorporate the family history information generated by the MFHP tool into clinical care. Most prevalent was the idea of using the information as an introduction to discussion of disease risk and prevention. One individual expressed that the MFHP tool would provide a helpful visual representation of a patient's family history and provide a way to track health history changes over time. Respondents expressed interest in incorporating the pedigrees generated by the MFHP tool into a patient's electronic health record. Additional comments highlighted the variability of the tool's utility across specialties and patient populations:

> "…probably good for primary care, when trying to identify unknown risk factors for all possible disease states; not so good for Emergency care, when you're trying to diagnose a specific condition. [It's] easier to just ask family history that actually has a bearing on what is going on that day. Also, if your patient is 70+ [years old], which many patients are, family history becomes rather obsolete."
>
> ~4th year medical student

Participants reflected on the need for more provider education regarding interpreting and utilizing family history information in their requests for additional resources. These included information about inherited health conditions, their associated risks, and recommendations for screening and genetic testing. One individual commented on the need for information on how to take a family history that is targeted towards a specific clinical setting. Respondents questioned the abilities of health care providers to interpret the family history information generated by the MFHP tool:

> "[One of] the biggest concerns [is the] ability to improve patient care with the information provided. It is very possible that physicians miss important red flags on the pedigree, or likewise make a big deal out of a minor family history."
>
> ~2nd year medical student

Other participants felt that the tool generates more information than is useful in the clinical setting. One individual was concerned about the legal ramifications of receiving a family history from a patient and not interpreting the history to determine if the patient is at an increased risk for health conditions. Of note, one participant recognized that providers themselves may have limited knowledge of their own family histories:

> "…[this] also made me realize that even as a physician, I truly do not have an updated family history to tell my PCP at appointments. [It] gives me more incentive to role model good behaviors to my patients by knowing my full family history."
>
> ~3rd year medical student

Discussion

This is one of the first studies to ask future health care providers to enter a family history into the online Surgeon General's MFHP tool and comment on the potential uses of this tool in clinical practice. Ninety-seven individuals participated in this study, and of note, two-thirds indicated they would recommend the MFHP tool to their patients. While the current study focused on the MFHP tool, the participants commented on issues that are pertinent to online family history tools in general. The findings suggest that providers are receptive to receiving family history information from patients using online tools, which supports previous research studies with health care providers (Fuller et al. 2010; Kanetzke et al. 2011). The present sample generally found the MFHP tool to be understandable and easy to use, and they perceived it as suitable for general public use. They indicated being most likely to use the family history generated by the MFHP tool as a way to record patient history in the medical chart and to identify patients at increased risk for disease. These results are consistent with the original intentions of the MFHP tool (Guttmacher et al. 2004).

A large majority of participants disagreed that genetic specialists should be solely responsible for obtaining family history information; these results support previous findings that health care providers recognize their shared responsibility in obtaining family history information and using this information to guide patient care (Hayflick et al. 1998). The majority reportedly would encourage their patients to enter family history information into the MFHP tool, and almost 40% indicated they would even ensure staff assistance to help patients use this tool. Of note, the time needed to enter family history information into the MFHP tool was approximately 15 min, and the longest time for completion was less than an hour. Therefore, online family history tools may be a reasonable and time-efficient option for patients to collect and record family history information prior to a clinic visit.

Previous research suggests health care providers feel that family history information generated by online tools would be more comprehensive than information gathered during an appointment, and it would improve providers' abilities to determine a patient's risk for disease (Fuller et al. 2010). However, some concerns regarding the tool's clinical utility were raised. A minority of the participants in the current study expressed concern that the MFHP tool generates too much information and may hinder health care providers' abilities to quickly and accurately identify risk factors. Participants with more clinical experience indicated they would be less likely to encourage their patients to use the MFHP tool; these participants, knowing the time limitations of clinic visits, may already have concerns regarding provider time required to utilize the information generated by online family history tools.

Participants also raised concerns about provider ability to interpret this information and felt that additional resources would be beneficial. These findings support previous research suggesting providers' limited knowledge regarding interpretation of family history information is a barrier to utilization of this information in clinical care (Frezzo et al. 2003; Hayflick et al. 1998; Rich et al. 2004; Suther and Goodson 2003; Wood et al. 2008) and that further provider education and resources are needed. Suggestions for improvement identified by the present sample include providing resources for interpreting family history information (e.g., risk algorithms and screening and testing recommendations), as well as including questions regarding health behaviors. Of note, several of these features are already prominent in another online family history tool created by the CDC entitled "Family Healthware," which is not currently available to the public (Yoon et al. 2009). This tool collects information about risk factors and health behaviors as related to six common diseases (coronary heart disease, stroke, diabetes, and breast, ovarian, and colorectal cancer); calculates a risk for these diseases (weak, moderate, or strong); and generates personalized recommendations for screening and health behaviors (Yoon et al. 2009). At the time of this study, research about the opinions of health care providers regarding Family Healthware had not been conducted (Dr. Mack Ruffin, personal communication, 2010).

While research suggests online family history tools may provide a time-efficient option for recording family history, there are limitations associated with their online format. Commonly cited criticisms echoed by the present sample include accessibility (Wallace et al. 2009), terminology (Kanetzke et al. 2011), and security of information (Arar 2010; Murray et al. 2009). The MFHP tool is currently only available on the Internet as either an interactive online form (version 2.0) or as a blank form that can be printed (version 1.5; United States Department of Health and Human Services), thus limiting its use to those with Internet access. The MFHP tool uses complex medical terminology that may not be understood by the general public. Additionally, public users may have difficulty navigating the tool's prompts for information. Although the tool does not save any family history information to a database, research suggests individuals are still concerned about the security of information entered online (Arar 2010; Murray et al. 2009).

Participants of this and other studies have suggested improvements including providing clear instructions for use, using terminology that is commonly understood by the general public, defining complex medical terminology, expanding the number and types of conditions available in the pre-selected list, and providing paper formats of the online tool (Kanetzke et al. 2011). Participants in this study also expressed interest in

the ability to import pedigrees generated by online family history tools into a patient's electronic health record (EHR). Other studies have echoed this finding, suggesting that an EHR interoperability feature is important to providers and should be included in online family history tools (Kanetzke et al. 2011). Since the time of data collection in the present study, the MFHP tool has been upgraded to allow for EHR interoperability (Feero 2009). Individuals who use the tool can save the generated history information on their own computers in a format that can then be uploaded into an EHR.

Study Limitations

There are several limitations to this study. The low response rate of 9% may limit the ability to generalize the results, as our participants may not be a representative sample of medical students and house officers. However, the demographics suggest the percentage of participants from each year of training is generally comparable to the total eligible population, with the exception that, overall, house officers are overrepresented in our sample while medical students are underrepresented. While participants' current opinions about the MFHP tool may not correlate to their future opinions as practicing health care providers, their opinions and concerns are similar to those seen in another study with practicing pediatric providers (Kanetzke et al. 2011). Given the participants were all well-educated, young, computer literate medical trainees, many of whom had previous experience gathering their personal family history information, they may have overestimated the ease of use of the MFHP tool. Therefore, the opinions of medical trainees are likely not the most appropriate predictors related to ease of use among healthcare providers or general patient populations. However, these participants did experience similar challenges to those previously reported in patient populations (Murray et al. 2009; Wallace et al. 2009). Another limitation to our study is the simplicity of the provided sample family history. It is possible that respondents who entered this history may have felt differently about the tool if they had entered a more complex history. The majority of our participants did report entering their personal family history instead of the sample history. For participants who used their personal family history, we did not ascertain the number of individuals or the number of medical conditions entered.

Research Recommendations

A limited number of studies have been published regarding practicing health care providers' opinions regarding the potential clinical uses for the Surgeon General's MFHP tool. Future studies should include practicing providers in a variety of health care settings to ascertain their opinions towards this and other online tools. It would be helpful if providers could analyze such tools in actual clinical settings with their patients to obtain a more accurate assessment of their opinions towards using these tools in clinical care. Additionally, patient opinions should be obtained regarding the use of family history information generated by these tools as part of their health care. Future survey instruments should include questions regarding the amount of family history information entered into these tools to determine if this has an effect on opinions regarding the tools' use.

Practice Implications

The findings of this study suggest strong support for use of the MFHP tool in clinical practice. Medical student and house officer participants not only endorsed its use, they identified areas of improvement that may be applied to this and other online family history tools. Previously identified barriers to the incorporation of family history information into health care have included provider time involvement and interpretation. The present results suggest that online tools help to address limitations related to provider time constraints by allowing patients to collect and record family history information prior to a clinic visit. Health care provider interpretation of family history information is more challenging and will require global efforts. If health care providers are not willing to encourage their patients to use online family history tools or to utilize the information these tools generate, then these tools will have a limited impact on health care. As a consequence, opportunities for appropriate triage and referral to genetic and other specialty services may be negatively impacted. There needs to be a multi-faceted approach to increase access, encourage patient use, and facilitate physician interpretation of family history information in order to realize the promise of family history tools in clinical care.

Acknowledgments This study was funded by a Rackham Graduate Student Research Grant. The authors would like to thank Joe Kazemi, MA, for his assistance with statistical analysis.

Disclosure of Interest The authors declare no conflicts of interest, financial or otherwise. The authors have full control of all primary data and provide permission for the Journal of Genetic Counseling to review this data if requested.

Appendix: Survey Questions

The Surgeon General's "My Family Health Portrait" tool is intended to be used by **patients** to record their family history and share this history with their physicians and with family members. We are interested in your opinions regarding the utility of this tool.

Age _____

Gender F M

Year in Medical School 1st 2nd 3rd 4th

Intended area of specialization (for medical students only)

___Anesthesiology ___Dermatology ___Emergency medicine ___ Family medicine
___Internal medicine ___ Neurology ___ OB/GYN ___Oncology
___Opthalmology ___Otolaryngology ___ Pathology ___Pediatrics
___Physical medicine/rehabilitation ___Psychiatry ___Radiology
___Surgery ___Unknown

Year in Residency 1st 2nd 3rd 4th

Year in Fellowship 1st 2nd 3rd

Area of Specialization (for residents and fellows only)

___Family medicine ___Internal medicine ___Pediatrics ___OB/GYN

1. Did you enter a family history into the Surgeon General's "My Family Health Portrait"?
_____ Yes _____ No

2. If you answered "no" to the above question, what were your reasons for not completing the Surgeon General's "My Family Health Portrait" tool? (**select all that apply**)
_____ Did not have time to complete
_____ Not interested
_____ Tool was too difficult to use
_____ Not important
_____ Other (please explain): _____

If you answered no to question 1, you may stop here. Thank you for completing this survey.

3. Have you gathered information about your own personal family health history previously?
_____ Yes _____ No

4. Have you heard of the Surgeon General's Family History Initiative prior to participating in this study?
_____ Yes _____No

5. Have you used the "My Family Health Portrait" tool previously?
_____ Yes _____ No

6. If you answered "yes" to the question above, whose information was entered? (select all that apply)
_____ My family history _____ Patient family history

7. Have you used any other electronic family history tools? (**select all that apply**)
____ Geneology tool
____ Cancer family history tool
____ Other (please explain) _____
____ I have not used any other family history tool

Using the Surgeon General's "My Family Health Portrait" tool

8. Which family history did you enter into the tool?
_____ My family history _____ Sample family history

9. How long did it take you to enter the family history (in minutes)? _____

10. What challenges did you have in completing the Surgeon General's "My Family Health Portrait" tool? (**select all that apply**)
___ Getting started with the tool
___ Knowing where to enter the information into the tool
___ Knowing how to enter the information into the tool
___ Navigating the tool's different options for viewing information
___ Time involved
___ Other (please explain)_____
___ None

Please answer the following questions according to the scale below:

1=Strongly disagree 2=Disagree somewhat 3=Neither agree or disagree 4=Agree somewhat 5=Strongly agree

11. The Surgeon General's "My Family Health Portrait" tool is understandable.
1 2 3 4 5

12. The Surgeon General's "My Family Health Portrait" tool is easy to use.
1 2 3 4 5

13. I believe that the Surgeon General's "My Family Health Portrait" is suited for the general public's use.
1 2 3 4 5

Please answer the following questions in terms of your future practice according to the scale below:

1=Strongly disagree 2=Disagree somewhat 3=Neither agree or disagree 4=Agree somewhat 5=Strongly agree

14. I believe that taking a family history is an important component of providing patient care.
1 2 3 4 5

15. I believe that only medical geneticists or genetic counselors should be responsible for taking a family history.
1 2 3 4 5

In future practice….

16. I would recommend that my patients complete the Surgeon General's "My Family Health Portrait" tool prior to their appointment.
1 2 3 4 5

17. I would ensure that a nurse/medical assistant is available to assist patients with completion of the Surgeon General's "My Family Health Portrait" tool prior to their appointment.
1 2 3 4 5

18. I would use the information generated by the Surgeon General's "My Family Health Portrait" tool to record a patient's family history in his/her medical chart.
1 2 3 4 5

19. I would not use the Surgeon General's "My Family Health Portrait" tool because it would not benefit my patients.
1 2 3 4 5

20. I would not use the Surgeon General's "My Family Health Portrait" tool because it generates more information than necessary.
1 2 3 4 5

21. I would use the information generated by the Surgeon General's "My Family Health Portrait" tool to identify and counsel patients who may be at an increased risk for certain diseases.
1 2 3 4 5

22. I would not use the Surgeon General's "My Family Health Portrait" tool because it is time-consuming to review the information it generates.
1 2 3 4 5

23. I would not use the Surgeon General's "My Family Health Portrait" tool because I would not feel comfortable interpreting the information generated by the tool.
1 2 3 4 5

24. I would use the information generated by the Surgeon General's "My Family Health Portrait" tool to make recommendations for preventative health behaviors.
1 2 3 4 5

25. I would use the information generated by the Surgeon General's "My Family Health Portrait" tool to make referrals to genetics or other related services.
1 2 3 4 5

26. I would not use the Surgeon General's "My Family Health Portrait" tool because I may not be reimbursed for the time I spend discussing the information generated by the tool.
1 2 3 4 5

Please choose your top TWO reasons for utilizing the Surgeon General's "My Family Health Portrait" tool in future practice:

____ Collecting/recording patient family history as part of medical record
____ Updating patient's medical record
____ Identify individuals at increased risk for disease
____ Inform how I would counsel patients on their risk for disease
____ Inform my recommendations for preventative health behaviors
____ Inform my referrals to genetics or other related services.
____ Other (please explain) _____
____ None of the above-I would not consider using the tool in future practice.

Please choose your top TWO reasons for NOT utilizing the Surgeon General's "My Family Health Portrait" tool in future practice:

____ Time-consuming
____ Not beneficial to patients
____ Too much information generated
____ Uncomfortable interpreting information from tool
____ May not be reimbursed for time spent interpreting tool
____ Other (please explain)_____
____ None-I would utilize the tool in future practice

Please choose the top TWO resources that you would find most helpful in guiding interpretation of a family history:

_____ A list of common "red flags" in a family history that indicate an increased risk for disease
_____ Information about common genetic and familial conditions, including support groups, information sheets, available testing, and treatment options
_____ Additional educational training on family history and its applications for patient care
_____ Evidence-based proof of utility of family history in patient care

Are there any additional resources that you would find helpful (please explain)?
_____

Please provide any additional comments about the Surgeon General's "My Family Health Portrait" tool:
_____

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