ORIGINAL RESEARCH

Comparing Electronic Health Record Portals to Obtain Patient-Entered Family Health History in Primary Care

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BACKGROUND: There is growing interest in developing systems to overcome barriers for acquiring and interpreting family health histories in primary care.

OBJECTIVE: To examine the capacity of three different electronic portals to collect family history from patients and deposit valid data in an electronic health record (EHR).

DESIGN: Pilot trial.

PARTICIPANTS, INTERVENTION: Patients were enrolled from four primary care practices and were asked to collect family health history before a physical exam using either telephone-based interactive voice response (IVR) technology, a secure internet portal, or a waiting room laptop computer, with portal assigned by practice. Intervention practices were compared to a "usual care" practice, where there was no standard workflow to document family history (663 participants in the three intervention arms were compared to 296 participants from the control practice).

MAIN MEASURES: New documentation of any family history in a coded EHR field within 30 days of the visit. Secondary outcomes included participation rates and validity.

KEY RESULTS: Demographics varied by clinic. Documentation of new family history data was significantly higher, but modest, in each of the three intervention clinics (7.5 % for IVR clinic, 20.3 % for laptop clinic, and 23.1 % for patient portal clinic) versus the control clinic (1.7 %). Patient-entered data on common conditions in first degree relatives was confirmed as valid by a genetic counselor for the majority of cases (ranging from 64 to 82 % in the different arms).

CONCLUSIONS: Within primary care practices, valid patient entered family health history data can be obtained electronically at higher rates than a standard of care that depends on provider-entered data. Further research is needed to determine how best to match different portals to individual patient preference, how

the tools can best be integrated with provider workflow, and to assess how they impact the use of screening and prevention.

KEY WORDS: family health history; electronic health record; EHR; provider-entered data.

J Gen Intern Med 28(12):1558–64

DOI: 10.1007/s11606-013-2442-0

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INTRODUCTION

Despite the longstanding interest of both patients and providers, substantial barriers exist to obtaining and integrating family health histories into primary care practice.^{1–7} Electronic tools for patients may facilitate the collection of these data so that providers have more time to discuss preventive health care consequences.⁸ Several factors are converging to drive interest in the adoption of effective and efficient systems for obtaining electronic data for family history from patients, including financial incentives for the "meaningful use" of electronic health records (EHRs),⁹ new evidence for the clinical utility of family history,¹⁰ and the growing use of genomics.¹¹ A recent report by Qureshi confirmed that adding family history improves the identification of persons with high cardiovascular risk in primary care practice.¹⁰ The use of DNA based screening will require family history in order to interpret rare sequence variations.¹²

This paper reports on work to compare the rates of documentation of family health history and the validity of data provided by three different electronic portals compared to "usual care," in a pilot trial.

METHODS

Setting and Participants

We included four primary care practices affiliated with Brigham and Women's Hospital. All of the practices used

Electronic supplementary material The online version of this article (doi:10.1007/s11606-013-2442-0) contains supplementary material, which is available to authorized users.

Received October 6, 2012

Revised February 1, 2013

Accepted March 20, 2013

Published online April 16, 2013

the Longitudinal Medical Record (LMR), an internally-developed, certified EHR.¹³ LMR includes a secure internet patient portal called Patient Gateway (PG), which is currently available only in English. Eligible patients were age 21 to 75 years with a scheduled visit for an annual exam at a participating practice between November 29, 2010 and March 11, 2012, had a phone number listed in LMR, and spoke English or Spanish. At the time this study was initiated there was no standard workflow to document family history. Although coded fields existed to store this information, and decision support was available to assess risk based on entered data, the fields were cumbersome for providers to use (Fig. 1). The study was approved by the Partners Human Research Committee and was registered at ClinicalTrials.gov (NCT00977847).

Intervention

The Surgeon General's My Family Health Portrait (MFHP) was launched in 2004 as a publicly available, web-based tool for gathering and organizing family history information.¹⁴

MFHP was one of the most highly rated family history tools in a recent Agency for Healthcare Research and Quality Evidence Report.¹⁵ MFHP is interoperable with messaging standards for EHRs (Health Level Seven [HL7]). It collects information about a broad set of health conditions for first degree and second degree relatives (<https://familyhistory.hhs.gov/fhh-web/home.action>).

For this pilot trial, patients from one practice were asked to complete the MFHP tool in the waiting room using a laptop, patients from a second practice were asked to complete MFHP at home and then transfer the file using PG, and those from a third practice were asked to complete the tool using an automated telephone script with content that mirrors that of MFHP. We selected a phone system because while many patients do not use the web regularly,¹⁶ nearly all have telephones. The telephone script was conducted using interactive voice response (IVR) technology (Vocantas, Ottawa, ON), and was designed to take approximately 15–20 min, and was available in English or Spanish ([English version available online](#)). The IVR server sat behind the health system firewall. Data was transmitted to the EHR using a Simple Object Access Protocol (SOAP)

Home Select Desktop Pt Chart: Fam/Soc History Oncology Custom Reports Admin Sign Results ?							
Lookup: click to add items		Select additional relative					
FamHist Name	Unspecified	Mother	Father	Brother	Sister	Grandmother, maternal	Grandfather, maternal
Anxiety	---	---	---	---	---	---	---
Asthma	---	---	---	---	---	---	---
Bipolar	---	---	---	---	---	---	---
Bladder cancer	---	---	---	---	---	---	---
Brain cancer	---	---	---	---	---	---	---
Breast cancer	---	---	---	---	---	---	---
Cerebrovascular accident	---	---	---	---	---	---	---
Colon cancer	---	---	---	---	---	---	---
Colonic polyps	---	---	---	---	---	---	---
Coronary artery disease	---	---	---	---	---	---	---
Depression	---	---	---	---	---	---	---
Diabetes mellitus type 2	---	---	---	---	---	---	---
Elevated cholesterol	---	---	---	---	---	---	---
Endometrial cancer	---	---	---	---	---	---	---
Glaucoma	---	---	---	---	---	---	---
Hypertension	POS	---	---	---	---	---	---
Hypertension	POS	---	---	---	---	---	---
Hypertension	---	---	---	---	---	---	---
Hyperthyroidism	---	---	---	---	---	---	---
Hypothyroidism	---	---	---	---	---	---	---
Lung cancer	POS	---	---	---	---	---	---
Myeloma	---	---	---	---	---	---	---
Myocardial infarction	---	---	---	---	---	---	---
Osteoporosis	---	---	---	---	---	---	---
Ovarian cancer	---	---	---	---	---	---	---
Pancreatic cancer	---	---	---	---	---	---	---
Prostate cancer	---	---	---	---	---	---	---
Renal cancer	---	---	---	---	---	---	---
Skin cancer	---	---	---	---	---	---	---
Stomach cancer	---	---	---	---	---	---	---
Substance abuse	---	---	---	---	---	---	---
Unspecified allergy	---	---	---	---	---	---	---

Figure 1. Example of coded family history fields available in the longitudinal medical record.

over Hypertext Transfer Protocol Secure (HTTPS). The data were formatted using the Health Level Seven (HL7) family pedigree standard.

Protocol

Assignment took place at the level of the practice, where each practice was assigned a specific data collection modality (IVR, patient portal (PG), waiting room laptop, usual care). Practices were not selected randomly; the IVR practice was selected because of a large Spanish-speaking patient population who could potentially not access the patient portal; the patient portal practice was selected because of high rates of registration for this service, and the laptop practice was selected based on proximity to study staff.

Approximately 1 month before their visit, eligible patients in the IVR arm were mailed an letter with instructions on how to opt-out. Patients who did not opt-out within 2 weeks received up to 15 call attempts over a 2-week period. No messages were left. If the phone was answered and hung-up twice by anyone in the household, this was considered a “passive” opt-out. Patients who answered the phone heard a brief informed consent script and were asked to confirm their interest in participating. Patients were asked to state their birth date to confirm their identity.

Patients in the PG arm received the study invitation to their PG account with instructions for recording and returning the data. The invitation contained a link to a secure version of the MFHP; patients were asked to save the output file to their personal computer and then transfer this file using PG. Only one file could be transferred per patient.

Eligible patients in the laptop arm were approached by a research assistant in the waiting room and asked if they wanted to participate. Laptop computers ran a version of MFHP on a secure website behind the Partners firewall, and data were transmitted wirelessly to LMR. Informed consent was obtained on the initial screen.

For each of these three modalities, any patient-entered family history data was sent in real-time to LMR where the patient’s provider could view the information and decide whether to accept, reject, or modify the data before it was stored in coded fields in LMR. Data provided by patients that was never reviewed by the provider did not become part of the health record.

Validation

A subset of English-speaking patients in the three intervention arms were randomly selected for a follow-up phone call with a genetic counselor ($n=57$). The genetic counselor conducted a 5–10 min call building the family tree and

assessing the conditions of each first degree and second degree family member reported. Family members and diagnoses were then categorized as confirmed, amended, added, or removed by comparing the information elicited by the genetic counselor to that reported by the patient. Participants who completed this validation were entered into a monthly drawing for a \$100 gift card.

Patients who were not selected for the validation call were asked to complete an IVR survey approximately 4 weeks following their visit. This survey included questions about whether they had discussed family history with their provider and preferences for data collection modality. A random sample of 20 % of eligible patients from the control practice was also contacted to complete a similar survey. Participants who completed this follow-up survey were entered into a monthly drawing for a \$100 gift card.

Outcomes

The main outcome was the proportion of participating patients with new documentation of any family history condition, positive or negative, in a coded LMR fields within 30 days after the visit. Secondary outcomes included participation rates in each of the three intervention arms, the validity of the family history data. Secondary validation focused on a limited set of core conditions, including coronary heart disease (CHD), diabetes, cancer (by type) and Alzheimer’s disease. Data from the follow-up survey was used to assess patient–doctor discussion of family health history, preferred route of reporting, and access to home internet.

Statistical Analysis

Three intervention practices were compared to the usual care practice. Logistic regression models were used to compute odds ratios (ORs) and 95 % confidence intervals (CIs) for the documentation of new family history data for the intervention compared to control patients, adjusting for sex, age, race/ethnicity, education, marital status, clinic, and personal history of breast or colorectal cancer, heart disease, and diabetes. The statistical analyses were conducted using SAS version 9.2 (Cary, NC), with $p<0.05$ as the criteria for statistical significance.

RESULTS

Recruitment and Enrollment

Rates of contact and reasons for non-contact varied by study arm (Table 1). Participation rates were modest for all

Table 1. Recruitment and Enrollment by Practice

	Pre-Visit Family Health History Collection		
	IVR	Waiting Room Laptop	Patient Portal
Potentially eligible	1,637	2,267	1,237
Not contacted/ never reached	470 (28.7 %)	1,802 (79.5 %)	836 (67.6 %)
Opted Out	955 (58.3 %)	135 (6.0 %)	280 (22.6 %)
Participated	212 (13.0 %)	330 (14.6 %)	121 (9.8 %)

three modalities (9.8–14.6 %). Reasons for non-participation varied. Patients in the laptop arm were most likely not to be contacted (79.5 %), as enrollment was limited by the availability of study staff to recruit patients. Sixty-eight percent of patients in the portal practice were also never contacted as they did not open their study invitations. In contrast, the majority of patients in the IVR intervention and control survey practice were reached. Of those reached, rates of study opt-out also varied greatly across the different modalities, with the highest opt-out rate for IVR and the lowest for the laptop, likely because the patients were approached by study staff and were offered assistance when needed. For patients in the IVR arm who participated, the median call length was 6 min (maximum length 33 min). Participants were similar to non-participants for average age, race/ethnicity, and educational status. Participants in the laptop clinic were more likely to be female (75.7 % versus 63.9 %, $p=0.03$), but there were no differences in gender by participation status at other sites. Participants at the IVR practice were more likely to be married (58.1 % versus 36.1 %, $p=0.01$) but there was no difference in participation by marital status at other sites. The majority (50.6 %) of patient-reported family history data was never viewed by a provider, 29.5 % was accepted by the provider without modification, 7.1 % was accepted with modification, and 12.8 % was rejected.

Description of the Sample

The groups differed across multiple demographic categories, including age, race/ethnicity, language, level of education, and marital status, which was anticipated because of the differences in practice characteristics (Table 2). Participants in the laptop group had few Spanish speakers despite the availability of MFHP in Spanish as the study staff did not speak Spanish; the patient portal did not have a Spanish option, and therefore participation was limited to English speakers.

Documentation of New Family History

Across the three intervention groups, 16.7 % (111/663) of patients had a new family history condition documented in their EHR compared to 1.7 % in the control group. In each of

the three intervention arms, new documentation of family health history compared to the control group was significantly higher after adjustment for differences in sociodemographic characteristics (Table 3). New documentation of family history was higher among participants in the laptop and patient portal practices than the IVR practice.

Genetic Counselor Validation of Family History

Through the validation of family history by a certified genetic counselor (Table 4), it was found that users of all three tools reliably recorded the majority of first degree family members (68 %, 71 %, 78 %) and core conditions (64 %, 82 %, 80 %) correctly, but were less likely to record conditions beyond our core set, particularly in the IVR arm. Participants in the laptop arm were more likely to have family members added. The addition of diagnoses during the validation was most frequent in the IVR arm. The absence of diagnostic information was common in the IVR arm, and upon discussion with the participant, the genetic counselor added diagnoses for 41 % of participants (23 % for core conditions).

Patient Outcome Survey

In contrast to the low rates of documentation in the coded LMR fields, a large majority of patients in every group reported discussing family health history with their provider (71 % IVR clinic, 83 % laptop clinic, 91 % patient portal clinic, and 77 % control clinic, $p=0.07$ for comparison across groups). When given the choice of phone script, patient portal or waiting room laptop to do this type of data collection in the future, patient portal was preferred by the majority of individuals in the laptop, patient portal and control practices; but the automated phone script was preferred by the majority in the IVR clinic, perhaps because only 49 % of these individuals reported access to the internet at home.

DISCUSSION

While it is accepted that family health history is an inexpensive and simple tool for the targeted provision of preventive services and screening,¹⁷ it is underutilized in primary care,¹⁸ and barriers to implementation are well-documented.^{18,19} We developed and evaluated three distinct EHR-integrated portals for engaging patients in the documentation of family history in an effort to overcome barriers to collection. We found significant increases in documentation in each of the three intervention arms despite modest levels of participation.

Table 2. Description of the Sample

	IVR	Waiting Room Laptop	Patient Portal	Control	<i>p</i> value
N =	212	330	121	296	
Average age (years)	47.1	50.1	51.2	54.8	< 0.0001
Female	149 (70.3 %)	224 (67.9 %)	72 (59.5 %)	179 (60.5 %)	0.04
Race/ethnicity					< 0.0001
White	80 (37.7 %)	214 (64.9 %)	116 (95.9 %)	240 (81.1 %)	
Black	20 (9.4 %)	65 (19.7 %)	2 (1.7 %)	33 (11.1 %)	
Latino	106 (50.0 %)	30 (9.1 %)	0	5 (1.7 %)	
Other/unknown	6 (2.8 %)	21 (6.3 %)	3 (2.5 %)	18 (6.1 %)	
Spanish-speaking	74 (34.9 %)	4 (1.2 %)	0	1 (0.3 %)	< 0.0001
Education					< 0.0001
Less than high school	31 (14.6 %)	8 (2.4 %)	0	3 (1.0 %)	
High school graduate	38 (17.9 %)	48 (14.5 %)	6 (5.0 %)	26 (8.8 %)	
Some college	33 (15.6 %)	50 (15.1 %)	18 (14.9 %)	49 (16.5 %)	
College graduate and beyond	72 (34.0 %)	150 (45.5 %)	79 (65.3 %)	178 (60.1 %)	
Unknown	38 (17.9 %)	74 (22.4 %)	18 (14.9 %)	40 (13.5 %)	
Married or living with a partner	86 (41.3 %)	193 (58.5 %)	95 (78.5 %)	200 (67.6 %)	< 0.0001
Personal history of breast or colorectal cancer	6 (2.8 %)	17 (5.1 %)	4 (3.3 %)	10 (3.4 %)	0.50
Personal history of coronary heart disease	2 (0.9 %)	10 (3.0 %)	4 (3.3 %)	7 (2.4 %)	0.41
Personal history of diabetes	17 (8.0 %)	24 (7.3 %)	5 (4.1 %)	23 (7.8 %)	0.56

Our study is one of the first to report on the integration of a patient-reported family health history tool with an EHR. Passed in 2009, the HITECH (Health IT for Economic and Clinical Health) Act requires that providers demonstrate “meaningful use” of EHRs, which is tied to fiscal compensation, and requires the electronic exchange of information between patients and providers.⁹ The electronic capture of structured family history for first degree relatives is a stage 2 meaningful use “menu objective” (must select three of six items), which makes the development and testing of these types of tools timely.²⁰

While several studies have evaluated the use of electronic tools to assess family health history, these have largely not been linked to an EHR. Family Healthware™ is a self-administered, web-based questionnaire, similar in format to the MFHP, developed by the Centers for Disease Control and Prevention, that is not EHR-integrated.⁷ A study of this tool in primary care practices found that messages that were tailored to an individual’s familial risk were associated with some lifestyle changes.²¹ Use of the Genetic Risk Assessment on the Internet with Decision Support, a web-based tool that was not EHR-integrated, was associated with a

significant increase in appropriate referrals to genetic clinics and with an improvement in practitioners’ confidence in managing familial cancer.²² The Genetic Risk Early Assessment Tool (GREAT) used IVR to collect family history before a cancer genetics visit, but was not EHR integrated.²³ In other work, we demonstrate that use of a web-based risk appraisal tool for EHR documentation of cancer family history in the waiting room was associated with increased EHR-documentation of family history.²⁴ The integration of patient-reported family history may also improve decision-making tools for patients and providers for the use of preventative health care.^{25,26}

Patient engagement is an important national health care priority, and collecting data directly from patients may facilitate this goal. These findings suggest that a waiting room laptop had the highest acceptance rate, but participation was limited by staff availability and may not work with

Table 3. New Documentation of Family Health History Within 30 Days of Visit Date Among Eligible Participants (n=959)*

Clinic	N (unadjusted %)	Odds Ratio (95 % CI)	P value
IVR	16 (7.5)	4.37 (1.53– 12.48)	0.0059
Waiting Room Laptop	67 (20.3)	14.23 (5.60– 36.17)	< 0.0001
Patient Portal	28 (23.1)	16.40 (6.10– 44.06)	< 0.0001
Control	5 (1.7)	Reference	

*Adjusted for sex, age, race/ethnicity, education, marital status, clinic, and personal history of breast or colorectal cancer, heart disease, and diabetes

Table 4. Validation of First Degree Relatives and their Health History

	IVR N=17	Waiting Room Laptop N=20	Patient Portal N=20	<i>p</i> value
Family members				< 0.0001
Confirmed	68 %	71 %	78 %	
Added	12	27	14	
Removed	0	1	0	
Amended	20	1	8	
All Conditions				< 0.0001
Confirmed	48	77	77	
Added	41	19	17	
Removed	11	4	6	
Core Conditions				< 0.0001
Confirmed	64	82	80	
Added	23	17	16	
Removed	13	2	4	

all office workflows. While opt-outs were highest for IVR, participation could be facilitated by leaving a message or including an option for inbound calling. Our results suggest that a “one size fits all” approach to patient engagement is probably not best. Many patients did not have access to internet at home.¹⁶ Meaningful use calls for providers to ask patients how they would like to be engaged, suggesting that practices will be need to be able to use different modalities for contact. Even patients with internet access may have concerns about providing health information over the net because of issues of computer proficiency or privacy concerns.²⁷

Increasing the availability of family health history in the EHR has the potential for both immediate uses as well as longer-term benefits. Immediate availability of family history in the EHR will allow for the identification of patients at risk for common disease, a necessary first step in the provision of targeted screening and prevention. With these data integrated into the EHR in a structured format, automated decision support tools can be used. Importantly, structured family history data will provide a longer-term benefit in contextualizing DNA sequence data.^{12,28} The results of this pilot trial suggest that each of the three electronic portals has the capacity to increase the availability of valid family health history in the EHR.

This study did not match the three practice groups based on demographics; this marks both a strength and a limitation. While demographic mismatches associated with the practice-based intervention assignments make it difficult to compare groups, we assigned interventions to maximize participation. Because each modality was only evaluated in one practice, our findings may not be generalizable; we chose MFHP as the internet tool because it is publicly available and output complies with EHR data standards. Because our system required a multi-step process to transfer the MFHP data into LMR, our findings may be more modest than systems where MFHP is integrated directly. Additional work is needed to assess whether integration of this type of information in an EHR improves the quality of preventive care and patient understanding of their personal risk.

Genetic counselor validation of individualized patient-entered data is not feasible at scale, meaning that the validity gaps need to be identified and addressed via adjustments in the data collection tools. The under-reporting of first degree relatives and their diseases will likely be addressable by providing additional prompts and by allowing patients time to review data with their family members. The GREAT study found that 94 % of first degree relatives and 67 % of second degree relatives were identical on pedigrees collected by IVR as compared with a genetic counselor.²³ However, accuracy in this study may be higher in a population referred for genetic evaluation of cancer risk compared to primary care. In a subset of patients from the CLINSEQ study, it was also noted that there was an under-

reporting of data on core conditions that led to a lower sensitivity for self-reported data using MFHP.¹⁴ In a surgical oncology setting a similar pattern was observed, namely that self-reported data has lower sensitivity compared to that collected by genetic counselors.²⁹ Some work suggests that data provided by electronic tools may be more complete and accurate.³⁰ Further work is needed to assess how to modify these tools to improve data completeness by streamlining the data collection and to promote physician use of patient reported data.

The alignment of patient interest, improved electronic tools, and provider incentives could lead to the more widespread incorporation of family health history data into EHRs, which could in turn improve screening and prevention. This study demonstrates that it is feasible to integrate a variety of portals with an EHR. Further research is needed to determine how best to use match these different portals to individual patients, how the tools can best be integrated with provider workflow, and to assess their impact on screening and prevention.

Acknowledgements: This project was supported by Award Number RC1HG005331 using American Recovery and Reinvestment Act (ARRA) funds from the National Human Genome Research Institute, and by Award Number U54CA163307 from the National Cancer Institute.

Conflict of Interest: The authors declare that they do not have a conflict of interest.

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