Connecting the Dots Between Patient-Completed Family Health History and the Electronic Health Record

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J Gen Intern Med 28(12):1547–8
DOI: 10.1007/s11606-013-2544-8

Family health history (FHH) is an important tool for detecting and managing chronic health conditions, as well as for the detection and diagnosis of rare single gene disorders.[1,2] Despite this, there is considerable evidence that a complete FHH is rarely collected in primary care settings.[3] Numerous barriers have been cited in the collection and use of FHH, including the time required to collect the information, the accuracy of the information collected, the lack of ability to store the information in electronic health record systems, patient confidentiality concerns, and insufficient provider training to interpret the information. A 2009 National Institutes of Health State of the Science Conference concluded that studies examining methods for more efficiently collecting FHH in primary care settings were desperately needed.[4] Family health history is likely to remain important as an aid to assessing the potential risk associated with genetic markers; for example, a recent study suggests a synergistic increase in colorectal cancer risk in individuals with both a high burden of risk variants and a FHH of colorectal cancer.[5] Additionally, many of the gold standard guidelines developed by the United States Preventive Services Task Force (USPSTF) can only be properly applied to patients for whom a FHH has been collected.

In this issue of JGIM, Murray et al. present data on a systematic study of methods for more efficiently collecting FHH information for clinical use in real world settings.[6] The study assigned three primary care clinics to different types of patient-completed FHH collection (phone collection using a structured voice response system, home access to a secure web site with a FHH tool, and physician office-based access to a FHH tool) and compared FHH data collection to usual care in a fourth clinic. These clinics were located near Boston, MA, and had characteristics suggesting that they were representative of primary care clinics in other U.S. urban areas. Importantly, the collected FHH information was electronically transferred to patient's providers for potential review and inclusion as structured information into the electronic health record (EHR) used by the study clinics. The study clinics were purposefully assigned to a particular FHH collection method based on the authors' assumptions regarding which method would likely work best in that clinic population. The web-based FHH tool used in two of the arms was derived from the U.S. Surgeon General's My Family Health Portrait (MFHP) tool, which is freely available for public use.[7] The primary endpoint of the study included the increase in new structured FHH information available in the medical record within 30 days of the recruitment visit. Secondary endpoints included patient participation rates, accuracy of the FHH information as compared to a gold standard of patient interview by a trained genetic counselor, and patient-reported discussion of FHH information with their health care provider.

A total of 663 patients participated in the three intervention arms, and were compared to 296 patients in the control practice, with 9.8–14.6 % final participation rates across the three intervention arms. Reasons for non-participation were protean and difficult to interpret due to the study design. Overall, the interventions significantly improved collection of new FHH information over usual care (16.7 % versus 1.7 %, respectively) within 30 days of the recruitment visit. Collection of new information was highest in the home web access and office-based arms, with odds ratios for collection four times higher than the phone collection arm, albeit with wide confidence intervals. The validation step by genetic counselors of FHH information collected in the three arms showed that about 75 % of the time participants identified all first-degree relatives correctly. Roughly the same level of accuracy was observed for participant identification of health problems in first-degree relatives. The phone collection arm performed the least well of the three approaches. There was no statistically significant difference in rates of patient reported discussion of FHH information with providers across the groups, with 71–91 % of participants in the various arms reporting a conversation. This high rate contrasts dramatically with the observation that 50 % of patient-reported family history information from the intervention groups was never reviewed by the provider to whom the data was sent.

Much of this study must be interpreted with caution. Possibly the most important limitation was the non-random nature of intervention assignment, and low participation

Published online July 11, 2013

rates. As a result, few, if any, conclusions can be drawn about the comparative utility of the different approaches. Additionally, estimates of the accuracy of collected data may be generous, as the participants may be more motivated regarding FHH than the majority group of non-participants. Additional limitations include effects of the linguistic barriers inherent to the intervention in the study populations, and the fact that medical staff was available to assist participants in the office-based arm, but not in the web-based or phone collection arms.

Four conclusions can be drawn from this study. First, rigorously answering the question of how to best collect FHH in real-world clinical settings will not be easy or inexpensive. Undoubtedly, the authors expended considerable resources in designing and implementing this study, but clearly could have used more support to ensure higher participation rates, availability of tools in appropriate languages, and deployment in a larger number of clinic environments. Second, the data suggests that in busy primary care settings FHH collection and interpretation is not a priority for patients or their providers, even if the collection itself does not detract from actual face-to-face time between the patient and provider. This is not surprising, given the large number of competing priorities for patient and provider time. Particularly troubling was the observation that providers ignored structured data that was made available for potential incorporation into the electronic health record about 50 % of the time. Third, the accuracy of raw patient-supplied data from the study populations was moderate at best. This strongly suggests that provider review of patient-supplied information is a critical step if such data is to migrate into electronic health record systems, particularly if such data is used to drive automated clinical decisions support. Finally, it is possible to devise strategies to supplement the amount of FHH information available in the electronic health record while avoiding direct use of the precious time a provider has with the patient in an office visit.

Clearly the results of the study by Murray et al. offer no panacea for family health history collection in primary care; rather, the findings raise a number of issues that merit additional research. Major questions include how patient FHH collection rates might be improved, how accuracy of self-reported FHH data might be boosted, and how the critical step of provider review and incorporation of FHH information into the electronic health record might be enhanced. Next steps might include expansion of this pilot, streamlining the protocol to compare two interventions: home web tool access and office-based tool access with clinical staff support. Appropriate study design would necessarily include that the user-friendliness interfaces and access to the tools be maximized in both settings, including availability of appropriate language versions. Importantly, the study must be conducted in randomly selected and representative populations that extend beyond a single health care system, so that the methods can be compared and conclusions generalized to a broader population. Initiation of such a reasonably large and complex clinical study will very likely require a commitment of public research dollars during a time of constrained resources. However, the benefits to the ultimate goal of fully harnessing the potential for FHH in improving health care delivery could be considerable.

Conflict of Interest: *The author declares no conflicts of interest.*

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