

# Comparison of a Focused Family Cancer History Questionnaire to Family History Documentation in the Electronic Medical Record

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## Abstract

**Introduction:** Family health history can be a valuable indicator of risk to develop certain cancers. Unfortunately, patient self-reported family history often contains inaccuracies, which might change recommendations for cancer screening. We endeavored to understand the difference between a patient's self-reported family history and their electronic medical record (EMR) family history. One aim of this study was to determine if family history information contained in the EMR differs from patient-reported family history collected using a focused questionnaire. **Methods:** We created the Hereditary Cancer Questionnaire (HCQ) based on current guidelines and distributed to 314 patients in the Department of Family Medicine waiting room June 20 to August 1, 2018. The survey queried patients about specific cancers within their biological family to assess their risk of an inherited cancer syndrome. We used the questionnaire responses as a baseline when comparing family histories in the medical record. **Results:** Agreement between the EMR and the questionnaire data decreased as the patients' risk for familial cancer increased. Meaning that the more significant a patient's family cancer history, the less likely it was to be recorded accurately and consistently in the EMR. Patients with low-risk levels, or fewer instances of cancer in the family, had more consistencies between the EMR and the questionnaire. **Conclusions:** Given that physicians often make recommendations on incomplete information that is in the EMR, patients might not receive individualized preventive care based on a more complete family cancer history. This is especially true for individuals with more complicated and significant family history of cancer. An improved method of collecting family history, including increasing patient engagement, may help to decrease this disparity.

## Keywords

medical history taking, family health history, hereditary cancer syndromes, genetic counseling

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## Introduction

Capturing family health history is a simple and cost-effective way to identify individuals at increased risk for cancer.<sup>1,2</sup> Recognizing individuals with higher familial risk can help prevent or detect cancer earlier and reduce cancer morbidity and mortality.<sup>3–6</sup> “High risk” individuals may benefit from individualized care ranging from enhanced cancer education to earlier cancer surveillance, and in some cases, chemoprevention or prophylactic surgery.<sup>7–9</sup>

In primary care settings, there are several barriers to collecting family health history.<sup>10</sup> Self-reported histories can be limited, inaccurate, or static.<sup>11,12</sup> Patients often relay information in an unprepared manner during an office

visit.<sup>13</sup> Physicians admit they lack the knowledge to assess risk for diseases based on family history.<sup>14–17</sup> Furthermore, physicians are often only focused on the primary indication of the appointment, are overwhelmed with competing demands, and constrained for time.<sup>18</sup> These complex factors make it difficult to identify familial health risks for the

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patient and determine whether referral for genetic counseling would be beneficial.

A robust family health history can be an indicator of risk for certain diseases and is used in guidelines for determining when to initiate screening.<sup>6</sup> However, there is large variability between how clinicians collect the information, how it is recorded in the medical record, how often it is updated, and how patients and physicians perceive the significance of family history.<sup>10,19</sup> Due to these discrepancies, patients with familial risk for cancer are often missed and do not receive individualized care.<sup>1</sup>

Providing patients with pre-emptive education on the value of family history has been shown to improve the accuracy of the reported information to an extent that a significant number of patients receive modified screening recommendations.<sup>20</sup> Previous studies suggest that disease-focused questionnaires provide a more accurate picture of a patient's familial risk.<sup>20,21</sup> Several family health history collection tools have been created, but few have been validated for widespread adoption and remain under-utilized.<sup>22-24</sup>

A practice improvement project was implemented to determine the impact of scaling family history awareness utilizing a family cancer questionnaire within a non-selected, general medicine population and to streamline referrals to genetic counseling. A retrospective chart review was conducted to compare the questionnaire responses to the information in the electronic medical record (EMR).

## Methods

A cancer-focused questionnaire was created and distributed to patients attending family medicine appointments. The Hereditary Cancer Questionnaire (HCQ) was created using Input Health (a company specializing in patient-input health tools). The questionnaire collected information about personal and family history of cancers. It was distributed on a tablet device from June 20 to August 1, 2018, to patients over the age of 18 in the family medicine waiting room after check-in. Risk for a hereditary cancer syndrome was estimated using a scoring methodology. The scoring system was created by a genetic counselor based on National Comprehensive Cancer Network (NCCN) guidelines,<sup>7,8</sup> Amsterdam criteria,<sup>25</sup> and revised Bethesda criteria.<sup>26</sup> Scores were divided into 3 ranges (low, medium, or high) based on the amount, type, and age of onset of cancers in their personal and family history. For example, a personal or family history of breast cancer was 1 point and cancers with onset under the age of 50 were 2 points. Those that met NCCN criteria for further genetic risk evaluation were assigned at least medium risk.<sup>7</sup> Patients categorized as high risk met criteria for further genetic evaluation based on multiple facets of their personal and/or family history. This scoring system was used to indicate which patients reported

a significant family history and subsequently offer a consultation with a genetic counselor. As this was not a validated risk score, we did not communicate scores to the patients.

The following cancers were surveyed in the HCQ: breast, ovarian, cervical, uterine, colon, pancreas, prostate, melanoma, sarcoma, gastric, kidney, leukemia, brain, adrenal cortical carcinoma, and thyroid. These specific cancers were chosen because they included those diagnoses identified by the National Comprehensive Cancer Network for potential discussion with patients being evaluated for hereditary cancer risk.<sup>7,8</sup> Cervical was included in an attempt to prompt patient consideration of whether a family member's gynecologic cancer diagnosis maybe have been ovarian, cervical, or uterine.

Permission to conduct retrospective chart review was given by the Institutional Review Board (ID:18-006277). The HCQ was treated as the baseline when comparing the patient charts. The data were extracted and coded by 3 of the authors. A subset of all the data was coded together to check for inter-rater reliability. Discrepancies were discussed and resolved through consensus. The institution's electronic medical record (EMR) provider at the time was Cerner Power Chart. The chart review looked at 4 different areas of the EMR:

1. "Patient's history" tab: the repository of family history within the EMR
2. Patient "family history": information provided by the patient
3. The most recent "family medicine comprehensive note": the equivalent of a complete history and physical
4. The oldest "family medicine comprehensive note"

Additional information was recorded when looking at the family medicine comprehensive notes:

- If the family history of cancer was addressed
- If direct action was taken because of family history

Fisher's exact test was used for statistical analysis. A *P* value less than .05 was considered statistically significant.

## Results

During a period of 3 weeks, 320 patients were approached in the waiting room prior to their Family Medicine appointment and offered the opportunity to fill out the hereditary cancer questionnaire (HCQ). Of those patients, 314 successfully completed the questionnaire with an average time of 3 min and 15 s. Patient characteristics are detailed in Table 1. The questionnaire was designed to be brief if there was little family history of cancer; the quickest time was 24 s. If patients did not have enough time to fill out the

**Table 1.** Patient Characteristics.

Characteristics	Total: 314
Female	180
Male	134
Average age	59.2 (youngest 18-oldest 95)

questionnaire before they were called into their appointment, they were allowed to take the tablet with them and fill it out during or after their visit. The longest questionnaire time was 1 h and 35 min. There were 213 patients classified as “Low-Risk” status, 76 patients classified as “Medium-Risk” status, and 25 patients classified as “High-Risk” status based on their score.

After the scores were calculated, the information provided through the questionnaire was compared to the recorded family history in the EMR. Family history in a patient’s EMR was frequently different than what they inputted in the HCQ. The HCQ repeatedly recorded cancers that were absent in the patient’s EMR. There were also some instances where cancers were mentioned in one or more areas of the chart, but not all. Another example of these inconsistencies was that some cancers were not included on the HCQ as it focused on cancers that were more likely to be hereditary, rather than environmental. Patients listed these other unspecified cancers as “other” on the HCQ. Lastly, there were some occurrences when a cancer was mentioned in EMR but not in the HCQ.

Across all areas of the EMR, those with significant family history of cancer, classified as “medium risk” or “high risk,” were more likely than those classified as “low risk” to have inconsistencies between histories in the EMR and HCQ.

Table 2 displays the comparison between the HCQ results and the “patient’s history” tab of the EMR. Histories were consistent across the 2 methods for over 56% of “low risk” individuals, but only 22.9% of “medium risk” individuals, and 0% of “high risk” individuals. Out of the 23 “high risk” individuals with available data in the “patient’s history” tab, none had consistent history between the HCQ and EMR data.

Table 3 displays data for the HCQ results compared to the patient-provided “family history” tab in the EMR. The results are similar to those in Table 2 as inconsistencies between the HCQ and EMR data are more frequent among those with higher risk. Family histories were consistent between the HCQ and EMR for almost 54% of “low risk” individuals, but only 25.7% of “medium risk” individuals and 4.6% of “high risk” individuals.

Table 4 shows the comparison between the HCQ results and the most recent “family medicine comprehensive note” in the EMR. Again, histories across the 2 methods were more frequently consistent among those classified as “low

risk” compared to those classified as “medium risk” and “high risk.” For this area of the EMR, 54.5% of “low risk” individuals, 25% of “medium risk” individuals, and only 8% of “high risk” individuals had consistent histories compared to the HCQ answers.

Finally, Table 5 displays data for the comparison between the HCQ and the oldest “family medicine comprehensive note” in the EMR, and remains consistent with previous findings. Family histories were consistent between the HCQ and EMR for 47% of “low risk” individuals, 15.8% of “medium risk” individuals, and 8% of “high risk” individuals.

Within the EMR itself, there were substantial deviations between the 4 sections studied. This pattern also increased as risk level increased. For the “patient’s history” tab and patient provided “family history” sections, data on the patient’s extended family were almost never included. The family medicine comprehensive notes included this information more often, but it was not common. For example, an aunt with cancer was recorded for 32 different patients in the HCQ, yet it was only mentioned twice in the “patient’s history” section, 0 times in the patient provided “family history” section, and 9 times in the most recent “family medicine comprehensive note.” There were also several instances where areas of a patient’s chart were not recorded or left blank. As seen in Table 2 above, the “patient’s history” section was not recorded in 51 out of 314 total cases (16.2%). Similarly, as seen in Table 3, patient provided “family history” was absent in 40 out of 314 total cases (12.7%). The “family medicine comprehensive note” sections were complete for all 314 participants.

Results from genetic counseling referral and genetic testing will be reported elsewhere.

## Discussion

The EMR notes had more details about types of cancer, onsets of cancer, and greater specification of which family member had the cancer. If a cancer was noted in a family medicine comprehensive note, the healthcare provider could better document nuance, such as questions on onset or primary. Another study found similar findings for free text sections of the EMR.<sup>27</sup>

However, the HCQ often provided more information about a patient’s family history of cancer. It had other benefits such as the ability to flag patients for referral to genetic counseling. This is difficult to accomplish by searching through patients’ EMR as it requires the physician to have time to look in several different locations and have up to date knowledge of guidelines. Advancements in Natural Language Processing code may help extract and interpret text notes in the EMR to document a better family history.<sup>28-30</sup> While the HCQ accuracy had limitations as well, it appeared to be a better source of information to determine who should be referred to genetic counseling.

**Table 2.** Hereditary Cancer Questionnaire (HCQ) Responses Compared to the “Patient’s History” Tab in the Electronic Medical Record (EMR).

Risk category (n)	Missing	Chart history not the same as HCQ	Chart history same information as HCQ	P-value (vs low)
Low risk (179)	34/213 (16.0%)	78/179 (43.6%)	101/179 (56.4%)	N/A
Medium risk (61)	15/76 (19.7%)	47/61 (77.1%)	14/61 (22.9%)	P < .001
High risk (23)	2/25 (8.0%)	23/23 (100.0%)	0/23 (0%)	P < .001

**Table 3.** HCQ Responses Compared to the Patient-Provided “Family History” in the EMR.

Risk category (n)	Missing	Patient provided family history not the same as HCQ	Patient provided family history same information as HCQ	P-value (vs low)
Low risk (182)	31/213 (14.6%)	84/182 (46.2%)	98/182 (53.9%)	N/A
Medium risk (70)	6/76 (7.9%)	52/70 (74.3%)	18/70 (25.7%)	P < .001
High risk (22)	3/25 (12%)	21/22 (95.5%)	1/22 (4.6%)	P < .001

**Table 4.** HCQ Responses Compared to the Most Recent “Family Medicine Comprehensive Note” in the EMR. No Data was Missing in This Area of the EMR.

Risk category (n)	Recent family med comp notes not the same as HCQ	Recent family med comp notes same information as HCQ	P-value (vs low)
Low risk (213)	97/213 (45.5%)	116/213 (54.4%)	N/A
Medium risk (76)	57/76 (75.0%)	19/76 (25.0%)	P < .001
High risk (25)	23/25 (92.0%)	2/25 (8.0%)	P < .001

**Table 5.** HCQ Responses Compared to the Oldest “Family Medicine Comprehensive Note” in the EMR. No Data was Missing in This Area of the EMR.

Risk category (n)	Oldest family med comp notes not the same as HCQ	Oldest family med comp notes same information as HCQ	P-value (vs low)
Low risk (213)	113/213 (53.0%)	100/213 (47.0%)	N/A
Medium risk (76)	64/76 (84.2%)	12/76 (15.8%)	P < .001
High risk (25)	23/25 (92.0%)	2/25 (8.0%)	P < .001

The HCQ often had more instances of cancer reported than the EMR, possibly because it focused on cancer specifically, rather than all familial disease. However, the HCQ did not always have more information than the EMR. This could be because of several reasons, most likely because the questionnaire was offered on the spot without opportunity to gather more information from family members and it only asked about certain types of cancers. Further research is needed to determine if giving patients a family health history tool in advance would provide more complete information as they would have more time to complete the questionnaire and call relatives to confirm family history.

By understanding the differences between the medical chart and questionnaire responses, we can see where recording family health history in the medical record can be improved. With this information, we can understand how

often there are variances in the information collected versus what is seen by the provider during the visit. We can identify and remove barriers and improve physician education to capture familial forms of diseases sooner in patients and their families.

This study has several limitations. The cohort was recruited from only 1 tertiary care medical center that may not represent all patient populations. Furthermore, only 1 EMR provider was observed, and other systems may not have the same challenges. Additional research is needed to confirm whether these results occur in other populations and if another tool may be more useful in assessing family history for genetic referral.<sup>31</sup> However, another study found that even with a short family history questionnaire, primary care physicians would be hesitant to adopt it.<sup>32</sup>



There are several family history tools available with unique features.<sup>22-24,33-37</sup> The HCQ in this project was different than the other tools because it focused specifically on cancers<sup>20,21</sup> and provided a threshold scoring system for easy identification of those who should be referred to genetic counseling.

## Conclusion

Based on our findings, it is apparent that one of the barriers to identifying familial cancer risk is medical chart documentation. This was especially true for individuals with more complicated and significant histories. Physicians have a variety of places to look for family health history, but not all those locations have the same information. Therefore, physicians do not have a complete picture of their patient's hereditary risk. Having one main place to input family history information into the EMR may alleviate some of this problem. However, even in a single location within EMR, family history may not be complete or up to date. If family history is addressed, many physicians may not know how to quantify hereditary risk for referral to genetic evaluation. Future research is needed to validate a similar scoring system based on guidelines and to determine if this method could be implemented to automate referrals. A focused family cancer history tool with clear indicators for referral, given to patients with advanced notice and adequate time to complete, may help improve medical record documentation of family history that could lead to better guidance for physicians to enhance prevention and early detection of cancer.

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## Supplemental Material

Supplemental material for this article is available online.

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