Center for Health Research

Final Report:

Family History in Clinical Practice

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Family History in Clinical Practice:

Current practices and clinician evaluation of family history tools

1. Background

The CDC developed a risk assessment tool (Family History Tool) designed to: collect information about family medical history for common diseases and other major risk factors; assess an individual's risk level for several common conditions; and provide information to the individual about her/his risk level and prevention and screening recommendations appropriate to risk level for condition. Using this tool, the CDC is conducting research to assess the impact of personalized risk level and intervention information on patients' prevention and screening behaviors, compared with standard prevention and screening message. In contrast, this study collected clinician perspectives on the usefulness and acceptability of the CDC's Family History Tool in primary care. There is no existing knowledge that directly addresses clinician perspectives on these issues. This information is an important adjunct to the CDC's intervention study in that clinicians play a key role in motivating their patients to engage in appropriate screening and prevention behaviors. Thus, it is important to design a tool that is useful and acceptable to clinicians.

We conducted a qualitative study within the Kaiser Permanente Northwest health care system to: learn about current practice regarding the use of family medical history in clinical care; develop family history scenarios for evaluating the CDC's Family History Tool; and evaluate the CDC's Family History Tool using family history scenarios.

2. Methods

2.1 IRB approval

This project, and all modifications and materials, were approved by KPNW's IRB.

2.2.Overall description of design and methods

Qualitative methods allow participants to describe beliefs and experiences in their own words and make relevant associations. These methods illuminate how people conceptualize, experience, and talk about health-related issues. Because of their ability to elicit the participant's perspective, qualitative methods are useful in defining the range and variability of beliefs, behaviors, and experiences of study populations, as well as the language people use to discuss them.

This study relied on an approach known as "focused ethnography." Focused ethnography has been used in health services research to understand the dissemination and acceptability of a wide range of interventions. Initial data collection focuses on understanding the vocabulary and local concepts related to the study and is followed by "member checks" to ensure construct validity as well as more structured data gathering that can include both open-ended and structured methods. We used an iterative design to conduct this focused ethnography, with three major data collection phases, described below.

Phase I: Learn about current practice

The goal of this phase was to learn how primary care clinicians currently collect and use family history information and to begin to gather information about their receptivity to a patient-centered family history risk assessment tool. We conducted individual, in-depth interviews with eight internal medicine clinicians. Clinicians were selected from several clinics, reflecting diversity in the patient population's race/ethnicity, primary language, education, and health literacy.

In-depth interviews

Dr. McMullen conducted in-depth interviews using a series of open-ended questions to elicit factual information on family history collection, risk assessment in current practice, risk categories of family histories, and reactions to the CDC family history tool. We finalized the concepts and questions and developed the interview guide in collaboration with our partners at the State. Each in-depth interview lasted approximately 30-45 minutes. Dr. McMullen took extensive notes and the interviews were audio recorded.

Interviews were conducted in person, asking participants:

- To describe current practices relating to family history collection and use for risk assessment.

- Whether family medical history is routinely used to make prevention or screening recommendations.

- At what type of visit family medical history is collected.

- How family medical history is collected and recorded in the medical chart.

- How family medical history is interpreted (e.g., qualitative risk level vs. actual risk).

- How risk level and interventions are communicated to patients.

- To describe the usefulness of family medical history in clinical care.

- Identify barriers to using family medical history in clinical care, and potential solutions to these barriers.

- To provide feedback on the acceptability of the CDC's Family History Tool in their current practice.

Phase II: Develop family history scenarios to evaluate the CDC's Family History Tool

The goal of Phase II was to develop family history scenarios to obtain specific clinician feedback about the CDC's Family History Tool. We developed a series of potential family history scenarios based on information gathered in Phase I, informal consultations with a medical informatics colleague who is also a primary care physician (Dr. Paul Gorman, OHSU), and detailed information from the CDC about their Family History Tool. Information from the CDC included:

- Information collected as part of the Family History Tool;

- Assessments of risk level for six adult-onset diseases, based on information collected with the Family History Tool;

- Prevention and screening interventions recommended for each risk level and evaluated condition.

The family history scenarios were developed to reflect the variability in both clinical and workflow issues. An example of a clinical issue was a woman at high risk of breast cancer but whose significant family medical history was on her father's side. Workflow issues included prioritizing the tool's recommendations in the context of a visit intended to monitor existing chronic conditions or a patient mentioning at the end of an urgent care visit that the tool assessed his heart disease risk as high.

We developed the potential family history scenarios and developed the phase III interview guide in collaboration with our State and CDC partners. To finalize the family history scenarios, we conducted a second set of individual, in-depth interviews with five key informants to learn their reactions and suggested improvements to the case scenarios. Ethnographic research often utilizes key informants (individuals who are experts in a particular area) to help learn about a local cultural domain – in this case the culture of primary care in KPNW. We asked them to help us refine the scenarios so that they would be realistic in the KPNW setting, would generate good discussion among primary care clinicians, and would address key issues surrounding the acceptability and implementation a risk assessment tool such as the CDC's Family History Tool. Interviews with key informants were conducted in person.

Phase III: Evaluate the CDC's Family History Tool from a clinician perspective

The goal of this study phase was to evaluate the CDC's Family History Tool from the clinician's perspective. The CDC's tool is being developed for consumers or patients, with the recommendation that the individual share the information with her/his clinician. Thus, our study focused on the tool's evaluation of risk level and prevention and screening recommendations, rather than on data collection and user interface. Focus groups were held in different clinic locations, reflecting diversity in the patient population's race/ethnicity, primary language, education, and health literacy.

Focus group interviews

Focus group interviews are an important tool for investigating how people conceptualize, experience, and talk about issues, and examining the range of experiences. This technique provides an efficient mechanism for collecting qualitative data from a large number of individuals. Focus groups are often used to obtain feedback on previously collected data, marketing or educational materials, or new products. We used focus groups to explore clinicians' reactions to the CDC's Family History Tool utilizing the family history scenarios developed in phases I and II. During the focus groups, we asked participants to discuss topics that directly informed the acceptability of the Family History Tool. We used the family history scenarios developed in Phase II as a basis of discussion for three focus groups of primary-care clinicians. Interview guides ensured the same issues were discussed in all focus groups (see attached/Appendix).

Each session lasted about one hour and was audio-recorded. During focus-group discussions, assistants (Dr. Harris, Ms. Judy Wick) recorded the speakers' remarks and non-verbal responses. Drs. McMullen and Harris and Ms. Wick debriefed to summarize observations and issues raised in the discussion. The debriefing occurred immediately after the focus group. Audio files of the focus groups and debriefing discussions were transcribed. These transcripts became the data for subsequent analysis.

2.3. Recruitment

Study participants for all phases of the project were recruited using one or more of the methods below. We consulted with the Medical Director of Primary Care, Northwest Permanente, and clinic administrators to determine which methods would be most acceptable and effective:

- E-mail.

- Interoffice mail.

- Telephone call. This was an important way to contact key informants, in conjunction with written material sent via e-mail or interoffice mail. We used this method for phase I and phase III only when other methods were not effective in recruiting participants from a given clinic.

- Flyers placed in clinician mailboxes and posted in clinics.

The Principal Investigator (Harris), Co-Investigator (McMullen), and study staff (Gail Morgan, Judy Wick) recruited participants.

For phase II, we identified key informants using our own knowledge and key advisors (e.g., the Director of Primary Care, Kaiser Permanente).

2.4. Individual clinician interviews

Eight primary care clinicians from one of three target clinics (Beaverton, East Interstate, Rockwood) completed individual interviews. Five were women, and four were men. Six were physicians, and two had other clinical degrees. Type of practice: four internal medicine, one family practice, and three obstetrics/gynecology.

2.5. Interviews with key informants

Physicians participating in these key expert interviews included:

- Clinical geneticist, who also invited a genetic counselor to participate as part of this "individual" interview (both gave written consent)
- Primary care practitioner

- Preventive services specialist

- Informatics/electronic medical records specialist

- Clinical guidelines expert

2.6. Focus groups

One focus group was held at each of three clinics (Beaverton, East Interstate, Rockwood). There were nine participants total: four physicians, three physicians, and two non-physicians. Five men and four women participated. Participants included highly-experienced, long-time KPNW clinicians as well as clinicians newer to KPNW.

2.7. Data analysis methods

Phase I interviews:

Analysis of phase I interviews occurred at the end of the study. Dr. McMullen took notes during phase 1 interviews and later expanded these notes by listening to audiotapes of the interviews. Next, Drs. McMullen and Harris summarized two interviews each, and reached consensus about a categorization scheme for organizing interview summaries. This resulted in eight interview

summaries, in which the various topics raised by respondents were arranged according to the categorization scheme. As a final step, we synthesized the topics in each category, across all eight interviews.

Phase II interviews:

Analysis of phase II interviews was immediately conducted at the end of each interview. Dr. McMullen took extensive interview notes about a key informant's comments about each case scenario. Preparation for the next key informant interview involved incorporating these comments into the scenarios, so that these comments could be confirmed or critiqued by the subsequent key informant. This iterative process resulted in significant changes to the details of the case scenarios, and ultimately led to merging elements of two cases into one, more interesting case. In the end we presented three cases for discussion in our focus groups.

In preparation for the final report, we reviewed the interview notes from key informant interviews to find general comments that were relevant outside of scenario development issues. A document listing these general comments was reviewed alongside the phase I and phase III results in order to include key informants' expert opinions in the synthesis of findings from various data sources.

Phase III focus group interviews:

We used a content-analysis approach to distinguish salient constructs and issues. We generated summary of themes and issues raised by each focus group. Summaries for all three focus groups were compared to generate our findings.

Both Dr. McMullen and Dr. Harris reviewed sections of different transcripts in order to decide how to summarize the data. We concluded that the structured nature of the discussion – revolving around three family history case scenarios – should be preserved in the analysis. Consequently, we summarized the topics of discussion in each focus group according to comments that were specific to each case and comments that were more general in nature. These focus group summaries were later synthesized to describe areas of consensus and variability in case-specific and general comments.

3. Results

3.1. *PHASE I FINDINGS:* Individual primary care clinicians' current practices using family medical history and general opinions about the CDC Family History Tool

Family history data documentation:

Clinicians reported three ways of recording family history in KPNW's electronic medical record system, Health Connect. They could summarize family medical history in a section of their free-text progress notes. Clinicians could also use a special feature of Health Connect dedicated to family history, which provides pull-down menus to select for relatives and disease categories and has the capacity to incorporate additional information about age of diagnosis and specifics about the disease. Only three of the eight clinicians interviewed reported using this family history feature, and four reported never using it. While the family history feature results in easily retrievable data, most clinicians complained that it is too cumbersome and time consuming to use. Significant family medical history issues could also be recorded in a patient's problem list,

a summary of current conditions that is easily retrievable and often consulted. Three clinicians reported using the problem list in this way, although they recognized that "cluttering up" the problem list makes it less useful. Several clinicians mentioned that patients had requested *not* documenting certain family medical history information in their medical charts, such as BRCA testing results.

Family medical history information is collected on a paper questionnaire that most clinicians found difficult to use. They complained that the form was out-of-date and resulted in data that was nearly impossible to retrieve unless they transcribed it into one of the EMR sections noted above. Finally, there was variability in the process for recording family history data. Some clinicians entered this data directly into the computer during patient visits, while others wrote notes and entered the data after the visit.

When is family medical history collected?

There was a consensus about when family medical history is collected. Clinicians collect this information when seeing new patients, especially if the patients did not have an urgent medical problem. Clinicians also collect or update family medical history during "well-adult physicals" or annual exams for gynecology patients. Family medical history is collected during pre-op visits and when writing up "H&P" information for hospital admissions. Some clinicians reported collecting new family medical history data if that data was previously collected by a different clinician, suggesting that problems with retrievability and unsystematic documentation are leading to duplication of efforts. Other occasions for collecting family medical history included: patients with chronic diseases (diabetes or hypertension); health screening visits; problem visits where family medical history could guide diagnosis or follow up (i.e., chest pain in a young adult).

What information do clinicians gather?

Clinicians varied in terms of how much information they sought about family medical history. Most clinicians, however, reported asking for information about first degree relatives and occasionally grandparents. Family medical history was allocated about three-four minutes in a typical new patient or well-adult visit. Clinicians reported focusing on a select list of diseases, including early CAD, colon cancer, breast cancer, and diabetes. Other diseases patients often mention are cancer of any type and strokes. OB/GYN clinicians also ask about female cancers specifically, history of blood clots in the legs and/or lungs, thyroid problems, osteoporosis, or infertility and congenital deformity problems for obstetrical patients. When patients confirm a family history of a condition, clinicians follow up by asking about age of diagnosis. Occasionally, clinicians ask patients to gather more information about their family medical history. Patients, for example, may not know what type of skin cancer a relative was diagnosed with, may not be reliable in reporting heart disease, or they may report ovarian cancer when their relatives actually had a different type of cancer that was somehow related in their minds.

There was variability in how often clinicians asked patients to get information about their family medical history. While it was seen as a timesaving measure, poor family medical history knowledge could indicate estranged family relationships. Young patients were reportedly less likely to know their family medical histories. Examples of how clinicians ask about family medical history: "Are there illnesses that run in your family that I need to know about?"; If nothing volunteered, ask about major conditions (heart disease, diabetes, hypertension, stroke, cancers, osteoporosis); "Are there certain diseases that run in your family?"; "What do women

in your family tend to look like?" (OB/GYN); "How many brothers and sisters do you have?, Are both your parents living?, Did either of them have cancer?" (e.g., for early CAD, colon cancer, breast cancer & diabetes).

What actions does family history prompt?

Several clinicians said that the main purpose of family history is risk assessment. Family medical history also prompted recommendations for screening, diagnostics, and preventive health measures. Such recommendations included: colorectal cancer screening (if present in one 1st degree relative); breast cancer screening; medications for preventing CAD and stroke risk (statins, anti-hypertensive meds, aspirin); referrals to genetics, especially for BRCA-related cancer issues; infrequently, it will impact how aggressive a follow up is to determine whether CAD is causing symptoms (e.g., shortness of breath, chest pain); embolic events – would look at family history, protein C deficiency; for OB/GYN clinicians – identifying high-risk patients would result in initial screening tests and encouragement to see their primary care clinician.

Clinicians stated that family medical history did not prompt any actions related to ovarian cancer risk. They also felt that actions based on family medical history should be evidence-based and adhere to USPSTF guidelines.

Many of the clinicians said that eliciting family medical history information initiates discussions that facilitate doctor-patient communication and motivate patients. Examples include: motivating patients to adopt risk-reducing behaviors; general discussions of preventive health and lifestyle issues, especially with younger patients; and helping clinicians understand how a patient is thinking about their own health.

How do you conceptualize and communicate risk?

Most clinicians used categories (e.g., high, medium, low; or average/high) to conceptualize risk. Only two clinicians reported conceptualizing risk primarily in terms of percentages. Some clinicians said they didn't conceptualize risk in terms of percentages because they simply couldn't think in terms of percentages, and others said it was for lack of numerical risk data. Clinicians used prevalence in the family, relationship of affected relative, and age of onset to calculate disease risk.

Many clinicians referred to a chart that used family medical history, lifestyle factors, and lipid status to determine the risk of MI with and without the adoption of statin therapy. They liked that both percentages and color-coded categories were present in the chart, and said that this information greatly assisted communication about statin therapy with patients. They thought this was a model for tools that could be developed for other diseases. Electronic and paper versions of such a tool were seen as useful for everyday practice.

What could be done to enhance the use of family medical history in primary care?

Time is the primary barrier to increased use of family medical history in primary care. Lack of user-friendly, easily-entered, and easily-retrievable data is also a hindrance. Clinicians said it was hard to sort through information to determine what was important about family medical history and how to best assess risk for adult-onset diseases. Participants desired more accessible risk-assessment tools, more training about genetics, family medical history, and risk assessment, and more guidance on action items tailored to individual patients. They favored developing

more EMR components, such as clinical guidelines and decision support surrounding family medical history, risk, and action items.

Clinicians reacted favorably to ideas for collecting family medical history outside of the doctor patient visit. They saw this as a timesaving measure that could allow patients to ask relatives about medical history. Having this information collected in advance of a medical visit was seen as beneficial. However, clinicians expressed concerns about the accuracy of patient-entered information and also worried that family medical history tools might generate more questions than they answered. One clinician said she did not have time to deal with a family medical history pedigree, but would be able to incorporate pre-calculated risk assessments into conversations she was already having with her patients.

Comments on CDC tool:

Clinicians generally agreed that the CDC's tool would be useful for risk assessment and intervention recommendations for all six conditions. They found it especially helpful for cancers, and said that the tool might affect some of their recommendations about screening and prevention. A few suggested additional conditions: osteoporosis, depression, mental health more broadly, prostate cancer, and testicular cancer. Many found ovarian cancer challenging because risk assessment was not accompanied by effective screening or intervention measures. A few considered diabetes and stroke least relevant because of the widespread prevalence of hypertension and diabetes in the population, and because they were already aggressively screening and doing preventive care for these anyways.

There was disagreement about presenting family medical history risk, as opposed to overall risk, for adult-onset diseases. Some thought having a tool to disentangle family history risk from overall risk would be helpful, and felt that patients can understand the difference with little education. Others didn't like the emphasis on family history risk, and felt that this needed to be balanced with lifestyle issues and overall risk.

Training in use of family medical history and genetics:

More recently trained clinicians reported more training on genetics and using family medical history to assess disease risks. Clinicians said they did not have time to collect family medical history in the way they were trained. Subsequent training was also reported.

Clinicians were aware that genetics would play an increasing role in adult primary care in the coming years. They desired more training in the following areas: how to use and interpret genetic tests; ethical implications for clinicians of clinical genetics; ethical aspects of discussing genetics with patients; individual risk assessment – how to apply family medical history to individual patients (specific, concrete recommendations); variable penetrance; and ethnic differences.

3.2. Phase III results: Reactions from focus groups of primary care clinicians about three family history scenarios using the CDC Family History Tool

3.2.1. Case One

Clinical issue: Collecting data beyond first-degree relatives

Work flow issue: Availability of family history

Case history:

- 35-year-old woman with one brother, two living parents.

- In a routine physical, clinician asks, "are there any medical problems in the family history that I should be aware of?" Patient says there aren't any. Clinician asks whether any immediate family members have had heart disease, cancer, stroke, or diabetes. Patient says no.

- However, the patient's family history is as follows:

    - Father's mother and sister diagnosed with breast cancer in their forties.

    - Mother: no cancer

    - (No sisters)

Discussion points:

1) Limited time for family history elicitation

2) Patient not aware of what is relevant in family history.

3) Key information needed for family history risk assessment is not collected in this example of routine family history taking practice.

4) Limited family history questions are likely to miss father's family history of female-specific conditions such as breast, ovarian cancer, or endometrial cancer.

5) In everyday practice, clinicians tend only to ask about first-degree relatives' medical history.

Are clinicians aware that father's family history (2nd degree relatives of the patient) may contain important risk information for female-specific conditions?

6) Tool will pick up the information and will correctly estimate risk. When and in what format would information be most effective in capturing breast cancer risk at a primary care visit?

Comments specific to this case

A common content concern in all focus groups was the recommendation regarding ovarian cancer screening. There are no screening methods that are proven to be effective. Raising the possibility of screening for ovarian cancer as part of the tool puts the clinician in an uncomfortable position in talking with her/his patient – explaining the unproven effectiveness of screening, and then having to decide whether to order screening. The latter decision being based partly on patient demand.

There was also a question as to why ovarian cancer risk was increased in this case, and whether a geneticist would be more prepared to counsel this woman.

Collecting/documenting family history

Clinicians reported that having a family history diagram would save clinicians a significant amount of time in history taking. Having the diagram available would also illuminate gaps in family history information, especially since people often don't know their family history very well. They also felt that having patients fill out family history information on their own time, with ability to ask questions from relatives, would make the information more comprehensive

and accurate. The focus group clinicians felt that since physical exams decreased to 20 minutes, accomplishing the increasingly complex tasks of daily practice has become impossible. They felt that any tool that could gather information outside the visit would be help to ease this burden.

Risk assessment/communication

Our focus group participants expressed that they want information about the actual risk, and had questions about: "How high is the actual risk?"; "Does primary care have the right tools to deal with this situation?"; "Should another department, such as genetics, deal with this?" These physicians were also hesitant to hand patients a "booklet" if it addresses things that should be addressed in a one-on-one conversation. They did feel, however, that these reports would serve as a good supplement to the one-on-one conversation.

Risk management/clinical care/recommendations

The clinicians reported that if they identified someone at increased risk, they wanted to have effective interventions to offer the patient (e.g., screening for early detection and more effective treatment). They felt that the CDC's Family History Tool could provide clinicians with the information and recommendations, and then they could tailor, interpret, and prioritize this information. Clinicians also require different information than patients needs, including more evidence-based rationales and training.

Our focus group participants felt patient information should include messages that reinforce good existing behaviors, not only desired behavior they weren't doing. They also noted that these recommendations probably aren't new to people, but it is one more source of encouragement to do preventive health activities/lifestyle changes could have a positive effect. Some felt that more specifics about how to increase exercise, how to quit smoking, and local community resources would help patients in their behavior change. The study clinicians felt that patient recommendations should be brief, and include basic lifestyle recommendations. They also noted that information leading to resource utilization needs to be evidence-based and tailored to each patient's unique situation. Focus groups participants also felt that many patients look for information on the Internet – much of which isn't accurate or helpful. They felt the CDC's Family History Tool could lead patients to identifying accurate information on their own, which could increase patient knowledge and reduce the burden placed on busy clinicians.

Time management/clinical priorities

In terms of workload, study clinicians felt that if the Family History Tool created more work, it will be even more difficult to implement in daily practice. They also noted that if the tool generates more questions, these could take away from issues with higher priority. One recommendation was that having somebody else available to interpret the recommendations might ease the burden of these issues, should they arise. They also felt that recommendations to patients must be careful delivered so as not to create false demand for tests/services that are otherwise unnecessary.

3.2.2. Case Two

Clinical issue: Context of family history for risk assessment, balancing clinical priorities

Workflow issue: Information from tool brought to visit

Case history:

- 70 year old woman

- Brings risk assessment software report to a medical visit scheduled for monitoring diabetes and hypertension

- Complex and common family history, large family: father diagnosed with colon cancer at age 50; sister diagnosed with breast cancer at age 65; father, brother, and sister had heart attacks in their 60s.

- Six brothers and sisters.

- Three children in their 40s.

- Last mammogram six months ago.

- No colon cancer screening.

Discussion points:

1) What value does the family medical history add in this case?

2) What are the costs/cons of fully addressing family medical history in this case?

3) How does the family medical history affect this patient's management?

Would it change management of her heart disease since she is already high-risk? Would it influence colon cancer screening recommendations if she had not had screening in past 5-10 years? Is there tendency to focus on managing existing disease and neglect screening for other conditions, like colon cancer or breast cancer?

4) Why is it important to discuss the patient's family history?

5) When is it most appropriate to review this patient's family history?

6) Does the tool help in alerting MD and patient to routine preventive screening that might be overlooked due to competing demands on clinician's time to manage her chronic diseases

Although family medical history might not influence this patient's management, how might it affect prevention recommendations for her other relatives, especially her children (who most certainly are at increased risk for CHD and diabetes)?

7) If a patient has concerns about her family history, how is that typically addressed in the primary care setting? (It is important to find out why she has concerns. Maybe she is more worried for her children than for herself and needs help conveying this information to her children and dealing with it – seeing her pedigree, she might feel guilty about passing on risk to her offspring.)

8) When might a follow-up visit to discuss family history as a separate issue from her chronic disease management be considered?

9) When might a referral to a genetics professional be considered?

Comments specific to this case

This case raised the issue of integrating a patient's medical history with family history, to give the patient and clinician a more complete and less confusing picture. For example, this patient's stroke and diabetes risk is weak based on her family history. She has diabetes, and her stroke risk

is increased based on her current diagnoses. Not integrating that information could give false reassurance to the patient.

This case also raised the issue of tailoring recommendations to the patient's age and general health. This was seen most clearly in the discussion around colon cancer screening. If this patient were a healthy 70-year-old (e.g., at least 10 years life expectancy), many clinicians would recommend screening without knowing the patient's family history.

Collecting/documenting family history

For this case, our focus group felt that the patient's age is part of the decision about collecting (or collecting in detail) family medical history. The computerized tool may be a barrier to some people (elderly), whereas others might view it as the preferred method (teens). They would like the family tree information to personalize the information for the patient – but caution against "cookbook" or "textbook" approach that spells out patient's medical care. Patients often complete the risk assessments and bring them to clinicians because they are triggered by someone else's (a relative's) experiences, not just from "surfing the web." They also noted that in their experience no patients have mentioned the Surgeon General's campaign to "know your family history" as an impetus for screening or prevention.

Risk assessment/communication

Our focus groups felt that for older patients, disease risk was more age-related than family history-related risk. They also felt that the number of affected relatives and the relatives' ages at diagnosis are important (e.g., "there's a cluster here. These people are a little bit older, so I'm less concerned than if they were in the forties or fifty, but there's a cluster…"). Study clinicians felt that patients' understanding regarding risk was an area of concern. One participant noted, "I don't think people understand risk very well…" while another commented "A lot of people, they just accept things. Still, they expect to be told if they are going to get it or not."

Participants noted that they consider family history together with other risk factors when assessing risk, and that neither patients nor clinicians tend to look at family history separately, yet risk assessment presented in the CDC's tool focuses on family-history associated risk. They felt that the concept of "the impact of your family history on the risk of…" is too subtle and would lead to erroneous conclusions. They also felt it would undermine clinician's efforts at risk modification/treatment of existing conditions.

Risk management/clinical care/recommendations

Our focus group participants felt that the CDC's Family History Tool would be more effective for younger patients than for older patients. They also noted that the patient's general health is part of the decision-making process for clinicians when choosing between possible interventions and that clinicians need to consider existing diseases, age, and life expectancy, when making these complicated decisions. One participant noted, "It's an important factor that you know what the other overall health issues are. I don't know how a tool could ever do that…I think that's a discussion…people generally have a tendency to panic about their health and it's a delicate balance to help them put it into perspective." They also felt that tailoring this tool to older patient's functional status would make it much more effective.

3.2.3. Case Three

Clinical: Clear guideline promotes further evaluation or test

Workflow: Collecting and using information efficiently to improve patient management, reduce barriers to appropriate care

Case history:

- 30-year-old man.

- Urgent visit in primary care for flu.

- No regular primary care clinician.

- As doctor is leaving, patient says that he filled out an on-line risk assessment, and it said that he is at increased risk of having heart disease.

- His mother had a heart attack at age 35.

- He doesn't smoke.

Discussion questions:

1) With opportunistic family history screening, how do you ensure that patient follows up with other screening recommendations (e.g., lipid panel)?

2) Are the following common dilemmas for primary care??

balancing patient's immediate concerns with clinicians preventive health concerns

healthy young patients not concerned about preventive health

healthy young patients don't have many primary care visits

3) Does this scenario present a missed "golden opportunity" to intervene early?

4) Suppose the patient had not mentioned family history at all in this case. How could we improve our systems to identify this high-risk patient? Could an alert about the lack of family history information be useful? Are there ways outside of the primary care visit to ensure that this information is collected and acted upon?

5) Tool could identify high-risk individual and would provide risk assessment and recommendations prior to visit (e.g. go see doctor, have screening tests). If done outside context of a primary care visit (via web?), patient could be called to schedule a primary care visit, with appointment for lab tests prior to primary care visit.

6) Can family medical history data increase efficiency of primary care?

Comments specific to this case

Focus group participants felt that this was a rare case—a woman having a heart attack at age 35. It raised issues around the validity of self-reported family medical history of cardiovascular disease. "You never really know what happened." "…it just comes down through word of mouth that it was a heart attack."

It also raised the issue of managing "drive-bys"—patients raising important issues at the end of a visit. In this case, the patient raises a potentially important family history during an urgent case visit for a totally unrelated health issue.

Collecting/documenting family history

The focus groups felt that family history is an important consideration when gauging a patient's risk and choosing among possible interventions. They also believed that a more "proactive" approach to case finding - e.g., through the mail, rather than identification through primary care – could also make the tool more useful for primary care clinicians. They noted, however, that this approach is unlikely to make a big impact with identification through urgent primary-care visits, and will be most effective when patients complete the tool before a visit—in a waiting room or when taking vital. The participants warned that emailed or mailed invitations to complete the tool would go largely ignored.

A concern of the focus group was the need to improve validity/reliability of family medical history. Inaccuracy in family history can lead to unfounded concerns. Utilization is another concern, as a number of patients only use urgent care, thus excluding preventive care. In these cases, the tool's effectiveness will be severely limited. To capture high-risk individuals who aren't established with a primary care clinician, we could set up a computer terminal for people to use while they're waiting in urgent care. "Black boxes" are currently in clinic waiting areas with depression screening questionnaires may eventually be loaded with other questionnaires. Efforts aimed at collecting information that doesn't have to be done face-to-face holds promise for being more efficient and freeing up valuable clinic time.

Risk assessment/communication

Our participants felt that the tool would be most useful with younger people who haven't identified risk factors, but whose family history may illuminate possible health concerns (e.g., middle-aged patient whose siblings are having heart attacks). They also felt that the tool would help alleviate some of their concerns about lacking the most up-to-date information on certain conditions. Using the Family History Tool could help them identify specific information on a patient-by-patient basis, thus eliminating the onerous task of reviewing great bodies of literature.

Time management/clinical priorities

Our clinicians felt that conducting this type of risk assessment when episodic patients come in for urgent problems would allow clinicians an "invitation" to seriously address risk with patients when the episode is over and they can spend more time discussing their family history assessment. Likewise**,** having a patient's family history available in the medical record helps them determine what issues need to be addressed at each visit and recommend needed interventions. Prioritizing health issues was a concern of all participating clinicians, and having family history available could help them triage these issues in a short amount of time.

Having patients complete the tool in advance or having it available in the medical record may also further the problems it seeks to alleviate. Having patients prepare their family history before a visit or having family history available in the EMR will create a dearth of data, which could further tax already busy schedules. As prioritizing health issues is a concern this plethora of data could create medical records with lists or conditions with too many issues to address. This tool could also create more work for busy clinics in that it requires consistent follow-up. If a patient does not follow-up as scheduled, the clinic must reach out to the patient, creating additional work for medical staff. There are also unknown medical-legal concerns of having this information included in the patients' charts that have not been adequately addressed.

Participating clinicians felt that having a case manager for high-risk patients, identified using the Family History Tool or another electronic method, would ease some of their burden and would allow them to more effectively address pressing medical issues. Likewise, clinicians noted that conducting a health risk assessment interpretation in urgent care is not possible, and using this tool could help identify high-risk patients who do not have a primary-care physician. They also noted that this could be a great online tool for our members, could encourage them to visit their primary-care physician, and could spark conversation about family history and their current health risks.

While we currently use a number of electronic alerts in the EMR, there is no provision for family history alerts that could alert physicians to a patient's health concerns (e.g., history of CAD or diabetes). If this could be accomplished, the results of the Family History Tool could be summarized and easily displayed in the patient's EMR.

4. Conclusions

Primary care clinicians believe that, for many/most patients, family medical history plays an important role in providing care. The importance depends on the patient's age, general health, and specific medical conditions.

Clinicians typically do not have enough time to collect family medical information in any detail. They welcome methods that would improve the efficiency of collecting and interpreting family medical history. However, there are concerns about validity of the information and adequate follow-up if it is collected in an automated manner and put directly into the medical record.

Clinicians prefer to receive actual risks, although it may be presented differently to patients. They prefer that family history-associated risks be integrated with other risk factors and patient's medical conditions. The risks need to be interpreted and actions prioritized based on the patient's age and other health care needs. It would be helpful to have screening and prevention activities documented alongside the risk assessment.

Risk assessment and recommendations for interventions need to have an evidence base. Clinicians would like to have evidence available for their consideration when making recommendations. Risk assessments for which there are no subsequent actions steps are not valuable to clinicians.

Risk assessment and recommendations for interventions are really a conversation between the patient and her/his clinician. There's a fine line to walk when making "automated" recommendations to patients. Recommendations to patients should include standard health message when appropriate, reinforcing clinician messages for healthy behavior. Recommendations to patients should stay away from recommendations that may increase demand on resources for which there is no firm evidence, or for which there is considerable variability in clinical practice because guidelines are absent or differ among experts.

With electronic medical records and automated systems, we have a great opportunity to integrate family history risk assessment with the rest of the care that a patient receives. It could include simple reminders about collecting/updating missing family information, as well as recommended interventions for certain risk groups.

5. Implications, including next steps

This study's results suggest that any tool addressing family history needs to be able to be customized to incorporate a particular physician's group practices, or the printed recommendations need to include only those that are widely accepted and endorsed by primary care clinicians. In addition, the tool must include a clinician version of the report that includes actual risk estimates, scientific basis for the risk estimates, specific recommendations, and rationale and references for the recommendations. These components need to be developed in conjunction with physicians to refine the usability of a general manual, which is already available from the CDC, versus patient-specific support.

Future research should test ways for integrating patient-provided information that is collected electronically with primary care: waiting room Web-based data collection; integration of Web-based information with electronic medical records; combining family information with personal diagnoses and treatment, and screening and prevention activities; innovative methods for follow-up after patient/member provides the data. This will ultimately reduce the burden placed on busy clinicians while providing patients with superior care.

Future research should also attempt to learn more about clinician and patient prioritization in primary care. Learning what patients and clinicians value the most will help to further refine how the tool functions and increase the relevance of the reports it generates.