The current state of cancer family history collection tools in primary care: a systematic review

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Abstract: Systematic collection of family history is a prerequisite for identifying genetic risk. This study reviewed tools applicable to the primary care assessment of family history of breast, colorectal, ovarian, and prostate cancer. MEDLINE, EMBASE, CINAHL, and Cochrane Central were searched for publications. All primary study designs were included. Characteristics of the studies, the family history collection tools, and the setting were evaluated. Of 40 eligible studies, 18 relevant family history tools were identified, with 11 developed for use in primary care. Most collected information on more than one cancer and on affected relatives used self-administered questionnaires and paper-based formats. Eleven tools had been evaluated relative to current practice, demonstrating 46–78% improvement in data recording over family history recording in patient charts and 75–100% agreement with structured genetic interviews. Few tools have been developed specifically for primary care settings. The few that have been evaluated performed well. The very limited evidence, which depends in part on extrapolation from studies in settings other than primary care, suggests that systematic tools may add significant family health information compared with current primary care practice. The effect of their use on health outcomes has not been evaluated. *Genet Med* 2009;11(7):495–506.

Key Words: primary care, cancer genetics, family history, questionnaire, interview

A positive family history is a risk factor for many chronic diseases, reflecting “the consequences of genetic susceptibilities, shared environment, and common behaviors.”¹ The systematic collection and assessment of family history information is a potentially valuable tool in preventive medicine and is crucial in the identification of genetic risk.² In some situations,

family history information alone can form the basis for offering patients appropriately tailored preventive interventions.^{1,3} In addition, the clinical predictive value of even the most accurate DNA test depends on penetrance of the gene mutation and requires family history information for test interpretation.⁴ Thus, family history information is potentially useful both as a clinical tool in its own right and also as an important adjunct to DNA-based testing.

Cancers are a group of relatively common conditions in which, for at least some, family history seems to be an important risk factor. This report focuses on four types of cancer: breast, colorectal, ovarian, and prostate. These are some of the most common cancers where the role of family history is recognized as a risk factor.^{5–9} In some families, these cancers form part of recognized hereditary syndromes.⁹ In some cases, ethnic ancestry is also associated with risk of cancer-associated genetic mutation, such as breast cancer in the Ashkenazi Jewish community.^{10–13}

Family history taking can be conducted as part of a disease-specific approach, which aims to identify risk of selected single gene disorders (e.g., hereditary breast or colon cancer) for the purpose of offering appropriate specialist referral and management.^{14,15} Alternatively, it can be directed more broadly toward identifying possible multifactorial risk of common disorders such as cancer and diabetes.^{16,17} The extent of cancer family history collection has to be adequate to enable primary care providers (PCPs) to make appropriate clinical and prevention decisions, but it is not clear whether this necessarily requires the same approach as that used by a genetic specialist.³

This review explored how well the different systematic family history collection tools improve nonsystematic approaches to family history collection by PCPs. Both the format of available family history collection tools and comparison of these tools against current “optimal” and “standard” clinical practice were evaluated.

MATERIALS AND METHODS

Literature search

Search strategies were developed and undertaken for the time period 1990 to July 2007 in several electronic databases including: (1) Cochrane Central, (2) MEDLINE®, (3) EMBASE, and (4) CINAHL®. In addition to the electronic databases, the bibliographies of retrieved articles were reviewed, as well as key internet websites, for additional relevant articles. Keywords included prostate or breast or colorectal or ovarian and neoplasm or cancer, medical history taking, family health, pedigree, and genetic assessment or evaluation.

Study selection

Studies were eligible if they were published in English and included any of the four cancer populations of interest (breast, colorectal, ovarian, and prostate). Primary studies (both qualitative and quantitative) were eligible, but narrative and systematic reviews, editorials, letters (with no primary data), com-

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ments, opinions, abstracts and unpublished studies were excluded. Studies that focused on capturing, collecting, collating information on disease history, or illness in other family members by any method (self-report or by a professional) were eligible. We defined a family history tool as a systematic approach used to capture and document family history, appropriate for the clinical setting, with the potential to lead to decision making by a clinician.

Studies within primary care “clinical” settings or undertaken by the PCPs were eligible. Similarly, studies that identified tools that systematically collected family history in other settings but could be applicable to the primary care setting were also eligible. Full details of eligibility criteria are presented in the full Agency for Healthcare Research and Quality report.¹⁸ Also, relevant web-based tools were identified by exploring the gray literature and signposting by members of the project team and the external Technical Expert Panel. Applicability of tools in nonprimary care settings and web-based tools were assessed by two independent reviewers against five criteria: length of tool, ease of completion, need for specialist knowledge to complete tool, whether it was designed to capture data on at least all first degree relatives (1DRs), and clarity of layout (including appropriate structure and logical sequence). Articles were excluded if (a) there was a primary focus on genealogy (nonmedical family history), (b) they included mention of family history in some form but did not describe a tool or measure for use in clinical settings, (c) they were statistical or epidemiological studies designed to explore associations or test hypotheses relating to family history and cancer risk but did not describe a tool or measure, and (d) they reported data on patient psychosocial outcomes relating to cancer risk or family history taking, but did not describe a tool or measure. Trained reviewers independently evaluated citations at all levels of screening and any disagreements were resolved by consensus. Standardized forms within Systematic Review Software (SRS 4.0, TrialStat Corporation, Ottawa, Ontario, Canada) and reviewer guides were used to screen abstracts and studies and to extract data.

Data abstraction and quality assessment

Data extraction and quality assessment for all studies meeting the eligibility criteria were completed by two independent reviewers and standardized forms were used. The specific quality assessment scale used was dependent on the study design and the research question. Full details of quality assessment are given in the full report of the systematic review.¹⁸

Data extraction

A qualitative descriptive approach was used to summarize study characteristics and outcomes. Multiple publications on the same study cohort were grouped together and treated as a single study with the most current data reported for presentation of summary results. Two aspects of the studies using or evaluating family history tools were explored: descriptive data on the attributes of tools and outcome data comparing tools to clinical practice. We reported outcome data separately for those tools compared with an alternative method to systematically collect family history, considered by the investigators to be a more “optimal” approach than the tool being evaluated, and those compared with current “standard” primary care practice. In studies using “optimal” comparators, the comparator was information collected by a clinical genetic specialist or structured interviews administered by trained researchers; when current practice was the comparator, this information was collected in a way that was “standard” for the primary care setting (e.g., family history information recorded in patient charts).

Role of the funding source

The study sponsor (Agency for Healthcare Research and Quality) provided feedback on peer reviewers, draft and final versions of the related evidence report.

RESULTS

Studies reviewed

A total of 39 different family history tools, implemented in 40 unique studies, and reported in 45 publications passed full text criteria. Our initial focus was on identifying studies that described tools developed or used in a primary care clinical setting^{16,17,19–25}; however, after careful review, we noted that many studies described tools used in other settings that seemed potentially applicable to primary care (as defined previously). We sent email requests for copies of the tool to all authors of eligible studies who did not provide sufficient detail about the tool in the publication. Fifteen authors (of 16 publications^{26–41}) did not respond in time for the publication of this review, and therefore, we were unable to determine whether the reported tools were applicable for use within primary care. Six tools from seven publications^{42–48} were assessed as inappropriate for primary care. Of the remaining 22 publications, four^{22–25} described the prototype and final versions of the same primary care tool, which we counted as a single tool, and two^{49,50} were companion publications. Thus, from 22 publications, 18 distinct tools were identified, eleven developed for primary care populations and a further seven developed for other settings but applicable to primary care (Fig. 1). Nine web-based clinical tools were also identified.

Description of tool

As indicated in Table 1, 14 tools^{16,17,19,21,51–60} were designed for completion by patients, with three studies reporting that these were completed in the PCPs office.^{16,17,54} A further four tools (eight publications^{20,22–25,49,50,61}) were designed for use by health professionals. Four tools were described (seven publications^{16,19,20,22–25}) which were implemented in family practice settings, and four tools^{17,21,59,61} in internal medicine clinics. One tool⁵⁴ was implemented in a screening mammography setting, and another four tools^{55–58} were designed for use in cancer centers or clinics. A further three^{51–53} were implemented in genetic clinics. One tool (two publications^{49,50}) was web based and designed for use by any health professional, and the remaining tool⁶⁰ was used in a large population-based research study.

Cancer type identified and purpose of family history tool

On reviewing details of the tool in publications and actual tool (when available), 14 tools, reported in 17 articles,^{17,19–25,49–55,57,59,60} were designed to collect data on family history of breast or breast/ovarian cancer. Ten tools (12 publications^{17,19,22,25,49–51,55,57,59–61}) specifically captured data on colorectal cancer and five tools (six publications^{17,19,49–51,57}) on prostate cancer. Nine tools (10 publications^{19,20,22,25,51,52,55,57,60,61}) also captured data on one or more additional cancer types. For three,^{16,56,58} the tool seemed to invite information on any cancer type.

The output of five tools (nine publications^{22–25,49,50,53,54,57}) was linked directly to some form of defined risk assessment (i.e., the family history data were converted directly into a risk categorization). Three of these tools were developed for primary care populations.^{22–25,49,50,54}

Fig. 1. Publications identified, selected, and excluded.

Format

Eleven tools^{16,17,19,21,52,54–56,58–60} were paper based, generally in some form of questionnaire or structured questions. Four tools (eight publications^{22–25,49,50,53,57}) were presented in a format for use on a desktop or laptop computer, including web based and touch screen applications, and one on a personal digital assistant.⁶¹ Two of these electronic tools required the patient to initially complete a self-administered paper-based family history questionnaire before inputting data.^{22,25,53} One tool⁵¹ was an automated telephone interview, and one was a structured interview schedule.²⁰

Content and complexity

Sixteen tools^{16,19–25,51–61} reported in 19 publications were designed to capture data on all or selected 1DRs.

Thirteen tools (16 articles^{16,20–25,51,53–57,59–61}) were designed to capture data on all or some second degree relatives (2DRs), and one¹⁶ on grandparents only. Six tools^{16,51,53–55,57} explicitly went beyond 2DRs, although not necessarily to capture all third degree relatives (3DR). For the remaining tools, the extent of family history enquiry was not explicitly described.

For all tools, except five,^{19,56,58,60,61} there were explicit instructions for users to capture data on relatives on both sides of

the family. Seven tools^{16,17,21,22,25,51,56,57} were designed to capture ethnicity data. In most tools, age of diagnosis of affected relatives was reported, whereas five tools reported directing the user to enquire about unaffected relatives.^{16,51,56,58,60} The respondents were asked to score the certainty with which they recalled relatives' medical information in one of the tools developed for primary care.²⁰ Nine tools reported collating respondents' past medical histories: this varied from general enquiry in three tools,^{16,17,59} with two tools focusing on specific cancers^{19,60} and five identifying personal risk factors.^{19,51,56,57} The complexity of the paper-based tools varied from a sequence of 6–10 closed questions,^{19,54} to a more detailed questionnaire varying in size from two⁵⁵ to nine pages.⁵⁶ In some cases, the questions were presented in tabular form,^{16,17,56,59} whereas two of the electronic tools presented the information as pedigrees.^{22–25,49–51}

Other family history tools

Eleven web-based tools were also identified during the gray literature search. Nine tools were actually available on the web, and these are listed with relevance scores in the full report.¹⁸ For all except one (JamesLink),⁵⁷ which was included in the main review, no information was provided on their development or evaluation, which precluded their inclusion in the main review.

Table 1. Characteristics of family history tools

Paper	Tool	Cancer(s) and other conditions	Target user and setting	Medium, form of questions	Direct/automated pedigree output	Degree of relatives covered	Details on living affected relatives	Details on deceased relatives	Automatic/direct risk assessment output
Tools developed for primary care population									
Colombet et al. ^{49,50}	Personalized estimate of risks (EsPeR)	Breast, colorectal, prostate	Professional	Web-based, dynamic data input	Yes	Not reported	Not reported	Not reported	Yes
de Bock et al. ²⁰	Structured interview	Breast, ovarian, other cancers	Professional; family practice	In-person interview schedule, structured questions	Not reported	1DR, 2DR	Age at diagnosis (breast cancer only)	Age at diagnosis (breast cancer only)	No
Emery et al. ²²⁻²⁵	Genetic risk assessment in an intranet and decision support (GRAIDS ²)	Breast, ovarian, colorectal, endometrial	Professional; family practice	Web-based tool, form not specified	Yes	1DR, 2DR	Age at diagnosis	Age at death Age at diagnosis	Yes
Fisher et al. ⁵⁴	In-office family history questionnaire	Breast, ovarian	Patient; community mammography clinic	Paper, question flow chart	No	Selected 1DR, 2DR, and 3DR	Age at diagnosis (specify if <50)	Not reported	Yes
Frezzo et al. ⁶¹⁷	In-office family history questionnaire	Breast, prostate, colorectal, ovarian; and other conditions	Patient; internal medicine clinic	Paper, list of questions, some tabular	No	Not specified	Age at diagnosis	Not specified	No
Grover et al. ⁵⁵	Mailed family history questionnaire	Colorectal, stomach, pancreas, breast, ovarian, uterine, brain, bladder, kidney, thyroid	Patient; gastrointestinal cancer clinic	Paper, structured questions	No	1DR, 2DR, 3DR	Not reported	Not reported	No
House et al. ⁶¹⁹	Mailed family history questionnaire	Breast, colorectal, ovarian, prostate, uterine	Patient; family practice	Paper, structured questions	Not reported	1DR	Age at diagnosis location of cancer	Age at diagnosis	No
Hughes et al. ²¹	Mailed family history questionnaire	Breast, ovarian	Patient; Internal medicine clinic	Paper, structured questions	No	1DR, 2DR	Age at diagnosis	Not reported	No
Hurt et al. ⁶⁵⁶	Mailed family history questionnaire	All	Patient (1DR of cancer patients); cancer clinic	Paper, tabular questions	No	1DR, 2DR	Age at diagnosis location of cancer	Age at diagnosis cause of death location of cancer	No

(Continued)

Table 1. continued

Paper	Tool	Cancer(s) and other conditions	Target user and setting	Medium, form of questions	Direct/automated pedigree output	Degree of relatives covered	Details on living affected relatives	Details on deceased relatives	Automatic/direct risk assessment output
Tools developed for primary care population									
Murff et al. ⁵⁹	Mailed family history questionnaire	Breast, ovarian, colorectal	Patient; internal medicine clinic	Paper, tabular questions	No	Selected 1DR, 2DR	Age at diagnosis	Not reported	No
Qureshi et al. ⁶¹	In-office family history questionnaire	All and other conditions	Patient; family practice	Paper, tabular questions	No	1DR Selected 2DR, 3DR	Age at diagnosis	Age at death Cause of death Age at diagnosis	No
Schroy et al. ⁶¹	In-office personal digital assistant application	Colorectal (including adenomas) and other cancers	Professional; internal medicine clinic	Personal digital assistant, question prompts	No	1DR and selected 2DR	Age at diagnosis (cancer specify if <50 or ≥50)	Not specified	Yes
Yang et al. ⁶⁰	Family history questionnaire	Breast, colon, lung and others (excluding skin)	Patient; population survey	Paper, questions with tick boxes	Questions on family tree diagram	Selected 1DR, Selected 2DR	Age at diagnosis	Age at death Cause of death Age at diagnosis	No
Tools applicable to primary care									
Acheson et al. ⁵¹	Genetic Risk Easy Assessment Tool (GREAT)	Breast, colorectal, ovarian, prostate, other cancers	Patient; genetic clinic	Automated structured telephone interview	Yes	1DR, 2DR, first cousins	Age at diagnosis	Age at diagnosis	No
Benjamin et al. ⁵²	Mailed family history questionnaire	Breast, other cancers	Patient; genetic clinic	Paper, structured questions	No	1DR, further extent unclear	Age at diagnosis	Age at diagnosis Cause of death	No
Braithwaite et al. ⁵³	Genetic Risk Assessment in the Clinical Environment (GRACE)	Breast	Patient; genetic clinic	Interactive software, structured pedigree production	No	1DR, selected 2DR, selected 3DR	Age at diagnosis	Not reported	Yes
Kelly et al. ⁵⁸	In-office family history questionnaire	All	Patient; gastrointestinal cancer clinic	Paper, form not specified	No	1DR	Age at diagnosis	Not reported	No
Sweet et al. ⁵⁷	In-office JamesLink software	Breast, colorectal, ovarian, prostate, other cancers	Patient; cancer clinic	Touch-screen computer application, branched-point screens	No	1DR, 2DR, Selected 3DR	Age at diagnosis	Age at diagnosis	Yes

^aActual family history tool available.

1DR, 1st degree relative; 2DR, 2nd degree relative; 3DR, 3rd degree relative.

The highest scoring of these tools for applicability to primary care were the Family History Tool developed by the American Academy of Family Practice⁶² and the US Surgeon General's Family History Initiative.⁶³

Evaluating the family history collection tools

The tools were evaluated using a range of study designs and settings (Table 2). The term "controlled" indicates study design where there are at least two arms, one of which is the tool in question and the other an alternative method of capturing family history data.

Validity and reliability

Six tools (nine publications) were described as having undergone a development or piloting phase.^{16,19,22–25,51,54,58} Five studies assessed acceptability and ease of completion of the tool.^{22,25,51–53} Qualitative techniques were also described to assess face validity in studies of four tools, including semistructured interviews with practitioners^{23,24} and patients,¹⁶ and focus groups with practitioners.^{16,49,50} Three studies reported the length of time needed to complete the tool, ranging from 8⁵⁴ to around 30 minutes.^{51,53} One study, in a genetic clinic setting,⁵¹ reported test-retest reliability of 97% (401/413) for 1DRs, and 93% (620/667) for 2DRs, respectively, and 98% (322/328) for cancers identified.

Outcomes

There were six family history tools (seven publications) without a comparator group or control arm^{19–21,49,50,56,60} and one tool in a controlled study but no comparator to capture family history data.⁵³ These seven descriptive publications comprised two evaluating familial cancer risk assessment,^{56,60} two studies (three publications) only evaluating the content and face validity of the tools,^{49,50,53} and three publications ascertaining the prevalence of respective familial cancer histories.^{19–21} The performance of the 11 remaining tools was assessed in some way against a defined comparator. The tool was given first followed by the alternative "optimal" approach to systematic family history collection in three studies.^{16,52,54} The two cross-over studies did not take place in primary care but determined that the order of completion was not associated with differences in outcomes.^{51,58} For studies where concealment was necessary in qualitative assessment of the tool, only two studies provided evidence that this had been performed.^{16,52} Full quality assessment of the studies is reported elsewhere.¹⁸

Evaluation against an "optimal" genetic interview was undertaken for five tools^{16,51,52,54,58} (Table 2). Two tools were developed for primary care: Fisher compared the primary care interview to a genetic interview,⁵⁴ whereas Qureshi et al.¹⁶ compared a self-completed questionnaire to a structured genetic interview administered by a trained researcher. The three other tools, identified from other settings, compared the tool against clinical genetic interviews in two studies^{51,52} and compared against the identical interview schedule in the third study.⁵⁸ The measures used to evaluate tools against these genetic or structured interviews included: percentage agreement,^{16,51,54} sensitivity, specificity,^{16,52} Kendall's Correlation⁵¹ and Cohen's Kappa analysis.^{16,51} Most of these metrics assumed the alternative interview was the "gold standard" measure. The respective results are included in Table 2. The percentage agreement was for specific attributes of family history, such as number of relatives diagnosed,^{16,51} type of cancers identified,⁵¹ and risk categorization.^{16,51,54} Considering the tools developed for primary care, the percentage agreement on risk stratification varied from 77% (93/121)¹⁶ to 100% (89/89).⁵⁴ This was similar to the

75% (90/120) agreement for a tool used in the genetic setting.⁵¹ Further, in Qureshi,¹⁶ Kappa ranged from 0.10 to 0.70, this corresponding to more 2DRs identified in 51% of interviews (62/121) and more 1DRs in 15% of interviews (18/121). However, in Fisher,⁵⁴ of 45 women classified at population risk by the tool, none were reassigned at higher risk by the genetics interview, and of 45 women classified at elevated risk, none were reclassified as population risk. Similarly, in the clinical genetic setting, the tool developed by Benjamin identified 92%⁶⁴ of the 84 identified at increased cancer risk by genetic interview.⁵²

Evaluation against "current standard" practice was performed for six tools (seven publications^{17,23,24,55,57,59,61}). Four tools were developed for primary care,^{17,23,24,59,61} and the other tools for use in cancer clinics.^{55,57} One of the latter tools has also been adopted for use by the public as a web-based tool (as discussed later).⁵⁷ Current practice included the family history as recorded in patient charts,^{17,55,57,59,61} and accuracy or completeness of pedigrees derived from simulated patient histories drawn without access to a tool.²³ The study findings are displayed in Table 2. In Frezzo et al.,¹⁷ the outcome measure was the percentage agreement for identifying high-risk individuals between the patients' charts and the tool, reporting 78% better identification of significant family histories when the tool was used in an internal medicine clinic. This was compared with a 46% improvement in the cancer clinic setting.⁵⁷ In Frezzo et al.,¹⁷ of 32 patients at increased risk on tool, 18 were identified on patient charts; whereas in the cancer clinic setting,⁵⁷ the corresponding numbers were of 101 patients on tool, 69 were identified on chart. The other cancer clinic study presented concordance rates⁵⁵ and identified that a third of patient charts missed cancers in 1DRs captured by the tool. Emery et al.²³ describe the development of a primary care family history/risk assessment tool with data reported from an evaluation of the prototype (RAGS), in which 36 family physicians used three different methods to draw pedigrees and assess the risk of simulated patients. Pedigrees produced using the RAGS tool were statistically significantly more likely to be accurate than those prepared by a genetics software package (Cyrillic) or by traditional pen and paper methods (median correct pedigrees, 5/6 for RAGS, 3.5/6 for Cyrillic, 2/6 for pen and paper).

DISCUSSION

This review explores the effectiveness of tools for collecting familial cancer history that could be used in a primary care setting. Ideally, patients are able to report accurate information on their family history, assisted by effective tools, and health care providers are able to use the information to make beneficial preventive and clinical management decisions. The review identified a number of family history collection tools developed for use in a primary care setting, most of which had not been evaluated against "optimal" or standard primary care practice.

Because of the limited number of studies, the evaluation of family history tools was extended to relevant tools in nonprimary care settings. Sixty-one percent of the tools (11/18) were evaluated against current practice. There was reasonable agreement between the tools and measures of optimal or gold standard; however, there was limited consistency between studies on the standard chosen. A gold standard in clinical practice may be considered the pedigree-drawing interview performed by a genetic specialist, whereas in two of the identified studies, structured interviews administered by nonspecialists were used as surrogate approaches to the genetic interview.^{16,58} If we are

Table 2. Studies to evaluate family history tools

Study	Cancer and other conditions	Study design (controlled)	Setting	Family history tool	Comparator	Subjects recruited	Results	Study limitation
Alternative “optimal” comparator in primary care population								
Fisher et al., ⁵⁴ Australia	Breast, ovarian	Cross-sectional Survey	Breast-screening clinic	Personal interview	Interview with genetic specialist	89	Agreement on risk categories = 100% (89/89)	In 5% of participants errors in completing FHQ and excluded from analysis. Tool completed before optimal interview. Only included English speaking and women attending for rescreening
Qureshi et al., ¹⁶ UK	Any type	Cross-sectional Survey	Family practice	Self-completed family history questionnaire	Structured genetic interview by trained researchers	121	(a) ≥One 1DR relatives with Ca <60 kappa: 0.7 (95% CI: 0.5–0.9); % agreement: 92% (111/121). (b) One + 2DR relatives with cancer <60 Kappa: 0.1 (95% CI, 0.0–0.3); % agreement: 80% (97/121). (c) Risk categories for all conditions. Kappa: 0.52 (95% CI: 0.4–0.64); % agreement: 77% (93/121)	Tool completed before optimal interview
Alternative “optimal” comparator in other settings								
Acheson et al., ⁵¹ USA	Breast, ovarian, colorectal, prostate and 20 other types of cancer	Crossover study (First 8 mo of study, tool given 1st; second half of study tool given 2nd)	Genetic clinic	Automated family history telephone interviews	Interview with genetic specialist	120	(a) Agreement on breast cancer risk categories: kappa = 0.7; 81% (94/116). (b) Agreement on colon cancer risk categories: kappa = 0.5; 88% (102/116). (c) % of relatives recognized (tool vs. interview) 1DR 98.5 v 97.3 (<i>P</i> >0.05) [Total 1DR = 837] 2DR 94 v 74 (<i>P</i> <0.001) [Total 2DR = 1317]	27% of participants cancer genetics referrals, 93% of adult participants women, mean completion time = 34 min (range 8–55 min)
Benjamin et al., ⁵² UK	Breast, other cancers	Prospective cohort	Genetic clinic	Self-completed family questionnaire	Interview with genetic specialist	149	Compared to interviews’ risk categories: Sensitivity = 95% (75/78) [95% CI 89–99%] Specificity = 96% (23/24) [95% CI 79–100%]	Tool completed before optimal interview
Kelly et al., ⁵⁸ USA	Any type	RCT crossover study (controlled)	GI Cancer clinic	Self-completed family questionnaire	Structured genetic interview	96	No discrepant data between methods for affected and unaffected relatives	All participants were cancer patients. Interview and questionnaire identical and completed at same visit
Current “Standard” practice comparator								
Emery et al., ²³ UK	Breast	RCT with simulated cases (controlled)	Family practice	Software family history tool (RAG)	Pedigrees drawn with 1. pen and paper 2. electronic software	36	Median no. correct pedigrees RAGS—5.0/6, pen and paper—2.0/6, electronic—3.5/6 <i>P</i> <0.0001	

(Continued)

Table 2. continued

Study	Cancer and other conditions	Study design (controlled)	Setting	Family history tool	Comparator	Subjects recruited	Results	Study limitation
Current "Standard" practice comparator								
Frezzo et al., ¹⁷ USA	Breast, ovarian, colorectal, prostate, other conditions	Quasi RCT (controlled)	Internal medicine	Self-completed family history questionnaire	Patients' medical charts	39	No. at risk based on FHx. Tool vs. charts (a) breast/ovarian 2 vs. 0 and (b) colorectal 3 Vs 1	
Murff et al., ⁵⁹ USA	Breast, ovarian, colorectal	Cross-sectional survey	Internal medicine	Family history questionnaire	Patients' medical charts	310	IDR with cancer tool vs. chart: No. with breast 32 vs. 32, no. with ovarian 6 vs. 4, no. with colorectal 19 vs. 11, % with age of diagnosis noted 95% tool vs. 62% chart ($P < 0.0001$), 2DR with cancer tool vs. chart: no. with Breast 102 vs. 41, no. with ovarian 14 vs. 5, no. with colorectal 79 vs. 31, % with age of diagnosis noted 76% tool vs. 27% chart ($P < 0.0001$)	Response rate 30%
Schroy et al., ⁶¹ USA	Colorectal, other cancers	Cluster RCT (Controlled)	Internal medicine	Physician administered electronic questionnaire	Patients' medical charts	At exit interview: Doctors: tool 33, control 38. Patients: tool 51, control 69	% patients report physician ask about FHx of: (a) cancer: tool 33% (17/51) vs. control 25% (22/69) $P = 0.30$ (b) adenoma: tool 24% (12/51) vs. control 25% (17/69) $P = 0.89$	The study had low statistical power to detect small to medium effects. Residents supplied with the tool received extra educational intervention compared with controls
Grover et al., ⁵⁵ et al	Colorectal, other cancers	Cohort study	GI Cancer clinic	Self-completed family questionnaire	Patients' medical charts	387	Concordance of charts with tool (a) All relatives' cancer = 67% (258/387) (b) IDR or 2DR with cancer 59% (184/311)	
Sweet et al., ⁵⁷ USA	Breast, ovarian, prostate, colorectal, other cancers	Cross-sectional survey	Cancer clinic	Electronic	Patients' medical charts	362	Of 362 patients captured FHx by tools, only 308 (85%) FHx in charts	Highly selected population (362 ambulatory cancer patients)

IDR, 1st degree relative; 2DR, 2nd degree relative; 3DR, 3rd degree relative; FHx, family history; GI, gastrointestinal; No., number; RAG, risk assessment in genetics; RCT, randomized controlled trial.

evaluating the PCPs ability to emulate the standard of the genetic specialist pedigree-drawing interview then we have to read the findings of these studies with caution. However, as discussed later, this may not always be the role of the primary care tool. When compared with current standard practice, primary care tools identified significantly more relatives with cancer. Although only limited to a few studies, comparing tools with family history in patients' charts, the improvement in recording of family history was greater for the primary care tool than those administered in specialist cancer settings.^{17,55,57} In some cases, this would lead to reassignment of risk category and altered prevention plans. The clinical significance and added benefit of this information still needs to be explored.

The tools identified in this review varied considerably, from those which took a comprehensive approach, emulating the geneticist's pedigree-drawing interview, to those which focused on identifying selected cancers in specific relatives. With the limited studies available, it was not possible to compare the utility of tools designed to collect family history on single cancers to those that identified several conditions. Many tools were designed to be used in the physician's office, in paper based or electronic format. It has been suggested that other formats, such as web based or mailed surveys, allow patients to (potentially) take "ownership" of their family history, offer them the opportunity to gather information from relatives, and may make for better use of PCP time.^{16,22,25,51,52,54,59} Several organizations have set up similar web-based tools for public use.^{57,65–69} It is unfortunate that in 10 of the 11 applicable web-based tools, no published information on their development or evaluation was available. Of these, the tools developed by the American Academy of Family Practice⁶² and the US Surgeon General's Family History Initiative⁶³ scored highest on assessment of applicability to primary care. These may potentially be the type of tools that will be used by those providers with electronic medical records.

The acceptability and ease of completion of family history tools were assessed in only a few studies. These aspects of the tools' content and face validity should be an integral part of evaluating any future primary care tools. Pedigrees are the standard clinical genetic approach to present family history information; however, tabular format and lists may also be appropriate in the primary care setting, particularly in settings using electronic medical records.^{16,57}

Accurate risk assessment generally requires information on the side of the family (maternal, paternal, or both) to which relatives with cancer belong, and most tools identified this. Further, ethnicity (an indication of ancestry⁷⁰) may be associated with increased risk of particular cancers, but few tools were designed to capture such data on ethnicity. We suggest that, in future tool development studies, it might not be necessary to replicate the extent or type of data captured in a clinical genetics setting. Further, it would be useful to distinguish between two different purposes for tools—assembly and updating of "complete" family history information in a generic approach, and ascertainment of targeted information for specific disease risk assessment. For the latter, an "adequate" family history requires not only identifying relatives with and without the cancer but also the relationship of the affected relative, the age of onset of cancer in those affected, and identification of several cancer types beyond the "target" cancer in question (e.g., family history of endometrial and kidney cancer is relevant in considering risk for hereditary nonpolyposis colorectal cancer). Further, it may be logical to evaluate the performance of such tools as part of a disease-specific risk assessment tool, rather than as a stand-alone tool.

Considering the former generic use of these tools (where a specific condition is not being targeted), approaches to the tool's rational development would benefit from agreement on the "minimum family history dataset," bearing in mind that the goal in this primary care setting is usually to identify an index of suspicion for genetic predisposition, leading to more targeted enquiries if a possible familial cancer risk is identified. Based on the few studies identified in the review, it is not possible to recommend any specific family history tool. Further, choice will depend on purpose of the tool, patients' and providers' computer access, and personal preference. However, at the very least, family history information should include both sides of the family, all 1DRs, ethnicity and age of diagnosis of affected relatives. Table 3 lists some of the elements, which could be considered for inclusion in a more comprehensive dataset. It is presented to foster consensus about the extent of family history enquiry necessary for different clinical purposes and circumstances, taking into account the likelihood of accuracy of self-reported information for different relatives.⁷¹ For instance, although some authors have suggested that a minimum family history should cover three generations,^{3,71,72} the reliability of information beyond 1DRs and grandparents is not well evaluated and would suggest decreased accuracy.^{35,46,47,73,74}

Further, family histories are not static^{16,54}; however, practical issues of updating family history have not been explored. On the one hand, PCPs may be able to assemble a patient's family history information over time, but on the other, necessary updates consume time and resources. Acheson et al.² has reported that most family histories were completed on the first visit. It would be worth considering formally whether a staged approach over several visits leads to more accurate or extensive information, and clarifying the optimum interval for updates. Barriers to the use of tools in practice also need considering. These include lack of time,⁷⁵ lack of PCPs' confidence in their knowledge and skills in genetics,⁷⁶ and reimbursement policies.³

It seems logical that family history tools are likely to produce most benefit if they are accompanied by risk assessment and management plans for patients at increased risk of familial cancer; otherwise, family history collection by PCPs and/or consumers may be wasteful of time, energy, health care resources, and may even be harmful. Although some guidelines⁷⁷ recommend that family history information should only be collected in response to patient enquiry about familial breast cancer risk or if the provider suspects increased cancer risk, others argue that family history collection is an integral part of good clinical practice in primary care and that failure to do so should be considered negligence.^{57,58,71}

In addition to using several web-based search engines, our search of relevant gray literature was constrained to sites specified by the investigators, our technical expert panel, and peer reviewers. Further, the studies reviewed in this report were limited to those published in English. However, our peer-review process allowed content experts in this area to identify any additional studies (both published and unpublished) of relevance for this systematic review thereby minimizing the likelihood of publication bias. Language bias also limited the ability to interpret non-English tools; however, this had a minimal impact on the studies described and evaluated. Our criteria for defining applicability to primary care were developed within our investigative team and have not been subject to external scrutiny. Further, the interpretation of the studies retrieved is limited because no study confirmed the family history collected by the tools with the relatives' actual medical histories.

Future tool development needs to integrate with other clinical and office systems, and consider contextual factors which might

Table 3. Potential Items for Inclusion in a Family History Dataset for a Generic Family History Tool**(a) Relatives on whom data may be captured**

Degree of relatedness	Relationship
	Informant ^a
	Spouse/partner ^b
First degree blood relatives	Mother, father
	Brothers, sisters
	Sons, daughters
Second degree blood relatives	Grandparents (both sides)
	Aunts and uncles (both sides)
	Half-brothers and half-sisters
	Grandchildren
Third degree blood relatives	Cousins (both sides)
	Nephews and nieces (both sides)

(b) Items of information that may be captured

Individual	Item
Informant/patient	Age or date of birth
	History of cancer, for each:
	Age at diagnosis
	Specific information (e.g., bilaterality)
	History of other relevant medical conditions (depending on cancer)
	Results of relevant investigations, including genetic tests
	Ethnicity or ancestry:
	Self-identified ethnic group
	Ethnic group of grandparents
Relatives	History of cancer, for each:
	Age at diagnosis
	Specific information (e.g., bilaterality)
	Source/certainty of information
	History of other relevant medical conditions (depending on cancer)
	History of relevant investigations, including genetic tests
Living relatives	Current age or date of birth
Deceased relatives	Age at death
	Source of information
	Certainty of information
	Cause of death
	Source of information
	Certainty of information

^aPersonal medical history important in risk assessment.^bMay be relevant in respect of environmental and lifestyle/behavioral aspects of risk assessment.

moderate their effect, and their marginal benefit in practice. The latter includes research to identify the specific strategies (e.g., sending tools home with patients) and tool features, which promote the most accurate reporting of family history information. Further, studies to evaluate tools should consider the benefits, costs, and harms of using patient-completed tools for systematic family history collection, as a substitute for, or complement to, tools designed for completion by health care providers. In addition to assessing technical outcomes such as accuracy and completeness of data captured, evaluations should consider outcomes, which relate to utility in routine practice, such as patient “empowerment.” In designing these studies, researchers should also adopt appropriate comparators (generally current practice) and ensure that tools are optimized (in terms of, for example, face and content validity) before evaluation.

In summary, family history is a fundamental element of health information, and the ability to take an adequate and accurate cancer family history should be recognized as a core skill for all PCPs, irrespective of the availability of tools. Very few tools have been developed for, and evaluated in, primary care settings. Further, few tools have been compared with either gold standard (genetic interview) or current primary care “standard practice” (family history as recorded in charts). Although the evidence is very limited, and depends on extrapolation from studies of tools in settings other than primary care, it suggests that systematic tools may add significant family health information compared with current primary care practice.

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