Collection and use of cancer family history in primary care

CRD summary
The authors concluded that accuracy of cancer family history reporting varied with cancer type, data collection method and cancer status. Family history tools performed well against current practice, but there was insufficient evidence about risk assessment tools. The authors’ cautious conclusions appeared to be appropriate given the evidence presented and are likely to be reliable.

Authors’ objectives
To evaluate the accuracy of patient reporting of cancer family history, the effectiveness of tools for collecting and using familial cancer history in a primary care setting and assessing their efficacy in promoting recommended actions.

Searching
MEDLINE, EMBASE, CINAHL and Cochrane Central Register of Controlled Trials were searched from 1990 to July 2007. Search terms were reported. Relevant grey literature was searched. References of eligible articles were scanned for additional references. Only studies in English were eligible for inclusion.

Study selection
Studies of any design were eligible for inclusion if they evaluated: accuracy of family history reporting of the cancer status of relatives (tools had to include at least one of breast, ovarian, prostate or colorectal cancer and not present aggregated data with non-eligible cancers); family cancer history tools designed to improve data collection; and risk assessment tools (defined as a knowledge resource using family cancer history to generate specific advice and support decision making). Studies had to evaluate interventions that were applicable to primary care settings. Primary care included family physicians, general practitioners, general internists, obstetricians, gynecologists, nurses, nurse practitioners, physician assistants, nutritionists and behaviour counsellors. Eligible studies had to include participants aged over 18 years to be included.

Included studies had the following characteristics:

1. Studies that evaluating the accuracy of family history that reported verified cancer status of relatives or the repeatability/reliability of reported information. Most participants had had cancer. The review assessed sensitivity and specificity.
2. Most studies of family history tools (FHxTs) were designed to be completed by patients and most were used for people with a family history of breast or breast/ovarian cancer. Some were designed for a general or target population irrespective of cancer risk and others for people with a familial risk of cancer. Most used a paper-based data collection format. Some studies compared tools with a generic interview or standard practice.
3. Studies that evaluated risk assessment tools (RATs) assessed the distribution of patients across risk strata compared with an independent standard. Each tool included a knowledge element. Tools were presented in a computer-, web- or document-based format.

Studies used different methods to collect data and verify cancer status (details were reported).

Two reviewers independently assessed studies for inclusion. Disagreements were resolved by discussion or through consultation with another reviewer.

Assessment of study quality
Validity was assessed using published criteria: QUADAS was used for the evaluation of accuracy studies; the Jadad scale was used for randomised controlled trials (RCTs); and the Downs and Black quality assessment tool was used for observational studies. Other study designs were evaluated qualitatively using a checklist.

Validity was assessed by one reviewer and checked for accuracy by a second reviewer.
**Data extraction**
Where data were available, sensitivities and specificities were calculated together with 95% confidence intervals (CI) for each individual study. One reviewer abstracted data onto a standardised form. Data extraction was checked for accuracy by a second reviewer. Disagreements were resolved by discussion or through consultation with another reviewer.

**Methods of synthesis**
The studies were combined in a narrative synthesis accompanied by tables. Outcome data from family history tools were reported separately for tools compared with best estimate and tools compared with current practice comparators. Outcome data on risk assessment tools were reported descriptively. Differences between studies were discussed.

**Results of the review**
A total of 56 studies were included (accuracy n=19, family history tools n=18 and risk assessment tools n=10). Only a subset of papers of traditional study design with control groups were assessed using the standard validity assessment scales. There was evidence of potential for spectrum bias in eight studies and evidence of verification bias in seven studies among those that evaluated the accuracy of family history reporting. Overall blinding of status of relative or informant was not undertaken in most studies. Most studies were of moderate quality. One case control study was excluded from assessment due to evaluation on the basis of reporting relatives with cancer rather than their cancer status.

1. **Accuracy of family history reporting** (19 studies reported in 20 publications): Studies that verified the cancer status of relatives reported as affected and unaffected. Specificity was generally high (91% to 99%) and ranged from 95% to 98% for breast cancer, 91% to 92% for colorectal cancer, 96% to 99% for ovarian cancer and 93% to 99% for prostate cancer. Sensitivity was lower and varied. It ranged from 85% to 90% for breast cancer, 57% to 90% for colorectal cancer, 67% to 83% for ovarian cancer and 69% to 79% for prostate cancer.

2. **Family history tools designed to improve data collection for primary care professionals** (18 tools reported in 22 publications): Few studies reported outcomes relevant to professional practice or patient outcomes. In general, family history tools appeared to identify more relatives, more relatives with cancer and more details about these relatives than standard practice.

3. **Studies that evaluated risk assessment tools** (10 tools reported in 16 publications): Results from controlled trials that evaluated three different risk assessment tools were mixed. Two risk assessment tools were associated with success in compliance to referral criteria (reported in three papers), but a subsequent study of one risk assessment tool showed no significant difference in the identification of patients at increased risk between tool and genetic specialist. Another study showed no significant difference between risk assessment tools and usual care in physician's confidence and patients' perception of risk.

**Authors' conclusions**
Accuracy of cancer family history reporting appeared to be dependent on cancer type and method of collection. Accurate reporting of absence of cancer (specificity) appeared to be greater than accurate reporting of presence of cancer (sensitivity). Generalisability was limited. Reporting accuracy varied among different cancer types. Family history tools that were identified performed well against both best and standard clinical practice. Evidence was lacking for the effectiveness in promoting recommended clinical actions of risk assessment tools designed for the primary care setting.

**CRD commentary**
The review question was clear and supported by detailed inclusion and exclusion criteria. Some relevant sources were searched and some attempts were made to locate unpublished studies. Limiting included studies to those in English meant that some relevant studies may have been missed. Methods were used to minimise reviewer errors and bias in the selection of studies, extraction of data, and validity assessment.

Validity was assessed using established checklists for only a subset of the included studies. Some qualitative assessment
was made of studies of less traditional designs, but this was only partially reported. Characteristics of the included studies were presented in tables. Details of individual study designs were not presented, which made it difficult for the reader to judge the quality of the studies. The tools identified in the review varied considerably. A narrative synthesis was appropriate due to the differences between the included studies.

The authors’ cautious conclusions appeared appropriate given the evidence presented and are likely to be reliable.

**Implications of the review for practice and research**

**Practice:** The authors stated that an adequate and accurate family history should be recognised as a core skill for all primary care providers. Until there was a clear evidence base a minimum adequate cancer family history should include information on siblings, parents and grandparents, specific enquiry as to whether other relatives had cancer and the ethnicity of the respondent. Age of diagnosis and other relatives with similar or related conditions should also be recorded when cancer was identified.

**Research:** The authors stated that further research was needed to evaluate the benefits, costs and harms of using patient-completed tools for systematic collection of family history instead of or as a complement to professional tools. Future research should consider accuracy, completeness of data captured, outcomes related to patient empowerment and the use of practitioner and health care resources. Additional research was needed to identify specific strategies and tools that promoted the greatest accuracy of reporting of family history and the optimal interval for updating patient family history information in a primary care setting. Further evaluation of family history tools and risk assessment tools in routine clinical settings and practice should adopt appropriate comparators, ensure tools are optimised, measure outcomes relative to utility in routine practice and outcomes that provide information on potential costs, harms and benefits as well as address and explore contextual factors such as practice infrastructure and time available.

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