

Efficacy of a touchscreen computer based family cancer history questionnaire and subsequent cancer risk assessment

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Abstract

Objective—A computer based touchscreen family cancer history questionnaire was developed and implemented to facilitate the provision of cancer risk assessments for the ambulatory and out-patient populations of a free standing cancer hospital.

Methods—A questionnaire consisting of a series of branched point decision making screens was developed which enables the participant to enter demographic data, personal cancer history, and cancer histories for first and second degree relatives. A freestanding touchscreen computer kiosk system was used to place the questionnaire in public areas of the cancer hospital and clinic. Genetic professionals analysed the data received, using published criteria, and provided a basic cancer risk assessment and surveillance recommendations within 10 business days. A survey was completed by a small random group of users (n=59) three to six months after receipt of their risk assessment.

Results—After 11 months, 1440 people had entered information and received a written communication. Only 2% of completed questionnaires contained insufficient information to provide a basic risk assessment. Of the small group of participants surveyed, almost all (95%) felt “very comfortable” using the system, 93% remembered receiving the risk assessment letter when queried three to six months later, 42% felt their perceptions about cancer risk had changed, and 20% had made changes in their or their family’s cancer surveillance practices.

Conclusion—The touchscreen computer family history questionnaire allows easy collection of family history information, provision of risk assessments to a broad population, and promotes increased awareness of familial risk and appropriate surveillance.

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Keywords: genetic counselling; risk assessment; computers; medical informatics

The development of the field of clinical cancer genetics has created a new mode of cancer prevention through assessment of hereditary cancer risk and the provision of genetic counselling and any appropriate predictive testing for

families affected by cancer. At a minimum, cancer risk counselling necessitates a multigenerational family history, knowledge of hereditary cancer predisposition syndromes, and Mendelian risk calculations. Lifestyle and environmental factors are also important but, at present, are much more difficult to use to provide a quantitative risk. The interaction of genetic and environmental factors is just beginning to be elucidated.

Although the acquisition of a family history has always been a part of the standard protocol for the medical history, the information is often recorded as “family history positive” or “family history negative” with no further delineation.¹ Since the 1970s, however, the notation of “positive family history for cancer” has more clinical importance since the revelation that 5–10% of cancers show evidence of familial clustering suggestive of hereditary cancer predisposition of a Mendelian nature. With identification in the 1990s of specific genes causing cancer predisposition syndromes, the consequences of an incomplete family history are even greater. A thorough family cancer history, including specific information about the nature of relatedness (parent, child, sib, grandchild, grandparents, aunts, uncles, nieces, and nephews), type of cancer, and age of onset, became relevant for both the primary care physician and oncologist. Screening recommendations for at risk families are being developed and practitioners have an obligation to provide available recommendations to appropriate people.^{2,3}

The time honoured method of family history acquisition is a face to face interview. Genetic professionals typically require 15 to 30 minutes to transcribe detailed information about each family member in a three to four generation pedigree. The busy oncologist or primary care physician does not have the time or trained personnel in the office to acquire the necessary or requisite information. Telephone interviews decrease the time required in the office setting but still require personnel time to perform. An automated telephone system has been used to acquire information needed to perform breast cancer risk assessment.⁴ A limited family history (limited to first degree relatives with breast cancer) was taken as part of the survey.

Paper questionnaires have also been used, eliminating the need for personnel to take the information but still requiring interpretation, either by hand or computer scanning. Many physicians who use a paper family history questionnaire place it into the patient medical

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record without adequate assessment of details. One study looked at the use of a paper questionnaire with and without the assistance of a study assistant.⁵ Only a small number of families were affected by missing or incorrect data when the family history questionnaire was completed without help. While 94% of the family history questionnaires required changes or additional information on review by the study assistant, only 4% were altered enough that the risk categorisation changed. All high risk families remained in the high risk category.

Self administered computer questionnaires have been used effectively to take medical and behavioural histories. Studies have confirmed acceptance in users from adolescents⁶ to women between the ages of 50 and 70.⁷ Using computers as a permanent fixture within a medical practice can help address barriers to prevention, including lack of time, forgetfulness, and difficulty raising prevention issues with patients. No studies are available that specifically address the use of computers and family cancer history acquisition.

The authors have developed a touchscreen computer program in a freestanding kiosk structure for self-reported family history data acquisition.

Methods

KIOSK

The kiosk system consists of a freestanding, wood and laminate cabinet, completely containing the PC on which the data collection software resides. A 17" Elo touchscreen monitor is mounted by its frame (without its case) into the upper portion of the cabinet, with the CPU box and printer below. The current system includes a Pentium 233 MHZ MMX processor, tower case, 64 Mg RAM, 6.4 Gg hard drive, 4 Mg video card, 32X CD-ROM drive, network card, plus standard speakers, keyboard, and mouse. The keyboard and

mouse are included for administration purposes; these components are not used in the process of data collection and are not visible in any way to a person entering data from the kiosk. The system is incorporated in the hospital local area network (LAN) to simplify administration of the database. The kiosk's operating system is Windows NT 4.0. Guardian Angel, a remote rebooting application, is also installed. The system includes Internet Explorer 5.0 as much of the touchscreen technology incorporates significant portions of the Explorer browser for its functionality.

System security is well controlled. The computer portion of the kiosk system is contained entirely within the physical cabinet and locked. Keyboard and mouse are neither visible nor available to the person entering the family history. Touchscreens can only be used to enter information into the database. The PC's operating system and all files are inaccessible to the user; no files or other computers within the hospital network can be accessed via this PC. No-one can dial into the machine from the outside via a modem. All data and program files on the server and kiosk are only accessible by the Network Administrator and the Database Administrator. All data collected are entered and maintained in an Access® relational database. The database is encrypted and password protected; security levels within the database and network are set such that only the two administrators may make any changes to the database or its data.

A single kiosk was initially placed in the registration area of the surgical oncology outpatient clinic. A second kiosk was placed in the registration area of the breast specific outpatient clinic approximately seven months later. Eight months after initiating the programme, the original kiosk was moved from the surgical oncology area to the main lobby of the

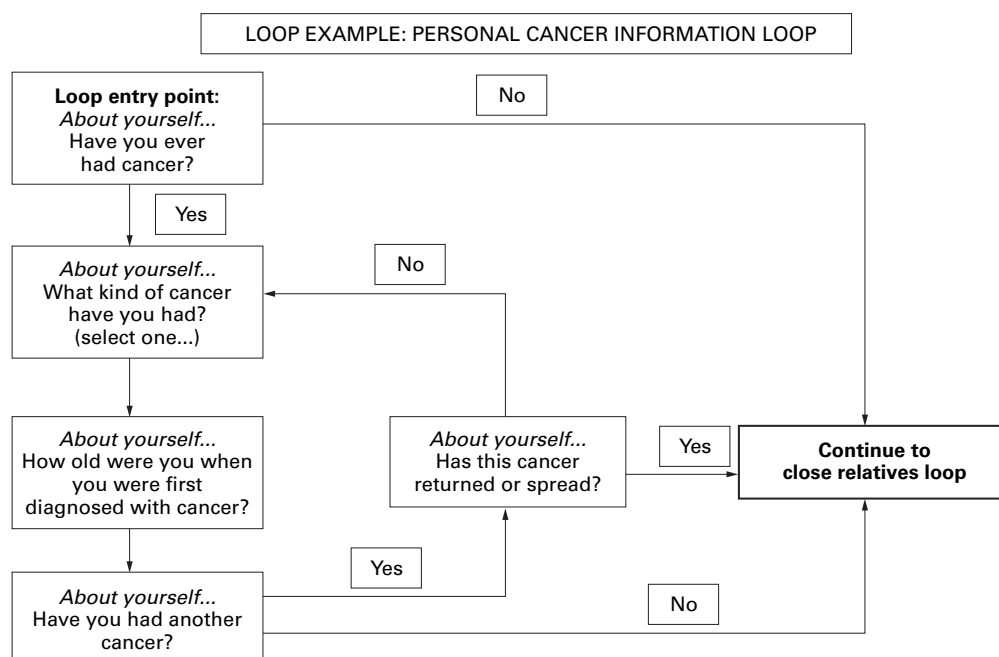


Figure 1 Decision tree for personal cancer history.



Figure 2 Entry of demographic information.



Figure 3 Example of screen design.



Figure 4 Example of screen design.

cancer hospital. Use of the kiosk is entirely voluntary.

QUESTIONNAIRE

The family history questionnaire consists of a series of introductory screens followed by branched point decision making screens that lead the person through the questionnaire. The branches of the decision tree mimic face to face counselling and are what distinguish interactive media from a paper questionnaire. The participant is asked for consent for the Clinical Cancer Genetics staff to evaluate the questionnaire. If consent is not given, the program ends. If consent is given, the participant is asked to enter name and mailing address in order to receive a cancer risk assessment letter specifically tailored to his/her family history. The user is then asked to enter demographic information, the number of first degree relatives alive and dead, and family heritage. Three decision making loops follow. The first loop invites the person to enter any personal cancer history data including cancer type, age at diagnosis, and additional cancers. A schematic of a decision tree is shown in fig 1.

The loop is repeated until all cancer occurrences have been recorded. After completion of the personal loop, the person proceeds to a loop seeking information about first degree relatives (parents, sibs, and children). If a first degree relative has had cancer, the person proceeds to a loop similar to the personal cancer history loop and enters information. If no cancer has been diagnosed in first degree relatives, or when the cancer history is completed for all first degree relatives, the person proceeds to a cancer history loop for second degree relatives (grandparents, aunts, uncles, grandchildren, nieces, and nephews). The presence of multiple primary cancers is ascertained for each person; metastatic cancers are explained as not being relevant to the risk assessment. Examples of screen design are shown in figs 2-7.

Twenty seven types of cancer are available for selection by the participant. Cancers are arranged in three groupings, most common to least common. Users may also select unknown type or enter a specific cancer using a keyboard screen. Cancer groups are shown in table 1. At the conclusion of the questionnaire, the participant is asked to provide a telephone number if he/she wishes to be available for a follow up telephone survey.

RISK ASSESSMENT AND COMMUNICATION

Through an extensive review of published reports, a list of cancer predisposition syndromes and their diagnostic criteria was compiled. These risk assessment criteria were used to identify patients at increased risk for cancer based upon their family history.

The hereditary cancer syndromes were divided into a gradient of risk for the risk assessment criteria. The highest risk group was defined conservatively following the published criteria (Amsterdam criteria for hereditary non-polyposis colorectal cancer).⁸ Families meeting these criteria received a recommendation to have genetic counselling as well as

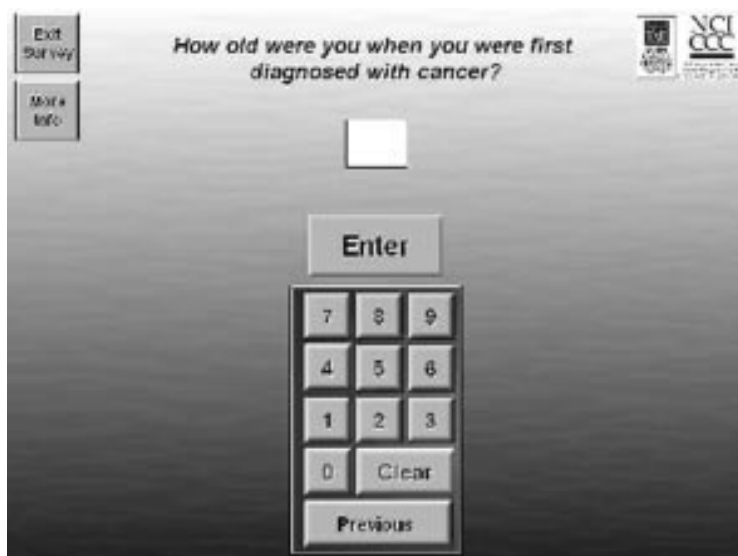


Figure 5 Example of screen design.

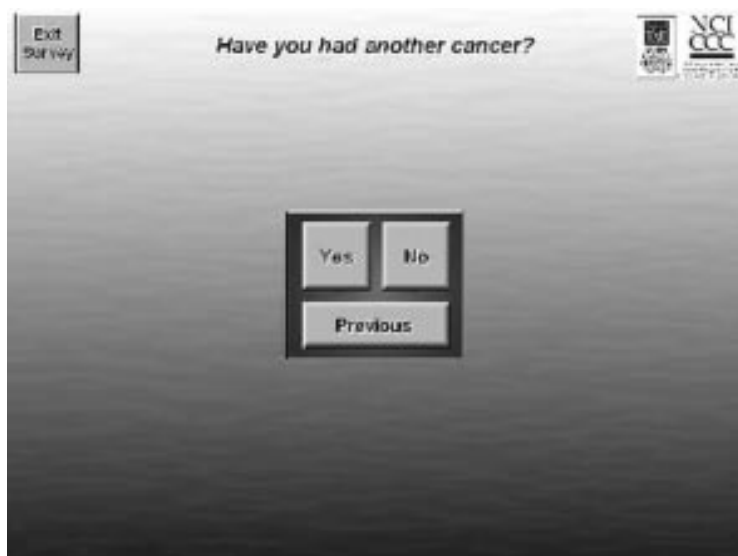


Figure 6 Example of screen design.



Figure 7 Example of screen design.

Table 1 Cancers included in questionnaire: group 1 (most common) to group 3 (least common)

Group 1	Group 2	Group 3
Bladder	Brain	Adrenal
Breast	Cervix	Multiple myeloma
Colon/rectum	Oesophageal	Parathyroid
Hodgkin's disease	Kidney	Retinoblastoma
Leukaemia	Melanoma	Wilms tumour
Lung	Mouth/throat	
Non-Hodgkin's lymphoma	Other skin	
Ovarian	Sarcoma	
Pancreas	Stomach	
Prostate	Testicular	
Uterine/endometrial	Thyroid	

screening recommendations. In addition, these criteria were relaxed for the purposes of wide scale screening. For example, people meeting Bethesda guidelines for HNPCC⁹ also received a recommendation to have genetic counselling.

Those families with a significant cancer history that did not meet the specific diagnostic criteria for a hereditary cancer syndrome were classified as a "familial" risk necessitating increased screening. The occurrence of one or two cases of certain cancers (colon, breast, ovarian, melanoma, prostate, and thyroid) in a family can increase the risk for certain family members to such a degree that individualised screening is recommended. People with first degree relatives affected with cancer before a certain age may be placed in this category. This category also includes people with a relative risk of 2.0 or greater for the development of any cancer.

A genetic counsellor or clinical geneticist or both evaluated each questionnaire. Participants received a tailored risk assessment communication within 10 business days of completion of the questionnaire. Each letter was tailored to include fields such as participant's name, gender appropriate pronouns, specific cancer found in family, relatedness of affected family members, and screening recommendations appropriate to the reported cancer(s). The information on screening and surveillance was appropriate for the level of risk assigned to the participant. No specific risk percentages were reported to the user.

RANDOM USER SURVEY

People who had completed the questionnaire between June and August 1999 and who had consented at the time of the questionnaire to be contacted by telephone (n=207) were asked to participate in a telephone survey in October 1999, three to six months after receipt of their familial cancer risk assessment. Of the 1440 total participants, 51% voluntarily agreed to subsequent telephone contact. Among the 207 in the three month study period, 140 (68%) were unable to be reached by telephone; 109 did not answer or repeatedly had busy connections and 31 did not return messages left on answering machines. Of the 67 people spoken to by a research assistant, eight (4%) declined to participate in the survey and 59 (29%) completed a brief telephone survey.

The risk assessment categories assigned to members of the random user group who completed the follow up survey were similar to the

Table 2 Distribution of risk in first year of operation

Location	Total No of risk assessments	General population risk (%)	Familial cancer or affected first degree relative (%)	Hereditary cancer syndrome (HCS) (%)	Early onset/not clearly HCS (%)	Insufficient history to assess (%)
Cancer hospital lobby	259	163 (62.9)	48 (18.5)	17 (6.6)	4 (1.5)	27 (10.4)
Breast specific outpatient clinic	625	371 (59.4)	82 (13.1)	65 (10.4)	36 (5.8)	72 (11.5)
General surgical oncology outpatient clinic	556	308 (55.4)	111 (20.0)	72 (12.9)	1 (0.2)	62 (11.2)
Total	1440	842 (58.5)	241 (16.7)	154 (10.7)	41 (2.8)	161 (11.2)

proportions noted in the larger study (table 2): 39 (66%) general population risk, eight (13.5%) familial cancer, five (8.5%) hereditary risk, four (7%) early onset, and three (5%) insufficient history to assess.

Results

The distribution of cancer risk categories obtained from the first year of use is summarised in table 2. The average time for completion of the questionnaire was 4.5 minutes. The majority of people completing the questionnaire were either patients (30.8%) or relatives of a patient (40.7%). Jewish heritage was identified in 4.0% of users and was defined as having one or both parents of Jewish origin. The kiosk located in the breast specific clinic had a 71% female user population. The kiosk in the other areas had 59% female users.

Only 11% of the 1440 questionnaires contained insufficient information to complete a basic risk assessment. The majority of these (82.3%) were because the person left the kiosk before completion of the questionnaire. It is not possible to determine whether the reason for walking away was a summons to the examination room by the staff, lack of interest in the questionnaire, or difficulty operating the system. Only 29 people (2% of 1440) with completed questionnaires, therefore, provided insufficient information to provide a risk assessment. Each was sent a letter requesting additional historical information in order to complete the risk assessment.

Each participant whose risk was felt to be consistent with a hereditary cancer syndrome (154 of 1440) received a letter recommending that they receive genetic counselling. In the 11 month study period, only four participants subsequently scheduled an appointment. Two additional participants had received full genetic counselling before their completion of the touchscreen questionnaire. The time from receipt of risk assessment letter to request for appointment ranged from one to six months. Concern about health care insurance was given as the reason for the delay.

The random user survey group data indicated that 95% (56 of 59) felt "very comfortable" using the system and 93% (55/59) remembered receiving the risk assessment letter. When asked to recall the familial risk level for cancer given in the letter, 28 (47%) stated a risk equal to the general population, 12 (20%) an increased risk, and one (2%) a hereditary cancer syndrome risk. Two people contacted as part of the survey had received letters requesting more information; one ex-

pressed resentment that more information was needed and felt that enough had been provided. Sixteen (27%) did not remember the level of risk assessed. One of these had been suspected of having a hereditary cancer syndrome on the basis of his/her questionnaire.

The user telephone survey also asked if they thought any differently about their cancer risk. Twenty five (42%) felt that their perceptions had changed. Changed perceptions included relief among those given the same risk as the general population, heightened anxiety among those given an increased risk, concern about family members in all risk groups, and a need for improved or continued screening in all risk groups. Two people in the lowest risk group expressed disbelief at their lower assessment and stated that they continued to believe that their risk was greater than that assigned.

Users were asked if they had done anything differently about cancer screening since receiving the risk assessment. Twelve (20%) stated that they had made changes. These included making appointments with health care providers, increasing the frequency of health provider visits, notifying family members of a need for increased surveillance, talking to family members about lifestyle modification (smoking cessation), and participating in a research study. One person in the "familial" risk group stated that she had not taken time to pay attention to her results and a second stated that he/she would do nothing different about their screening because they were "still young".

Discussion

Users uniformly felt comfortable providing family history data through a touchscreen computer questionnaire. This confirms previous investigators' reports of the acceptance of computer technology by the majority of people.^{6,7}

The data from the three locations of the kiosks show three unique populations, none of which can truly be described as a random population. The cancer hospital lobby population consists of family and friends of patients who are hospitalised with cancer with the majority of users at any location consisting of affected people or relatives of an affected person. As such, the lobby group is most like the population at large, but is still significantly biased towards those with an affected first degree relative. The breast specific outpatient clinic population is heavily female (71%) and includes many women receiving care for benign breast disease rather than a specific family history of cancer. The proportion with a suspected hereditary cancer syndrome in the

clinic groups (10.4-12.9%) is relatively high when compared to the theoretical 5-10% incidence of hereditary cancer.¹⁰ The difference in occurrence of HCS between the breast specific and general oncology populations is not statistically significant ($p=0.174$). The difference between the two clinic locations and the lobby population approaches significance ($p=0.076$ for the breast specific and lobby groups, $p=0.006$ for the general oncology and lobby groups) and re-emphasises the differences between a general population and one further enriched for cancer occurrences. The general distribution of risk approaches the predicted distribution of inheritance patterns in cancer (5-10% hereditary, 10-20% familial, 70-85% sporadic) and serves as a confirmation of the methodology of cancer risk assignment.

The risk assessments were made based solely on the family history as entered by the participant. No attempt was made to confirm diagnoses. A report of a negative family history has been found to be generally correct as reported (specificity 0.97) while the sensitivity of self-reported positive family histories is estimated to be approximately 0.85 with reporting of abdominal cancers to be the least accurate.^{11,12} The reporting of more distant relatives, such as third degree relatives, is less accurate than for first and second degree relatives, requiring confirmation of medical records in most instances. The addition of third degree relatives to the questionnaire would add significantly to the amount of time necessary to complete the computer survey (4.5 minutes). The limitation to first and second degree relatives may reduce the ability of the questionnaire to ascertain hereditary breast/ovarian cancer with a paternal lineage but is sufficient for other hereditary cancer syndromes. A disclaimer was included in the risk assessment letter explaining that the assessment was only as accurate as the information provided by the user. In addition, the letter states that the "service does not evaluate cancer risk based on personal medical history, lifestyle, or environmental factors."⁹

Tailored written communication of cancer risk assessment was used to personalise the risk for each participant. Broad risk categories were assigned rather than specific risk figures because they have been shown to be more effective.^{13,14}

In the small sample randomly surveyed (4% of the total), excellent recall of receipt of letter (93%) was shown and 69% accurately recalled the assigned level of risk three to six months later, an intermediate period of recall. This is considerably higher than the late recall shown in studies of patient recall of informed consent content, a non-tailored form of written communication.^{15,16} The level of recall shown in the study is similar to the early (less than one month) recall of broad risk categories given in face to face genetic counselling¹⁴ and superior to the recall of information of specific risk figures.¹⁷ Receipt of written communication is an important component of improved recall.¹⁸ In addition, 42% felt their perceptions about their personal cancer risk had changed and

20% had altered their cancer surveillance practices to parallel their cancer risk, the ultimately desired goal of the cancer risk assessment process.

Individualised risk feedback has been shown to be effective in altering risk perception,¹⁹ but the changes in perception and personal health practices shown here may be significant and, in the small group surveyed, are equivalent to the changes in practice seen in the most comprehensive smoking cessation programmes.^{20,21} Further, it seems that the risk assessment letter may serve to spur users to decrease other lifestyle factors that can lead to cancer as evidenced by survey comments indicating smoking cessation behaviours, an unintended benefit of this programme.

The number of people who responded to the recommendation to receive full genetic counselling has been small (four of 154) with significant delays of one to six months from the time of receipt of risk assessment to scheduling an appointment. The stated reasons were concerns about health care insurance and either the likelihood of coverage of counselling services or potential discrimination. While this sample is too small to allow the development of significant conclusions, concerns about the impact of presymptomatic genetic testing is more pervasive in the United States^{22,23} and is a significant barrier to the provision of appropriate genetic counselling to high risk populations.²⁴

The combination of computer technology, knowledgeable genetic professionals, and tailored risk assessment communication has been shown to be efficient, feasible, and effective in promoting desired modification of health behaviours. Additional computer programming is now required to allow automation of the risk assessment portion of the process, the only remaining personnel intensive portion of the process, and allow the receipt of immediate risk assessment feedback information. The family history questionnaire would then be exportable to any health care provider's practice location as well as to the general public.

It is clear from lawsuits in the United States's judicial system that health care providers have a duty to inform patients and other family members if their family may have a hereditary cancer susceptibility syndrome (*Pate v Threlkel*, Florida Supreme Court; *Safer v Estate of Pack*, New Jersey Appellate Court). As such, all practitioners must obtain sufficient family history information to make a risk assessment or face the medical/legal liability.²⁵ The computer based touchscreen family cancer history questionnaire is an effective method of meeting this challenge in our new prevention based health care system.

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