Educational Tools Which Relate to Adult-Onset Disorders For Which Genetic Testing Is Available

Final Report

Prepared for

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by

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Final Report

Executive Summary

Under contract to the Health Canada, PICEPS Consultants, Inc. assisted the *Working Group on Public and Professional Educational Requirements Related to Genetic Testing of Late Onset Disease* by identifying a representative sample of tools used to facilitate the education of patients and primary care providers regarding adult onset disorders for which genetic testing is available.

Key informant interviews, identification and review of the published literature, an Internet search, and surveys of publication first authors and organizations constituted the data collection protocol for this project. The Working Group approved the emphasis to identify educational tools that have been formally evaluated, as well as innovative approaches to educate patients and primary care providers.

The literature review yielded over 170 articles that included descriptions and/or evaluations of educational tools, information aids, multi-media tools, web-based instruction, and brochures. These tools covered areas such as genetic counselling, risk assessment, risk communication, family history taking, and issues concerning the implementation of educational tools in primary practice.

A total of 15 key informant interviews were conducted with individuals from Canada, the United States and the United Kingdom. Key informant interviews were conducted to identify educational tools currently in use or plans to develop tools, barriers associated with the implementation of such tools, and evaluation indicators.

Some 301 organizations and authors of published articles were surveyed to identify any other tools, to obtain copies of tools and/or evaluation reports, and to identify future plans for the development of tools. Email surveys were returned by 66 individuals, 30 of which provided specific information about genetic testing educational tools.

Finally, over 300 web sites pertaining to risk communication, risk assessment, genetic counselling, were identified, and each of these was reviewed to determine: (1), presence of tools or programs to educate patients and/or primary care providers; (2), information regarding the educational tools; (3), access to this information.

Summary of Results

It is extremely challenging to identify educational tools for primary care practitioners and patients regarding genetic testing for adult onset disorders that have gained widespread dissemination and acceptance. We identified 102 genetic testing educational tools that were designed to educate primary care practitioners, patients or both. These tools varied in their scope and their formats (CD, video, paper, audiocassette, Internet-based). Nineteen tools were identified for use with patients (14 of which focus specifically on issues related to testing for breast or ovarian cancer risk); seventeen tools were for use with primary care practitioners (7 of which focus specifically on breast or ovarian cancer risk). The 65 remaining tools were web-based with either a specific audience focus or a broad audience application (e.g., public, patients, health care providers), and were disease specific. Of the tools we identified, we determined that most were developed locally, but only a few have been evaluated formally (possibly due to resource constraints).

Qualitative and/or quantitative evaluation studies have been done on thirteen of the thirty-six educational tools that were not Internet-based. Evaluation studies ranged from informal, in-house evaluations (focusing on end-user satisfaction or ease of implementation) to more formal evaluations that have been published in the peer-reviewed scientific journals (or are in process of being published). Outcome measures have included the impact of the tool on: i) factors influencing patient decision-making (e.g. knowledge of genetics and genetic risk, decision uncertainty, screening attitudes, and risk perception and comprehension); ii) factors influencing physician uptake and use (e.g. physician satisfaction, perception of how tool worked in practice); iii) appropriate decision-making (e.g. referrals) among physicians; and iv) time taken to decision-making for physicians. Behaviour change (e.g., changes in screening behaviour, contacting relatives) are also important indicators to measure the efficacy of tools, but there appears to be little evidence that these indicators have been used as outcome measures in the evaluation studies conducted to date.

Summary of Key Themes and Issues

The following points are offered as key issues and considerations for the *Working Group on Public and Professional Educational Requirements Related to Genetic Testing of Late Onset Disease* as they discuss further any plans for the development, implementation and/or evaluation of educational tools with regard to genetic testing for late onset disorders.

1. Many key informants and survey respondents expressed interest in being made aware of the long-term plans that the Health Canada Working Group has with regard to the development, implementation and/or evaluation of educational tools for genetic testing for late onset disorders.

2. A “gold standard” genetic testing educational tool for either primary care practitioners or

patients does not exist.

3. Most educational tools are developed locally; much of the work does not appear in the published, peer-reviewed literature and/or does not have widespread dissemination.

4. There are very few and limited evaluation studies to assess the design, implementation, efficacy or effectiveness of genetic testing educational tools.

5. Family history taking tools are often developed for research purposes (e.g. in genetic testing clinics) and not for educational purposes. The Working Group should consider how such tools might differ and/or overlap with regard to their respective purposes, their design and their implementation.

6. In comparison to other disease sites, there appears to be a much greater number of educational tools that have been developed for breast/ovarian cancer risk. This is also supported by survey responses, the literature review, the web site review, and the key informant interviews.

7. In addition to innovations in the development of tools per se, that there are also innovative approaches to genetics education more broadly. One such example is the Community Genetics and Ethics Project (CGEP) which takes a community development approach to the education of primary care practitioners and the public in general. This approach involves 3 phases that include i) intensive retreats for professional groups (clergy, policy, physicians, medical students); ii) recruitment of more professionals using phase 1 participants as gatekeepers, and iii) community forums. This project has been evaluated using pre- and post-test comparisons of knowledge. Focus groups are also conducted 6 months after the session to assess what the participants have done with their information.

8. There appears to be a need for carefully designed, easy-to-use educational tools for primary care practitioners that take into consideration their non-expert level of knowledge about genetics, the time required to train physicians, and the ease with which the tool can be implemented into a primary care setting. The tools should provide educational information about genetics, regardless of the disease site.

9. As primary care becomes a more common point of entry by which people are referred to genetic testing, in addition to knowledge about human genetics, physicians need to be aware of the types of concerns and questions their patients may have (e.g., psychosocial issues).

10. Educational efforts oriented towards physicians need to take into account both physicians-in-training and practising physicians. The development of tools for primary care

practitioners needs to be accompanied by a commitment to genetics education in medical schools. Continuing medical and nursing education may comprise promising avenues for educating primary care practitioners about issues related to genetic testing for late onset disorders. This approach may facilitate appropriate referrals for high-risk cases, and may help to ease any discomfort of primary care practitioners in discussing issues related to genetic testing for late onset disorders.

11. The successful development of educational tools for primary care providers requires, in part, clarification of the role that is appropriate for the primary care provider in the provision of patient advice concerning genetic testing for late onset disorders.

12. It is challenging to use existing tools for different populations (including disease-site characteristics and patient/public demographic criteria such as SES, age, location).

13. A number of position papers and resource documents were identified as a result of the key informant interviews, the surveys and the web site reviews. These documents provide insight into various issues related to genetic testing for late onset disorders, and some are an additional resource for the identification of web-based educational tools.

14. There is an increasing number of private and public initiatives involved in the development, design and/or implementation of tools to assist in the education of primary care practitioners and patients about genetic testing for late onset disorders.

Educational Tools Which Relate to Adult-Onset Disorders For Which Genetic Testing Is Available

Final Report

A. Project Background

Under contract to the Health Canada, PICEPS Consultants, Inc. has been asked to assist the Working Group on Public and Professional Educational Requirements Related to Genetic Testing of Late Onset Disease to identify a representative sample of tools used to facilitate the education of patients and primary care providers regarding adult onset disorders for which genetic testing is available.

Adult-Onset Disorders:
There are a number of adult-onset disorders, for which genetic testing is available. We will attempt to identify educational tools in use or planned for the following adult-onset disorders:

- breast cancer
- ovarian cancer
- hereditary non-polyposis colon cancer (HNPCC)
- familial melanoma
- Huntington's disease (HD)
- familial hyperlipdemia
- myotonic dystrophy
- familial Alzheimer's disease (FAD)
- polycystic kidney disease

Types of Tools:
- algorithms or flow sheets
- interactive web sites
- CD-ROM
- educational module package/manual
- audio- and video-tapes
- pamphlets and brochures may be identified, but these have been given comparatively low priority by the Working Group

Content of the Tools (*tools may have elements of one or more of the following content areas*)
- communication/decision-making for health care professionals
- family history taking by health care professionals
- risk assessment (patients and health care professionals)
- risk communication (patients and health care professionals)

- decision-aids for at-risk patients
- genetic counselling aids for health care professions

B. Project Goal & Key Tasks

The goal of this project was to identify representative examples of each type or category of tool, as described under the Content of the Tools section above. Preference will be given to the tools that have been formally evaluated. However, the consultant will also attempt to identify any tools that may be under development as well as tools that are currently in use that have not been formally evaluated. Equal weighting will be given to the identification of educational tools for patients and health care professionals (as much as is possible, based on those tools that are available).

In order to achieve the above stated goal, the key task areas of this project were:

(1) to review published literature, with an emphasis on literature that focuses on the description and evaluation of tools to assist in the education of primary care practitioners and patients about genetic testing for late onset disorders;
(2) to identify, review and download tools from relevant web sites; and
(3) to conduct key informant interviews with individuals identified by the consultant and the Working Group;

While not specifically required for the project, PICEPS Consultants, Inc. also developed and implemented a survey of representatives from genetic risk assessment centres or organizations involved in genetic testing for late onset disorders, in order to identify any tools that may be currently in use or under development (i.e., innovations)**.**

C. Project Design

Four strategies were employed to accomplish the key task areas described above. The four strategies were undertaken in such a way so that the results from each task area can be used to inform other task areas: a literature review, key informant interviews, a survey of published authors and organizations, and a website search. For example, the first authors identified by the literature review have been included as survey recipients. Some survey respondents and key informants have identified relevant publications and web sites in addition to those identified through formal searches such as MEDLINE. By feeding back the results of one task area to the other task areas, this has helped to optimize the comprehensiveness of our findings.

1. Literature Review

i) Protocol
Relevant published literature was identified using two strategies:

(a) articles were identified from the consultant's existing library that focus on educational tools regarding genetic screening; specific articles that describe and/or evaluate educational tools were selected;

(b) MEDLINE keyword searches were conducted using the following terms:

Search Terms	# Hits	# Kept
LATE + ONSET + DISEASE +GENETIC +TESTING	24	24
RISK + COMMUNICATION + GENETIC + SCREENING	7	7
PRIMARY + CARE + GENETIC + TESTING + EDUCATION	16	16
FAMILY + HISTORY +TAKING	4	4
GENETIC + RISK + ASSESSMENT + PRIMARY + CARE	40	21

Published articles identified for this project are listed in Appendix D. Articles identified by key informants and survey respondents that were not already identified by the literature reviews were also added to this list.

The article abstracts were reviewed and assessed for their relevance to the objectives of this consultation, and those articles judged to be clearly beyond the scope of the consultation were removed. Articles that focus explicitly on development, implementation and/or evaluation issues are presented separately at the beginning of the list.

2. Web Site Review

(i) Protocol:
The following search terms and hits were achieved using the search engines: Copernic 2001 Basic and http://www.google.com.

Search Term	# Hits
GENETIC + TESTING + EDUCATION	57
GENETIC + FAMILY + HISTORY	53
GENETIC + TESTING + DECISION + MAKING	50
GENETIC + RISK + COMMUNICATION	48
GENETIC + RISK + ASSESSMENT	52
GENETIC + TESTING + LATE + ONSET	43

3. Key Informant Interviews

(i) Protocol:

In order to optimize the success of the key informant interviews, each person identified as a potential key informant was faxed/emailed a recruitment package which consists of: (i) a letter describing the purpose of the project; (ii) a list of the interview questions; and (iii) a consent form (see Appendix E). Providing individuals with a complete package in advance increases the participation rate and the completeness of the data (i.e., they can refer to any documentation they may have to support their responses, and, as such, may provide fewer 'top-of-mind' responses). This fax/email was followed up by a telephone call to ensure that the individual received the package, to address any questions they might have regarding the project, and to assess their interest in taking part in an interview. Individuals who agreed to take part in a telephone interview were asked to fax their consent form to the consultant. Upon receipt of the completed consent form, an interviewer contacted the key informant and scheduled a mutually convenient interview time.

A total of 15 key informant interviews were conducted. A snowballing procedure was used to identify key informants. Five individuals were initially identified by the Working Group and the consultant. Potential key informants were chosen purposefully based on their experience in the development, use and/or evaluation of educational tools. These individuals represented a broad range of disciplines and professions, and included primary care practitioners, researchers, software developers, clinical geneticists and policy advisors.

Each key informant interview required approximately one hour to complete. The time required for the interview varied with regard to the person's knowledge about educational tools and/or his/her availability. At the end of each interview key informants were asked to identify other individuals and/or organizations that we could approach for information about educational tools. Key informants also identified relevant web resources, articles and organizations.

The analysis of the interview involved the identification of: i) educational tools; ii) any evaluations performed on the tool; iii) gaps in the types of educational tools being developed; iv)

barriers to the development and/or implementation of educational tools; and v) evaluation indicators that could be used to assess the effectiveness of the tools.

4. Survey

(i)Protocol:
A potential pool of survey respondents was identified from the following sources: (a) the first authors identified by the consultant's literature review; (b) representatives from genetic risk assessment centres; (c) representatives from regional genetics networks (primarily from the United States); (d) representatives from cancer centres and other disease-specific organizations; (e) representatives from professional genetics associations (e.g. Canadian Association of Genetic Counselors).

While the same information could not be solicited by the email survey process in comparison to the telephone interviews with key informants, the questions used to elicit responses were similar, and thus the survey process can be viewed as a quasi-key-informant data collection strategy. As with the key informants, survey respondents were asked to identify other individuals with whom we could speak regarding educational tools. In total, we contacted 301 individuals by email or by fax with survey questions adapted from the key informant interviews. The email request and survey questions are presented in Appendix F.

Individuals who did not respond within a week were contacted a second time to ensure that they received the first email. Individuals were informed in the second email that they would not be contacted a third time should they wish not to complete the survey. Survey respondents were also informed that any tools or information they provided to the consultant would not be used for any commercial interest.

(a) *First Authors*: First authors identified by the literature searches, and for whom email addresses were available, were contacted.
(b) *Genetic Risk Assessment Centres*: 18 genetic counselors belonging to the Canadian Association of Genetic Counselors and who practice in cancer genetics and/or adult genetics were contacted initially (see Appendix G). (Additional genetic counselors were contacted upon the recommendation of survey respondents).
(c) *Genetics Networks Representatives*: Representatives from 11 regional genetics networks in the United States were contacted. (See Appendix H).
(d) *Representatives from disease-specific organizations*: Representatives from disease-specific organizations and associations were contacted (see Appendix I).
(e) *Professional Genetics Associations:* Representatives from 11 associations in Canada and the United States were contacted (see Appendix J)
(f) *Members of CCGCG (Canadian Collaborative Group on Cancer Genetics*): All members of the CCGCG for whom email addresses were available were contacted (see http://ccmg.medical.org/cc-memb.htm)
(g) Representatives from Cancer Genetics Clinics in Canada: 32 representatives for

whom working fax numbers were available were contacted (see Appendix K).
(h) *Representatives from Huntington's Disease Genetics Clinics in Canada*: 20 representatives for whom working fax numbers were available were contacted.

D. Results

In this section, the results of each task area are described briefly below followed by a summary of the key themes that emerged from the data collected.

Overview of Educational Tools

The tools we identified were varied in their scope and their formats (CD, video, paper, Internet). The educational tools are presented in Tables 1, 2, and 3 (Appendices A, B, and C, respectively). Tables 1 and 2 focus on educational tools for patients and practitioners, respectively, that were identified through the various methodological strategies. Table 3 lists web-based educational tools specifically. Nineteen were identified for use with patients (14 of which focus specifically on issues related to testing for breast or ovarian cancer risk); Eighteen tools were for use with primary care practitioners (7 of which focus specifically on breast or ovarian cancer risk). The 65 remaining tools were web-based with either a specific audience focus or a broad audience application (e.g., public, patients, health care providers), and were disease specific. Where possible, we tried to obtain copies of these tools and to determine whether or not the tool has undergone formal evaluation (we indicate which tools have been obtained in the tables).

The tools that we have identified have not gained widespread dissemination and acceptance. Of the 102 tools we have identified, only a few have been evaluated formally. In fact, we have learned that the majority of the tools have been developed locally, with little or no formal evaluation (possibly due to resource constraints). Qualitative and/or quantitative evaluation studies have been done on eleven of the 37 tools listed in Table 1 and 2. Evaluations ranged from informal, in-house evaluations (focusing on end-user satisfaction or ease of implementation) to more formal evaluations that have been published in the peer-reviewed scientific journals (or are in process of being published). In these evaluation studies, outcome measures included the impact of the tool on: i) factors influencing patient decision-making (e.g. knowledge of genetics and genetic risk, decision uncertainty, screening attitudes, and risk perception and comprehension); ii) factors influencing physician uptake and use (e.g. physician satisfaction, perception of how tool worked in practice); iii) appropriate decision-making among physicians; and iv) time taken to decision-making for physicians. Behaviour change (e.g., changes in screening behaviour, contacting relatives, changes in referral making) are also important indicators to measure the efficacy of tools, but there is little evidence that these indicators have been employed.

Summary of Findings - Key Task Areas

1. Literature Review

More than 150 articles pertaining to educational tools for patients and primary care providers concerning genetic testing were identified using online (MEDLINE) search strategies (see Appendix D). The majority of the articles identified did not specifically describe the tool or the development and/or evaluation of educational tools. Because of this, we have also included articles in Appendix D that consider issues related to the use of such tools and genetic testing more generally. We believe that these related articles (e.g. genetic counseling, risk communication, psycho-social issues, genetic risk assessment and primary care) will be informative with regard to the further consideration of the development and/or evaluation of educational tools for genetic testing for late onset disorders. Articles that were clearly beyond the scope of this project (e.g. articles on prenatal genetic testing, articles on public perceptions of genetic testing) were not included in the review.

2. Web Site Review

Not surprisingly, there was substantial overlap in the results of the searches for relevant web sites. Many of the web sites identified by the searches focus on genetics education and the human genome in general, and do not focus specifically on genetic testing for adult onset disorders. Only those web sites which concentrate on, or made reference to, adult onset disorders were included in the results. The web sites that focus on genetic testing for a specific disease or set of diseases often include information about genetics and heredity more generally, in addition to information about genetic testing for the specific disease/s in question.

The results of the web site review are presented in Table 3. Sixty-five web sites were chosen for inclusion in Table 3 because the educational material or information about genetic testing was either formally available on the web, or because it could be downloaded or ordered from the web site. We found that the majority of the web sites pertained to cancer, more specifically breast and ovarian cancer.

We discovered, perhaps not surprisingly, that many of the web sites and the links on some of the web-based tools were no longer viable. This points to the fact that these web sites may have lacked adequate resources to sustain the sites, and that web-based approaches more generally require ongoing maintenance.

In addition to these web sites, Dr. Alan Guttmacher of the National Human Genome Research Institute has provided us with a copy of his paper titled “Human Genetics on the Web”. The web sites included in this document, specifically those on Clinical Genetics and Genetics Education, were reviewed and incorporated into Table 3 of this report. Web sites were not included in Table 3 that focused exclusively on rare genetic disorders or birth defects.

3. Key Informant Interviews

The pool of key informants who participated in the project represented: Canada (n=3), the

United States (n=10) and the United Kingdom (n=2).

Description of Tools

Key informants spoke primarily to the tools with which they had first hand experience (i.e. they developed the tool and/or put it into practice). The tools with which key informants had direct experience included web-based tools, computer-based tools (e.g. CD-ROM programs for patients and physicians), as well as the development of patient and physician information packages that included algorithms for primary care practitioners to use during patient encounters. There was general consensus among the key informants that tools tend to be developed locally with little or no formal evaluation. Tools that have been evaluated do not appear to have gained any widespread use or acceptance.

Key informants varied with respect to their favoured approach to educating primary care providers about genetics . A broad-based educational tool was seen as providing a useful introduction to a wide range of issues related to genetics and genetic testing. The CD-ROM developed by Twisted Ladder Media was strongly endorsed as providing a comprehensive introduction to molecular genetics and genetic testing for a variety of audiences, including practising and training physicians and the public at large. In comparison to these broad-based approaches, educational tools that focus specifically on the issues relevant to primary care practitioners were seen as a more effective strategy to illustrate the salience of genetic knowledge for primary care practice.

Design and Evaluation Issues

Key informants agreed that there is little evaluation research on educational tools with regard to genetic testing for late onset disorders. This is in agreement with the lack of published research on the evaluation of these types of educational tools. Some key informants expressed a sense of frustration about the lack of educational tools that are well designed and evaluated. These individuals also felt that it is challenging to use existing tools for different populations (including disease-site characteristics and patient/public demographic criteria such as SES, age, location).

Some key informants advocated a "staged approach" to evaluation, with stage one involving a qualitative evaluation of the tool design and satisfaction with the tool, and the second stage involving a systematic quantitative assessment of the impact of the tool on behaviour change (e.g. appropriate physician referrals). Using this approach, the qualitative component can be used to examine in detail how such tools actually get used in the consultation and to assess the interface between the doctor, patient and computer. The quantitative evaluation component is suitable to understand the extent to which the tool has influence physician or patient behaviour. Some key informants emphasized that the qualitative component of the evaluation is essential to designing a tool that is effective, both by meeting its intended purpose and by presenting the information that is streamlined with the clinical encounter.

Evaluation indicators for web-based tools included:

- number of daily visits or "hits"
- email feedback mechanisms for ongoing assessments

Evaluation indicators for physician-oriented tools included:

- change in physician practice (e.g., communication about genetic testing)
- accurate risk assessment
- appropriate risk management
- physician knowledge

Evaluation indicators for patient-oriented tools included:

- knowledge
- risk perception
- patient anxiety levels
- attitudes
- behaviour change (e.g., an increase in screening; identification of other family members)
- patient satisfaction

Some key informants also identified certain "multiplier" effects that resulted from the use of their educational tools. For example, the development of certain web-based information resources on genetic testing clinics appears to have had an unanticipated effect of increasing communication between different laboratories.

Gaps in Tool Development

The most commonly recognized gap, according to the key informants, was the lack of well designed and evaluated educational tools for primary care providers– both providers in training and practicing health care practitioners. Practicing physicians appear to be seen to be particularly challenged in the sense that genetics was not part of their medical training

The development of easy-to-use, paper-and-pencil tools for use by primary care practitioners, including a "usable pedigree" that is designed for use by non-geneticists, was specifically identified as a need. Additional gaps noted by key informants were:

- lack of pedigree tools that are confidential and not run by commercial companies
- lack of family history taking tool that patients can do on their own time
- lack of cancer genetics curriculum in medical training
- lack of risk assessment tools so physicians can interpret pedigrees appropriately
- lack of development of tools that attempt to stimulate critical reflection about insurance implications, informed consent procedures, predictive value of genetic test results

Barriers to Tool Development and Implementation

Key informants identified various barriers to the development and implementation of educational tools. Barriers to the development of effective tools included:

- cost associated with development of computer-based tools
- cost associated with the maintenance of web sites (e.g. hotlinks)
- technical problems associated with computer-based tools
- development of computer-based tools requires careful collaboration between experts in

the subject matter (e.g. clinical geneticists), graphic designers and computer programmers
- grant-writing for funding is time intensive

Key informants also noted that successful development of educational tools requires collaboration among and between various key players, including, for example, genetic experts, members of target audiences (e.g. physician, patient), computer programmers and graphic designers.

Barriers to the implementation of educational tools included:
- lack of medical school curricula pertaining to genetics and genetic testing
- lack of clinicians to model for students the appropriate uses of genetic tests in clinical settings
- little financial incentive to get institutions to set up genetic counselling programs
- physician resistance to guidelines
- complex nature of collecting hereditary information
- lack of continuing medical education in genetics
- physician-driven continuing medical educational programs tend to overlook genetics education since this was not part of physicians' training
- lack of clear guidelines on the role of primary care providers with regard to doing genetic counselling with their patients and under what circumstances
- lack of supporting resources for primary care physicians (e.g. training of nurses to take pedigrees, etc.)
- lack of continuing medical education in human genetics
- lack of public understanding about genetics and genetic services (therefore low demand)
- lack of tools for non-geneticists (i.e. in plain English)
- lack of systematically evaluated information aids and educational tools that patients can use at their own leisure
- lack of a centralized information system available across genetic testing centres
- lack of sufficient time to incorporate genetic-related advice in primary care session
- lack of physician training in information technologies
- lack of knowledge about genetics resources and testing centres prohibits appropriate referrals from being made

Key informants identified several factors to facilitate the implementation of genetic testing educational tools:
- public pressure / increased consumer demand
- professional pressure (e.g. development of standards of care with regard to how to advise patients about genetic testing in primary practice)
- pioneering efforts (of those involved in tool development, CME, etc.)
- demonstrate how knowledge about genetics will influence clinical practice

Other Related Issues

Other issues that were identified by key informants included:

- target population needs to be consulted in development of tools
- educational tools need to be sensitive to issues that are specific to the late onset disease in question
- strong need for coordination/integration of tools among genetic testing centres (especially centres with the same disease focus)
- strong need for evaluation of tools to ensure ease of use, user acceptance, compliance and other evaluation indicators that demonstrate the educational value of the tools (for primary care practitioners and patients)
- clarification of professional boundaries and responsibilities with respect to clinical genetics is necessary to facilitate appropriate referrals and management of individuals with familial risk (i.e. in addition to educating physicians, physicians need to know when to refer out)
- lack of funding to successfully transfer and disseminate genetic knowledge into clinical and primary care practice
- 'huge gulf' between public expectations and primary health care system - i.e. public expectations with regard to genetics (often due to increased media attention) exceed primary care practitioners' understandings of genetic testing for late onset disorders - consumers see primary care providers as gatekeepers of information about genetics and genetic tests
- need identified to conduct ongoing surveys of medical practitioners re: their state of knowledge with regard to genetics and the extent to which genetic knowledge has influenced their practice
- there is a need for greater support for research on the diffusion of genetic knowledge into general practice

4. Surveys

Of the 250 individuals initially contacted, 166 of the email requests for participation were returned. Of the 166 replies, approximately 60 were either undeliverable or the reply indicated that the recipient was "out of office" or on vacation. Of the remaining 106 surveys returned, 32 responses were useful in that the respondents indicated that they had knowledge of educational tools pertaining to genetic testing. The recipients of the surveys would often forward our request for information to other individuals with whom they were associated. We estimate that our survey reached a total of 301 individuals.

We also undertook a search to identify representatives of Continuing Medical Education Departments at major North American universities. A search of Continuing Education catalogues and clearinghouses resulted in few references to genetic education curricula pertaining to adult onset disorders. The following hot links to tools for primary care practitioners were identified:

http://mchneighborhood.ichp.edu/wagenetics/906317226.html
http://www.ama-assn.org/ama/pub/category/2380.html

Because the mode of communication for this survey was email-based, this posed special challenges and opportunities to the survey process. The ease with which email can be forwarded to others meant that many individuals who were not aware of educational tools would take it upon themselves to forward our request for information to other individuals. One individual from the New York State Department of Health forwarded the request for information on to an informal mailing list. She initiated this mailing list in an effort to reduce the isolation she experienced in her job which involves incorporating genetics into programs that focus on adult health issues and chronic disease. The mailing list is geared towards primary care providers, genetic counsellors, and medical geneticists who work in areas of adult onset disorders. Only 1 person responded to the list serve posting.

In addition to the opportunities that email affords in reaching large audiences of individuals, this can also be a drawback. For example, because potential survey respondents were identified through various different mechanisms, this meant that various individuals at the same clinic or organization would receive our request for information (although this was not apparent from the email address). This email survey strategy was necessary given the relatively short time we had to identify and distribute surveys and compile the results. However, we learned that selected individuals in the clinics may be persons with whom in-depth follow-up as key informants may yield additional data regarding educational tools for genetic testing.

Of all the respondent types we contacted, the genetic counsellors and representatives from the Canadian cancer genetics risk assessment centres responded most frequently. Genetic counsellors typically identified the educational "flip book" developed by Myriad Genetics and the "Counselling Aid for Geneticists" developed by the Greenwood Genetic Centre. The curriculum slides developed by the American Society for Clinical Oncology were also mentioned frequently. Many genetic counsellors indicated that they developed their own tools for use in their clinics. A good example of locally developed tools is provided by the Hereditary Cancer Program at the BC Cancer Agency (see Tables 1 and 2).

Summary of Key Themes and Issues

The following points are offered as key issues and considerations for the *Working Group on Public and Professional Educational Requirements Related to Genetic Testing of Late Onset Disease* as they discuss further any plans for the development, implementation and/or evaluation of educational tools.

- Many key informants and survey respondents expressed interest in being made aware of the long-term plans that the Health Canada Working Group has with regard to the development, implementation and/or evaluation of educational tools for genetic testing for late onset disorders.

- A "gold standard" genetic testing educational tool for either primary care practitioners or patients does not exist.

- Most educational tools are developed locally; much of the work does not appear in the published, peer-reviewed literature and/or does not have widespread dissemination.

- There are very few and limited evaluation studies to assess the design, implementation, efficacy or effectiveness of genetic testing educational tools.

- Family history taking tools are often developed for research purposes (e.g. in genetic testing clinics) and not for educational purposes. The Working Group should consider how such tools might differ and/or overlap with regard to their respective purposes, their design and their implementation.

- In comparison to other disease sites, there appears to be a much greater number of educational tools that have been developed for breast/ovarian cancer risk. This is also supported by survey responses, the literature review, the web site review, and the key informant interviews.

- In addition to innovations in the development of tools per se, there are also innovative approaches to genetics education more broadly. One such example is the Community Genetics and Ethics Project (CGEP) which takes a community development approach to the education of primary care practitioners and the public in general. This approach involves 3 phases that include i) intensive retreats for professional groups (clergy, policy, physicians, medical students); ii) recruitment of more professionals using phase 1 participants as gatekeepers, and iii) community forums. This project has been evaluated using pre- and post-test comparisons of knowledge. Focus groups are also conducted 6 months after the session to assess what the participants have done with their information.

- There appears to be a need for carefully designed, easy-to-use educational tools for primary care practitioners that take into consideration their non-expert level of knowledge about genetics, the time required to train physicians, and the ease with which the tool can be implemented into a primary care setting. The tools should provide educational information about genetics, regardless of the disease site.

- As primary care becomes a more common point of entry by which people are referred to genetic testing, in addition to knowledge about human genetics, primary care practitioners need to be aware of the types of concerns and questions their patients may have (e.g., psychosocial issues).

- Educational efforts oriented towards physicians need to take into account both physicians-in-training and practising physicians. The development of tools for primary care practitioners needs to be accompanied by a commitment to genetics education in medical schools. Continuing medical and nursing education may comprise promising avenues for educating primary care practitioners about issues related to genetic testing for late onset disorders. This approach may facilitate appropriate referrals for high-risk cases, and may

help to ease any discomfort of primary care practitioners in discussing issues related to genetic testing for late onset disorders.

- Different positions were taken in the key informant interviews with regard to the educational approach that is best-suited to primary care physicians, with some advocating an approach including a broad range of topics and some advocating an approach that focuses specifically on the ways in which genetics will influence primary care.

- It is challenging to use existing tools for different populations (including disease-site characteristics and patient/public demographic criteria such as SES, age, location).

- A number of position papers and resource documents were identified as a result of the key informant interviews, the surveys and the web site reviews. These documents provide insight into various issues related to genetic testing for late onset disorders, and some are an additional resource for the identification of web-based educational tools.

- A wide range of tools currently exists for primary care practitioners, including introductory primers on genetics, risk assessment and communication tools, tools to facilitate family history taking, and tools that focus on the ethical issues concerning genetic testing. Some continuing medical education efforts were also identified through this consultation. This variety in educational tools suggests that more than one kind of tool may be necessary to facilitate different processes that may be involved as genetics becomes more integrated into primary care. In order to support the types of tools most appropriate and relevant for primary care settings, there needs to be some clarification of the roles and responsibilities of primary providers in advising their patients about issues concerning genetic testing for late onset disorders. This clarification may require a more in-depth investigation, specifically within the Canadian health care context, of the needs of primary physicians with regard to incorporating information about genetic testing in their practice.

- The clarification of professional boundaries between primary care providers and genetics specialists will require constructive partnerships between professional groups / organizations.

- There is an increasing number of private and public initiatives involved in the development, design and/or implementation of tools to assist in the education of primary care practitioners and patients about genetic testing for late onset disorders.

Some individuals whom we contacted as key informants or survey respondents expressed some degree interest in maintaining some level of connection to the activities of Health Canada's Working Group (e.g., to share information, or possibly to engage in projects or activities of mutual interest and benefit). This may provide an ideal opportunity for the Working Group to articulate it's long-term plans with respect to the development of educational tools, as well as to identify other potential collaborations. We recommend that the extent and nature of the interest of

these individuals be reassessed once the future activities of the Working Group are clarified. We have compiled a list of these individuals as follows.

Organization	**Individual**
Director Secretary's Advisory Committee on Genetic Testing National Coalition for Health Professional Education in Genetics (NCHPEG)	Joe McInerney em: joemcinerney@genetic-medicine.org
Senior Clinical Advisor National Human Genome Research Institute (NHGRI)	Alan Guttmacher tel: 301-402-0955 em: guttmach@mail.nih.gov
Genetic Counsellor Vermont Regional Genetics Network	Wendy MacKinnon tel: 802-652-6808
Research Scholar Program for Genomics, Ethics & Society Standford Center for Biomedical Ethics Stanford University	Sally Tobin tel: 650-725-2663 em: tobinsl@leland.stanford.edu
Clinical Geneticist Cancer Genetics Research Clinic Tom Baker Cancer Center Calgary, Alberta	Rhiannon Hughes tel: (403) 670-2438 em: rhughes@ucalgary.ca
Harvard University Professor Emeritus Dept. of Social Medicine and Professor of Psychiatry ***Dr. Eisenberg is involved in organizing conference to discuss genetics education for medical students*	Leon Eisenberg tel: 617-432-1710 em: Leon_eisenberg@hms.harvard.edu
Oxford University Family Genetix	Dr. Jon Emery tel: 011-44-1223-330595 em: jde10@medschl.cam.ac.uk
ICRF General Practice Research Group University of Oxford	Dr. Robert Walton tel: 011-44-1865-224707 em: robert.walton@public-health.oxford.ac.uk

Organization	Individual
Vice President New Century Healthcare Institute	James Ensign tel: 415-439-6800 em: jmensign@sirius.com
Policy Analyst American Medical Association **Dr. Goldberg specializes in issues pertaining to medical education in genetics*	Simon Goldberg tel: 312-464-4964 em: Simon_Goldberg@ama-assn.org
Consultant Clinical Psychologist ICRF Psychology Group Medical Oncology Unit Western General Hospital Edinburgh	Ann Cull tel: 0131-537-1837 em: a.cull@icrf.icnet.uk
Psychosocial Research Group Institute of Oncology University of New South Wales Randwick, NSW Australia	Bettina Meiser tel: 02-9382-2638 em: b.meiser@unsw.edu.au
Cancer Genetics Education Project Officer Anti-Cancer Foundation Unley, SA Australia	Clara Tait tel: 08-8291-4153 em: ctait@cancersa.org.au
Clinical Geneticist & Medical Director, GeneTests Editor-in-Chief, GeneClinics	Roberta (Bonnie) Pagon em: bpagon@u.washington.edu
Nurse Educator Hereditary Cancer Program BC Cancer Agency	Mary McCullum tel: 604-877-6098, ext. 2325 em: mmccullum@bccancer.bc.ca
Postgraduate Scientist ICRF Psychology Group Medical Oncology Unit Western General Hospital Edinburgh	Sally Appleton tel:0131-537-1838 em:S.Appleton@icrf.icnet.uk

In addition to these key individuals, we also identified a number of initiatives or programs for which the development of educational tools or resources is an established goal or mandate. The

Working Group may wish to make these organizations aware of their future activities, and to solicit partnerships with one or more of these initiatives as part of those activities:

- **The Secretary's Advisory Committee on Genetic Testing (SACGT)**: (http://www4.od.nih.gov/oba/sacgt.htm) The mission of the SACGT is to advise the government about all aspects of the development and use of genetic tests, including the complex medical, ethical, legal, and social issues raised by genetic testing. As part of this mission, the SACGT has conducted public consultations on the oversight of genetic tests (see http://www.edc.org/SACGT/consult.pdf)
- **Alberta Cancer Genetics Program (ACGP)**: A stated goal of the ACGP is 'to develop educational tools that encourage appropriate use of cancer surveillance tests and encourage lifestyle behaviours associated with cancer risk reduction'. A web site is currently in development which includes information for the general public and health professionals on hereditary cancer susceptibility and the ACGP. This site should be on-line by September, 2001.
- **Genetics in Primary Care**: This 3 year research contract (1998-2001) aims to plan, implement and evaluate the outcomes of training programs in genetics. The target audience includes faculty from family medicine, general internal medicine and general pediatrics (http://bhpr.hrsa.gov/dm/genpc.html)
- **National Coalition for Health Professional Education in Genetics (NCHPEG)**: This is a national effort to promote health professional education and access to information about advances in human genetics. One of the stated goals of the NCHPEG is to 'develop educational tools and information resources to facilitate the integration of genetics into health professional practice'. The Core Competency and Curriculum Working Group of NCHPEG has produced a report outlining the core competencies for health professionals in genetics : http://www.nchpeg.org/news-box/corecompetencies000.html. Educational tools for use by health professionals can also be posted on the NCHPEG web site.
- **National Genetics Society (NGS)**: This recently established Canadian-based charitable foundation is in the early stages of development. The goal of this organization is to produce a public web site and physician newsletter to educate physicians about issues related to a variety of genetic tests and disorders, including adult onset disorders.
- **Genetics and Molecular Medicine (GeMM)**: This component of the American Medical Association directs various educational initiatives in genetics. Recent activities have included a survey of consumer attitudes towards genetic testing, an ongoing project to define the current status of medical genetics in continued professional development, and conferences on genetics and the practicing physician. http://www.ama-assn.org/ama/pub/category/1799.html

Final Remarks

In this report, we have identified a number of educational tools that are currently in use, or in development, to assist in the education of primary care providers and their patients about various aspects of genetic testing presently available for late onset disorders.

As basic science continues to identify new genes (at an ever-increasing rate), which assist in predicting the onset of adult (and non-adult) diseases, there will be greater pressure to integrate this genetic knowledge into Canadian health care. As this happens, the development and evaluation of educational tools needs to be discussed alongside a consideration of the broader contexts (e.g. social, medical, political, scientific, ethical, cultural) within which these tools are developed and implemented. The uptake and support of educational tools should be critically reviewed in light of the predictive value of genetic tests for which the tools in question are developed. Serious ethical issues are posed for patients who are exposed to educational materials about genetic testing for a condition for which there is little or no demonstrated efficacy or predictive value. Similarly, primary care practitioners should be made aware of the predictive value of genetic tests for which they may be encouraged to provide referrals. The successful uptake of such tools in primary settings is also contingent, at least in part, on the clarification of professional boundaries that distinguish the responsibilities of primary care providers from those of genetics specialists (e.g. genetic counsellors).

Given the limited public and professional understanding about human genetics, how the development of educational tools for patients and health professionals can be undertaken as part of a larger public debate about the integration of genetics into primary care and public health needs to be considered. Some initiatives that seek to promote critical thinking about genetics among the public at large have been identified in this report, and there have been a number of public consultations in this area in the United States and the United Kingdom. These initiatives may act as models for promoting greater public dialogue in Canada about the integration of genetics into primary care and patient/public education.

APPENDIX A: Table 1: Educational Tools for Patients

** copy of educational tool has been obtained by the consultant

Disease Site/s	**Source (**e.g. survey, lit review, key informant)	**Title of Tool**	**Description** (audience, purpose, etc.) **Purpose of Tool**	**Year, Developer & Location**	**Evaluated? (**Y/N) Published? Peer-Reviewed? In-house?	**Type of Evaluation? Study design?**	**Outcomes / Indicators**
Br HNPCC	First Author http://www.ohri.ca/programs/clinical_epidemiology/OHDEC/decision_aids.asp	Making Choices	audio-guided booklet and worksheet to be used post-counseling target audience is for men and women who have tested positive to having a BRCA mutation or HNPCC mutation **will be available on Alberta Cancer Genetics Program web site in mid-July	2000 **Hughes-Benzie, R**. U of Calgary **O'Connor, A**. Dept. of Nursing, U of Ottawa Order Info: Liz Drake, Ottawa Health Research Institute ldrake@lri.ca	No prototype in development	-	-
Br Ov **	web site	Testing for Hereditary Risk of Breast & Ovarian Cancer: Is it Right for You?	Video for people considering genetic susceptibility testing	**Myriad Genetic Laboratories**, 1999	N	-	-
Br Ov **	web site	Genetic Testing for Risk of Breast and Ovarian Cancer: Is it Right For You?	Educational resource kit for patients includes 2 education booklets, family history q'aire, consent form & price list	**Myriad Genetic Laboratories** with MDS Laboratory Services	N	-	-

HNPCC **	web site	Genetic Testing for Hereditary Nonpolyposis Colorectal Cancer: Is it Right For You?	Educational resource kit for patients includes patient information guide, family history q′aire, consent form & price list	**Myriad Genetic Laboratories** with MDS Laboratory Services	N	N	N
Br **	First Author	Breast Cancer Risk & Genetic Testing	CD-ROM for women considering genetic testing for BRCA 3 learning sections: breast cancer, heredity, gene testing	**Green, M.** Departments of Humanities and Medicine Penn State University **Frost, N**.	results of clinical trial using CDROM in preparation for publication 1. Crowe, JP (1999). J of Women′s Health, 8, 25-6. 2. Dabney, MK & Huelsman, K. (2000). Genetic Testing, 4, 43-4. 3. McGee, G. (1999). JAMA, 281, 1652. 4. Baty, BJ. (1999). Am J Med Genet, 86, 93-4.	1. tracking article 2. Tracking article 3. in-house software review by expert on genetic counseling issues, 'unscientific survey' of students and subjects -NOTE: tool is also currently being evaluated by Wang, C. using an RCT design to compare pre-post knowledge of cancer and genetics when the CD Rom is added before the counseling session	DK

Br	First Author Web Site	SDMP (Shared Decision Making Program)	to support decision between participation in breast cancer screening program and prophylactic mastectomy	**Stalmeier, P.F.M.** Nijmegen Institute for Cognition and Information, University of Nijmegen, Holland	Yes Stalmeier et al. (1999). Medical Decision Making, 19 (3), 230-241.	Quantitative one group pretest-posttest design	decision uncertainty, decision burden, subjective knowledge, risk comprehension
Br	First Author	SDMP (Shared Decision Making Program) (1995, 2000) tool may be obtained later in year once evaluation is completed	-	**Stalmeier, P.F.M.** Nijmegen Institute for Cognition and Information, University of Nijmegen, Holland	Stalmeier, PFM (1998). Medical Decision Making,18 268. Stalmeier, PFM (199). Medical Decision Making,19 230. Stalmeier, PFM (2000). Medical Decision Making,20 251. New SDMP evaluation in progress - randomizing 1.a new brochure plus video, 2. Time tradeoff plus formal decision analytic counseling - publication will be 2 years - will be able to disseminate tool once patients recruited	initial evaluations used pretest-posttest design	DK (have not been able to retrieve articles)

Br **	First Author	Hereditary Breast Cancer	Booklet and audiotape Information about hereditary breast cancer to facilitate understanding of whether there is increased risk and need to seek more information from a doctor	**Carroll et al, and the Canadian Cancer Society**	process used to develop booklet published in: Health Expectations, 1999, 2, 118-128. Carroll, J. (2000). A Community Study of an Information Aid for Women with a Family History of Breast Cancer. At: http://www.cfpc.ca/FMF/abstracts2000/abstract1.htm (under peer review)	one group pre-test-posttest design to measure anxiety, knowledge and screening attitudes (for women) q′aire to measure satisfaction with information aid physicians completed q′aire on satisfaction with aid	acceptability of aid and physician information package in family practice impact on breast cancer-related knowledge, anxiety, risk perception and attitudes towards screening
Br	Key Informant	Genetic Testing for Breast Cancer Risk: It′s Your Choice	This booklet provides an overview on genetic testing for breast and ovarian cancer risk. It describes testing and explains terms like family history, genes and genetic testing	**National Cancer Institute** see https://cissecure.nci.nih.gov/ncipubs/searchResults.asp?subject2=Genetics	N	-	-
Br	Key Informant	Genetic Testing for Breast Cancer Risk: It′s Your Choice	This booklet provides an overview on genetic testing for breast and ovarian cancer risk. It describes testing and explains terms like family history, genes and genetic testing	**National Cancer Institute** see https://cissecure.nci.nih.gov/ncipubs/searchResults.asp?subject2=Genetics	N	-	-

var	Key Informant	Understanding Gene Testing	This 30-page booklet explains what genes are, how they work, and how faulty genes trigger disease such as cancer. It discusses the benefits and limitations of gene testing and the role of genetic counselors.	**National Cancer Institute** see https://cissecure.nci.nih.gov/ncipubs/searchResults.asp?subject2=Genetics	N	-	-
Br	Key Informant	Understanding Cancer & Genetics	CD-ROM & flip book for patients	**University of Michigan** health media research lab and oncologists www.mi-cancergenetics.org	evaluation of CD in progress flip book not evaluated formally	RCT - CDROM + counselling vs. counselling only	knowledge about cancer and genetics
Br **	Survey Respondent Literature Review	1. Breast Cancer in the Family 2. Genetic Testing in Breast Cancer Families	2 Videos	**Imperial Cancer Research Fund** Medical Oncology Unit Western General Hospital Edinburgh	Cull et al. British Journal of Cancer 1998; 77(5):830-837.	RCT	DK
Br Ov **	survey	Understanding Hereditary Breast and Ovarian Cancer	booklet which includes review of information re: hereditary breast and ovarian cancer as discussed in a genetic counselling session	**Hereditary Cancer Program** BC Cancer Agency	Y in house, informal evaluation consisting of physician feedback and forms	-	-

var **	survey	Hereditary Cancer: Is my Family at Risk?	Goal is to help people recognize that most cancer is NOT hereditary, therefore genetic testing would not be indicated. It is distributed through physician offices, mammography clinics, BCCA public events, CCS information line (BC office), etc. Booklet and Video - to complement genetic counseling and can be provided beforehand (video is currently in development)	**Hereditary Cancer Program** BC Cancer Agency	Y in house, informal evaluation consisting of physician feedback and forms	–	-
Br **	survey	Genetics: Is Breast Cancer Inherited?	Video 20 minute video designed 'for women who may have a high chance of breast cancer because of their family history. It describes the role genes play in breast cancer, genetic testing and some of the management options.'	**Hereditary Cancer Clinic,** Prince of Wales Hospital, Sydney, Australia produced with the assistance of the NSW Genetics Education Program	Y in house, focus group evaluation	-	-

var	key informant	GREAT - Genetic Risk Easy Assessment Tool (currently in development	automated interview provided via Internet or phone, pedigree created up to 3rd degree relatives, pedigree e-mailed to user	**L. Acheson** Case Western Reserve University	evaluation planned	comparison of GREAT pedigrees with genetic counsellor pedigrees to examine: i. Risk assessments; ii. agreement within each category of relatives	
Br Ov **	-	Understanding How Breast and Ovarian Cancer Can be Inherited	-information leaflet to guide individuals in their consideration of genetic testing	**Ontario Cancer Genetics Network**	-	-	-

APPENDIX B: Table 2: Educational Tools for Primary Care Practitioners

** copy of educational tool has been obtained by the consultant

Disease Site/s	Source (Lit Review, Key Informant, web site, etc.)	Title of Educational Tool	Description (audience, purpose, etc.) Purpose of Tool	Year, Developer & Location	Evaluated? (Y/N) Published? Peer-Reviewed? In-house?	Type of Evaluation? Study design?	Outcomes / Indicators
Br Ov	-key informant -Literature Review	Risk Assessment in Genetics (RAGs) http://www.acl.icnet.uk/lab/react.htm. ** is possible to obtain copy but need to discuss further with developers - contact is John Fox at jf@acl.icnet.uk video of RAGs in use available on-line at www.openclinical.org	computer program to support primary care providers in recording and interpreting family histories of breast and ovarian cancer	**Jon Emery**, ICRF General Practice Research Group, Oxford	1. Emery, J, et al (1999). BMJ, 319: 32-36. 2. Emery, J, et al (2000). BMJ, 321: 28-32.	1.qualitative evaluation using semi-structured interviews video recordings of simulated consultations 2. Quantitative evaluation, comparative study with simulated cases, RAGs compared to Cyrillic (pedigree drawing program for clinical geneticists) and to pen & paper, crossover experiment with balanced block design	1. use of computer program - how program worked 2. # appropriate management decisions, mean time to decision

Br Ov **	Myriad Genetics web site	BRAC Analysis - For genetic suscepbility to breast and ovarian cancer: Physician Guide	Resource package to give preview of comprehensive BRCA1 and BRCA2 sequence testing Package includes: info re: frequency of BRCA1/2 mutations and tamoxifen risk, family history q′aire, patient consent form, genetic testing authorization form, price list, as well as patient info package	**Myriad Genetics** and MDS	N	-	-

HNPCC **	Myriad Genetics web site	COLARIS - Genetic testing for hereditary nonpolyposis colorectal cancer: Health care Professional Resource Package	Resource package to give preview of comprehensive genetic susceptibility testing for gene mutations in the determination of HNPCC cancers. Package includes: 3 peer-reviewed articles, family history q′aire, patient consent form, genetic testing authorization form, price list, as well as patient info package	**Myriad Genetics and MDS**	N	-	-
Br Ov HNPCC **	Myriad Genetics web site	Genetic Susceptibility Testing for Hereditary Breast and Ovarian Cancer and Nereditary Nonpolyposis Colorectal Cancer (HNPCC): A patient counseling aid for health care professionals	flip chart for health care professionals - designed to facilitate a discussion of hereditary cancer risk between health care professionals and patients	**Myriad Genetics**	N	-	-

n/a **	First Author Key Informant	The New Genetics: Courseware for Physicians can be ordered for $59.95 at: http://www.ornl.gov/hgmis/publicat/twistedladder/	CD-ROM for physicians who wish to update their knowledge of genetics and genomics -CME credits are available through Stanford U. Includes lessons on 1. genetics, 2. Techniques, 3. Clinical Applications, 4. Implications	2001. Twisted Ladder Media **Tobin, S.** PhD, MSW, Research Scholar, Program for Genomics, Ethics & Society, Standford Center for Biomedical Ethics, Stanford University. **Boughton, A.** Twisted Ladder Media	Y In house evaluation funding to this point has focused primarily on development	beta version of CD-ROM circulated to physicians across the US	-software design -physician knowledge
n/a	first author	CD-ROM for practicing and student nurses	to educate nurses about genetic testing, ethics, and nursing responsibilities for persons considering genetic testing	in development **Janet Williams**, College of Nursing, U of Iowa **Dr. Patricia Donahue**	n/a evaluation components built into development and testing phases	-	-
n/a	web site genetic counselor	ONCOSEP: GENETICS	comprehensive self-education tool to aid learners in developing competencies in genetic counseling, risk assessment and specific areas of genetic disease.	**ASCO** (American Society of Clinical Oncology) **http://www.asco.org/prof/ps/html/m_oncosep-genetics.htm** for purchase	N	-	-

var	genetic counselors	Greenwood Genetic Counseling Aid available for purchase for $50	flip book of karyotypes, AR inheritance, etc.	**Greenwood Genetic Testing Centre** 1 Gregor Mendel Circle / Greenwood, South Carolina 29646 1-864-941-8100 or 1-888-GGC-GENE	N	-	-
Br	Key Informant	Genetic Testing for Breast Cancer Risk: It's Your Choice (kit)	This kit for health professionals contains a 14 minute video, an accompanying booklet and fact sheet which present a balanced view of genetic testing for breast and ovarian cancer. The video and booklet, co-produced by NCI and the National Action Plan on Breast Cancer, may be used to facilitate education with women considering genetic testing.	**National Cancer Institute** can be ordered for free at: https://cissecure.nci.nih.gov/ncipubs/searchResults.asp?subject2=Genetics	N	-	-

var	Key Informant	1. Booklet on Genetic Counseling 2. Genetics and Your Practice 3. Our Genetic Heritage	1. Genetic Counseling - how family histories can predict birth defects 2. interactive CD-Rom. - how to integrate genetic information into patient encounters 3. video (1987), 14 minutes	**March of Dimes** can be ordered for minimal charge at: http://www.modimes.org/HealthLibrary2/Catalog/Genetics_BD/default.htm	N	-	-
var	Organization Web Search	Genetics and Your Practice	http://mchneighborhood.ichp.edu/wagenetics/906317226.html	**Robert Fineman** Washington State Dept of Health	N	-	-
var	Organization Web Search	on-line Family History Tools - includes family history forms, genetic screening questionnaires, sample pedigree	http://www.ama-assn.org/ama/pub/category/2380.html	**American Medical Association**	N	-	-

Br ** 	First Author	Hereditary Breast Cancer	Physician information package Information about hereditary breast cancer , triage and management recommendations, Ontario Breast Screening Program sites, outline of genetics consultation procedure, reference list	**Carroll J, Warner E and the Canadian Cancer Society**	process used to develop booklet published in: Health Expectations, 1999, 2, 118-128.	physicians completed q′aire on satisfaction with aid	acceptability of aid and physician information package in family practice
var **	survey	Physician Information Package	provided to physicians upon request to facilitate appropriate referrals includes cover letter, referral criteria, description of HCP, referral forms, family history forms, sample family histories	**Hereditary Cancer Program** BC Cancer Agency	N	-	-
Br Ov **	survey	For Health Care Professionals: Answers to Commonly Asked Questions about HBOC	provided to physicians upon request to facilitate appropriate referrals pamphlet added to requests related to breast/ovarian cancer	**Hereditary Cancer Program** BC Cancer Agency	N	-	-

HNPCC **	key informant	Identifying and Managing Risk for Hereditary Nonpolyposis Colorectal Cancer and Endometrial Cancer	Continuing Medical Education Program	**American Medical Association & American Gastroenterological Association**	-	-	-
Br Ov **	key informant	Identifying and Managing Hereditary Risk for Breast and Ovarian Cancer	Continuing Medical Education Program	**American Medical Association**	-	-	-
var **	NCHPEG web site	InfoGenetics (c) version 3.0	CD-Rom containing 6 decision support tools	**Division of Medical Genetics, Dept. of Pediatrics, Eastern Va. Medical School**	-	-	-

APPENDIX C: Table 3: Web-Based Educational Tools

Web Site	URL	Late Onset Condition/s	Description (Format & Content)	Audience
Myriad Genetics Corporate	http://www.myriad.com/gt.html	Hereditary Breast Cancer Hereditary Colon Cancer	Web based information risk perception and understanding hereditary risk : Family history Finding risk assessment centre, Medical management options, Insurance implications	Patient
GeneTests ™ University of Washington / Seattle, Funded by National Library of Medicine	http://www.genetests.org/ *need to register	Various *not restricted to late onset disorders	Web-based information for consumers Teaching Module designed for professionals to use in the instruction of non-genetics healthcare practitioners.	Patient / Provider
GeneClinics ™ University of Washington / Seattle, Funded by National Library of Medicine	http://www.geneclinics.org/index.html	Various	-clinical genetic information resource (expert-authored, peer-reviewed) with concise descriptions of specific inherited disorders and current information on the role of genetic testing in the diagnosis, management, and genetic counselling of patients with these inherited conditions -Web-based, disease-specific information for various heritable conditions -Links to a genetics laboratory directory, genetics clinic directory, and educational materials (via GeneTests)	Provider

Genetic Health	http://www.genetichealth.com/ (Key informants indicated that this company has folded recently)	Alzheimer's Breast Cancer Colon Cancer Diabetes Heart Disease Hemochromatosis Ovarian Cancer	Web-based information on each condition (focuses on: i) general information about disease; ii) familial patterns of disease; iii) whether gt is available; iv) whether should consider gt; v) how to lower risk) Interactive tool to create family medical history ('Family Tree Builder') Interactive risk assessment tool	Patient / Provider
GenAssist	http://www.genassist.com/ *focus on prenatal conditions, but is focus on creating familial risk profile	Prenatal screening	Paternal and Maternal Risk Assessment Construct a family genetic profile for use by clients in concert with their physicians	Patient / Provider
My Genetic MD	http://www.dnamd.com/dnamd/home.asp *focus on prenatal and late onset conditions, emphasis on prenatal testing	various	information on genetic consultations and various inherited conditions (prenatal, late onset)	patient
GeneSage USA Private-Public	http://www.genesage.com/products/consumers/genebenefit.html http://www.genesage.com/products/providers/genesagerx.html http://www.genesage.com/products/consumers/genebenefit.html	various	GeneSageRx to help providers and consumers with immediate access to accurate clinical information and services related to genetic medicine. Will be available through health plans and institutions Includes GeneLetter, a newsletter with latest research findings and discussion of issues related to genetics	Patient / Provider

FORCE USA Non-profit organization	http://www.facingourrisk.org/ self-help approach		Focus on directing individuals to places / people for risk assessment	patient
Genetics Education Centre University of Kansas Medical Centre	http://www.kumc.edu/gec/ http://www.kumc.edu/gec/geneinfo.html		includes information on various types of educational resources, including books, videotapes, etc. Lists professional associations -focussed specifically on information for genetics professionals, but may also be of interest to primary care providers -includes genetics courses and lectures for medical professionals, pedigree drawing computer software	Patient / Provider
Your Genes Your Choices American Association for the Advancement of Science	http://ehrweb.aaas.org/ehr/books/contents.html	Various	Web-based brochure/book describes the Human Genome Project, the science behind it, and the ethical, legal, and social issues that are raised by the project.	Patient

Cancer Risk Assessment Patricia Kelly, PhD Medical Geneticist	http://www.dnai.com/~ptkelly/	Breast Cancer Ovarian Cancer Uterine Cancer Prostate Cancer Colon Cancer	assess hereditary and non-hereditary risks of cancer; provide information about these risks to enhance informed choices about genetic testing. -Services for Health Professionals include help to set up and provide high quality cancer risk counselling services, including counselling for genetic testing. -customized to meet individual and institutional needs; individualized consultations on risk assessment, patient concerns, and evaluation of scientific studies done by telephone, fax, and E-mail.	Patient / Provider
National Cancer Institute (US)	http://cancernet.nci.nih.gov/genetics/genetics_information.htm	Various Cancers	links to brochures for patient education, policy position statements, etc.	Patient / Provider
National Cancer Institute (US)	http://rex.nci.nih.gov/NCI_PUB_INDEX/GENBRST/INDEX.HTM	Breast Cancer	Web-based brochure Genetic Testing for Breast Cancer Risk: It's Your Choice	Patient
Cancer Genetics Services Directory NCI	http://cnetdb.nci.nih.gov/genesrch.shtml	Various	to assist in finding providers in cancer genetics services	Patient / Provider
Understanding Gene Testing US Dept of Health and Human Services	http://www.accessexcellence.org/AE/AEPC/NIH/index.html	na	web based brochure	Patient

GENETIC TESTING AND THE ASHKENAZI JEWISH WOMAN: A Guide for the Informed Consumer Columbia College of Physicians and Surgeons	http://www.societyandmedicine.org/breastcancerfinal.htm	breast cancer ovarian cancer	web based paper	Patient
Primer on Molecular Genetics Dept. of Energy	http://www.ornl.gov/hgmis/publicat/primer/intro.html	na	primer to genes, DNA, and chromosomes, mapping and sequencing and interpreting genetic information	-
Videos on Genetics and the Human Genome Project	http://www.ornl.gov/hgmis/education/videos.html#genetic	various	various videos for order that deal with issues influencing decision-making. Videos include: *A question of genes: Inherited Risks* *The Burden of Knowledge* *Deadly Inheritance* *Gene Blues: Dilemmas of DNA Testing* *Promise and Perils of Biotechnology*	patient
Know your Genes	http://www.knowledgene.com/	various	interactive community dedicated to providing genetic services and information to consumers and health care professionals	patient / provider (primary care physician, obgyn)
Breast Cancer & Genetic Screening US Govt, Human Genome Project, ELSI	http://www.lbl.gov/Education/ELSI/screening-main.html	breast cancer	web based information	patient

Breast Cancer Risk Assessment Tool NCI / NIH	http://bcra.nci.nih.gov/brc/	breast cancer	interactive risk assessment tool including questions on family history	provider
Ethical Issues: Genetic Testing and Alzheimer Disease Alzheimer Society of Canada	http://www.alzheimer.ca/alz/content/html/care_en/care-ethics-geneticstest-eng.html	Alzheimer's disease	discusses ethical issues related to genetic testing for Alzheimer's	provider
Cancer Genetics Education Program Dept. of Clinical Cancer Genetics, City of Hope	http://www.infosci.coh.org/ccgp/cgep.htm *must register	--	--	provider / patient
Does Cancer Run in Your Family? Understanding Inherited Risk Canadian Cancer Society	http://www.cancer.ca/info/pubs/content/genrisk/gnriske2.htm	breast cancer, ovarian cancer, colon cancer, familial medullary thyroid carcinoma, retinoblastoma, Li-Fragment syndrome, Wilds' tumour, von Hipped-Landau syndrome	web-based booklet discusses risk assessment	patient
Breast Cancer and Family History: What you need to know National Breast Cancer Centre	http://www.nbcc.org.ca	Breast cancer	web-based booklet discusses risk assessment and genetic testing	patient

The Huntington's Disease Assn Online private & corporate sponsorship UK	http://www.hda.org.uk/	Huntington's Disease	Web brochure Facts Sheets	Patient
The Huntington Society of Canada	http://www.hsc-ca.org/english/dloads.shtml	Huntington's Disease	Web Brochures and Publications on variety of topics	Patients, Families, Physicians
Genetic Testing for Huntington's Disease: A Guide for Families Huntington's Disease Society of America	http://www.lkwdpl.org/hdsa/hdtest.htm	Huntington's Disease	Web brochure HD and the HD gene Genetic Testing Resources and Research	Patient
Educational Tools & Fact Sheets University of South Dakota School of Medicine	http://med.usd.edu/som/genetics/curriculum/TableofContents.htm	Huntington's Disease (plus others)	Facts Sheets Visual Aids (genetic mutations, family history)	Practitioner
The Family Medicine Genetics Program Mt. Sinai Hospital Toronto, ON Canada	http://www.mtsinai.on.ca/familymedicine/genetics/	Alzheimer's Disease Cystic Fibrosis Hemochromatosis Huntington's Disease (to be expanded)	practical, current information regarding screening and prevention of hereditary disorders genetic web links for the family doctor	Family Physicians

Genes at Work Center for Human and Molecular Genetics University of Medicine and Dentistry of NJ - NJ Medical School	http://www.umdnj.edu/genesweb/	thrombophilia cancer	brochures and factsheets for patients and professionals	Primary care practitioners (including pediatricians, obstetricians, internists, family practitioners and advanced nurse practitioners)
Greenwood Genetic Center Greenwood Genetic Center 1 Gregor Mendel Circle Greenwood, South Carolina 29646	http://www.ggc.org/educ.html 1-864-941-8100 or 1-888-GGC-GENE	various	educational resource - includes FAQs about genetic counselling, information on patient support groups, professional training programs, web resources Counselling Aids for Geneticists (1995) available for $50	practicing physicians, physicians in training, health care workers, educators, and general public
ASCO American Society of Clinical Oncology	http://www.asco.org/prof/ps/html/m_oncosep-genetics.htm http://www.asco.org/prof/pp/html/m_genint.htm	various cancers	to aid learners in developing competencies in genetic counselling, risk assessment and specific areas of genetic disease. ONCOSEP: Genetics was developed in conjunction with the ASCO Task Force on Cancer Genetics Education. ONCOSEP Genetics -consists of text book, clinical scenario book, answer book, CD-ROM (CME credit available) Curriculum on Cancer Genetics & Cancer Predisposition Testing	oncology professionals

NSGC National Society for Genetic Counsellors, Inc.	http://www.nsgc.org/faq_consumers.asp	not specified	what to expect from genetic counselling	consumer
NCI CancerWeb National Cancer Institute	http://www.graylab.ac.uk/cancernet/810334.html	various	Elements of Cancer Genetics Risk Assessment and Counselling -describes current approaches to assessing and counseling patients about their chance of having an inherited susceptibility to cancer -includes sections on family history taking, risk perception, risk communication, risk management	
NCI National Cancer Institute	http://rex.nci.nih.gov/behindthenews/ugt/ugthome.htm	various cancers	This is an illustrated, web-based module designed to translate complex biomedical concepts into understandable and accurate information. It illustrates what genes are, and explains how mutations occur and describes gene testing	public health professional
Breast Cancer Genetic Network University of Michigan	http://www.mi-cancergenetics.org/resources/hereditary.html	hereditary breast cancer	list of hereditary predisposition resources on other web sites (e.g. NCI)	patients, public
Breast Cancer Genetic Network University of Michigan	http://www.mi-cancergenetics.org/living/index.html	hereditary breast cancer	web-based information from CD-ROM tool ‘Understanding Cancer and Genetics’	patients

National Coalition for Health Professional Education in Genetics AMA, ANA, NHGRI	http://www.nchpeg.org	various	national effort to promote health professional education and access to information about advances in human genetics contains information and links to other web sites and web-based tools can obtain copies of paper "Core Competencies in Genetics Essential for All Health-Care Professionals"	health professionals
Familial GastroIntestinal Cancer Registry Mt. Sinai Hospital Toronto, ON	http://www.mtsinai.on.ca/familialgican/	HNPCC	The Registry provides information for FAP and the polyposis syndromes to affected families across Canada and for HNPCC to Ontario families.	Patient
Mid-Atlantic Cancer Genetics Network Regional Center of the National Cancer Genetics Network	http://www.macgn.org/	cancer genetics, inc. breast/ovarian, colo-rectal, & prostate	The MACGN consists of researchers, physicians, genetic counsellors, nurses, and cancer patients and their families in the mid-Atlantic region includes various tools, including on-line brochures	Health Professionals General Public
Cancer Genetics Network Duke Comprehensive Cancer Center, Duke University	http://cancer.duke.edu/CGN/	various	The Network provides a resource to support collaborative investigations into the genetic basis of cancer susceptibility, integrate this new knowledge into medical practice, and address the psychosocial, ethical, legal, and public health issues associated with inherited susceptibility to cancer.	

New South Wales Genetics Education Program Australia	http://www.genetics.com.au/	various	includes various components, including general genetics facts, family health tree guide, books and pamphlets, support groups	Professional Patient
National Breast Cancer Centre Source New South Wales, Australia	http://www.nbcc.org.au/pages/info/risk.htm	breast cancer		
Federation of American Societies for Experimental Biology (FASEB)	http://www.faseb.org/genetics/careers.htm	na	includes various links to continuing medical education resources and medical school curriculum in genetics	Professional
Hereditary Cancer Program BC Cancer Agency	www.bccancer.bc.ca *currently under construction	various	info for providers describes: hereditary cancer syndromes, criteria for referral for genetic counselling & provides links to the referral forms, some cancer screening guidelines, process of genetic counselling & testing, etc.	Professional Patient
Breast Cancer and Family History: What you Need to Know NHMRC National Breast Cancer Centre New South Wales Australia	http://www.nbcc.org.au/pages/info/resource/nbccpubs/bcfamily/contents.htm	breast cancer	on-line booklet, reviews hereditary breast cancer and includes on-line self risk assessment tool	Patients
Drawing Your Family Health Tree Guide New South Wales Genetics Education Program	http://www.genetics.com.au/	various	assists in constructing a family health tree	Patient

Current best advice about familial aspects of breast cancer: a guide for general practitioners National Breast Cancer Centre	http://www.nbcc.org.au/pages/info/resource/nbccpubs/advice.htm	breast cancer	assists in understanding familial patterns, taking family history, levels of evidence, risk assessment, and referral making	Physician
Current best advice about familial aspects of Bowel Cancer: a guide for general practitioners Anti-Cancer Council of Victoria	http://www.accv.org.au/cancer1/professionals/gpbowelchart.htm	bowel cancer	assists in understanding familial patterns, taking family history, role of family cancer clinics, risk assessment and management	Physician
Victorian Family Cancer Genetics Service Anti-Cancer Council of Victoria	http://www.accv.org.au/cancer1/professionals/vcfgsbroc.htm	various	reviews services provided by family cancer genetics services, how to make appointment, provides referral forms	Patient
Genetics and Disease Prevention: Genomic Competencies for the Public Health Workforce CDC	http://www.cdc.gov/genetics/training/competencies/default.html	n/a	reviews core competencies in genomics for various types of health practitioners	various health professionals

Cancergene University of Texas Southwestern Medical Center at Dallas	http://www.swmed.edu/home_pages/cancergene/ can be ordered free of charge at http://www.swmed.edu/home_pages/cancergene/getting.htm	various	a computer program for estimating the likelihood that a family carries a mutation in one of the cancer predisposition genes Uses Duke University's BRCAPRO program to calculate statistical risk	health professsionals
Health Heritage **University of Virginia**	http://www.healthheritage.net/	various (approx. 90 conditions)	assess risk of various health conditions using family history information entered by user under development	Patients
Mountain States Genetic Network	http://www.mostgene.org/support/index.html	various	peer-reviewed web site or sharing medical genetics knowledge and resources with other health care practitioners, patients, and caregivers. Includes on-line publications, directory of genetic services & genetic support groups	Patients, Providers
Online Mendelian Inheritance in Man (OMIM) **National Center of Biotechnology Information**	http://www3.ncbi.nlm.nih.gov/Omim/	na	encyclopaedic resource including a database of textual information, pictures, and reference information on human genes and the genome	physicians, researchers
Office of Genetics and Disease Prevention **Center for Disease Control & Prevention**	http://www.cdc.gov/genetics/default.htm	na	includes on-line presentation, training opportunities, events listings and genomic workforce competencies	physicians and public health professionals

Genetics Resource Center **University of Pittsburgh**	http://www.pitt.edu/~edugene/resource/	na	online resource for and starting point for genetic counselling-related information includes a variety of public health education resources, including brochures, community education workshops an Online Genetics Learning Environment for Physicians	physicians, patients
CancerNet **National Cancer Institute**	http://cancernet.nci.nih.gov/genetics_prevention.html	various cancers	authoritative resource on cancer genetics	physicians, patients
Genetic Alliance	http://www.geneticalliance.org/	various	coalition representing more than 300 consumer and health professional organizations includes help line with genetic counselling services, links to ethical, legal and social issues,	patients
AMA CME - Ethical Issues in Genetic Testing for BRCA1 and BRCA2 **American Medical Association**	http://www.ama-assn.org/ama/pub/category/3634.html	na	beta version of on-line CME module focussing on ethical issues related to genetic testing module covers issues related to ethics in general, ethics of genetic testing, and provides a case study	physicians
Clinical Genetics: A Self Study for Health Care Providers **Virtual Hospital, University of South Dakota School of Medicine**	http://www.vh.org/Providers/Textbooks/ClinicalGenetics/Contents.html	na	electronic medical genetics text book	physicians

The Human Genome Education Model Project II **Georgetown University**	http://www.gucdc.georgetown.edu/hugem/	na	web site devoted to education on the new & genetic issues for health care professionals	providers
The Genetics Program for Nursing Faculty **Children's Hospital Medical Center, Cincinnati**	http://www.cincinnatichildrens.org/education/gpnf/	na	multifaceted genetics educational program for nursing faculty -funding by ELSI	nurses, physicians
InfoGenetics (c): Web Manager and Clinical Practice Tools	http://www.infogenetics.org/index.htm	various	genetics database accessible through either this web site or a stand-alone CD-ROM includes links to information on genetic contacts, support groups, genetic tests, cancer genetics, clinical care guidelines	health care providers

Appendix D - Literature

Relevant Literature on Educational Tools for Genetic Testing

Educational Tools & Evaluation Studies

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Health Canada Project

To Identify Educational Tools for Patients and Primary Care Providers Pertaining to Adult Onset Disorders for which Genetic Testing is Available

I am writing to you on behalf of Health Canada to request your participation in a consultation to identify and evaluate decision-making aids currently in use or in development to assist in professional and public education about genetic testing for late onset diseases. As part of this review, PICEPS Consultants, Inc., has been contracted to conduct interviews in May, 2001. You are being asked to participate in an interview because we feel that you are in a unique position to provide guidance and insight into the issues concerning the educational requirements necessary to assist in decision-making about genetic testing for late onset disorders. The interview will also take place by telephone, and will require about 30 to 45 minutes of your time.

Each interview will be conducted in the strictest confidence. PICEPS Consultants, Inc., will prepare a report that summarizes the responses made by everyone who is interviewed during this consultation. The names of individuals who agree to participate in the interviews will not be included in the report, nor will remarks or responses be attributed to any of the interview participants.

Attached is documentation to facilitate the interview process, including a copy of the interview questions and a consent form. The consent form describes the project and your role should you decide to participate. **If you agree to participate in the interview, we ask that you please sign the informed consent form and fax it me, Dr. Fred Ashbury, at 905-668-5205.** If you have any questions, please contact me at 905-668-8891. Should you agree to participate in an interview, someone will contact you to schedule a time that is convenient for you.

Thank you for considering to take part in this consultation.

Sincerely,
Fred Ashbury, PhD
President
PICEPS Consultants Inc.
tel: 905-668-8891
fax: 905-668-5205
Attachments.

Interview Questions

Please note that tools pertain to information aids and/or decision-making aids to educate patients and/or primary care practitioners about genetic testing for adult onset disorders. This may include, but is not limited to, tools that aid the processes of family history taking, risk assessment, risk communication, genetic counselling, and may include different formats such as CD-ROM, Internet, brochures, video, audio, etcetera.

1. Do you know of any tools that are used to educate patients and/or primary care practitioners about genetic testing for adult onset disorders? What are they? Who developed them?

2. What is the purpose of each of these tools? What issues are they designed to address? For whom are the tools designed (e.g. to educate patients and/or to educate primary care providers)?

3. Which of these tools, if any, do you use currently? Why did you decide to use this (these) particular tool(s)?

   (If yes) How have you used this (these) tool(s) in your work? In what ways has (have) this (these) tool(s) been effective? How could the effectiveness of this (these) tool(s) be improved? What barriers, if any, have hindered the effectiveness of this (these) tool(s)? How did you address these barriers?

4. Do you know whether this (these) tool(s) has (have) been evaluated?

   (If yes) How has (have) it (they) been evaluated? Do you know if this evaluation has been published?

5. Have you evaluated the effectiveness of the tool(s) that you use?

   (If yes) How did you evaluate this (these) tool(s)? What indicators or criteria did you use to demonstrate this (these) tool(s) effectiveness?

   (If no) If you were going to evaluate this (these) tool(s), what indicators or criteria would you use to demonstrate its effectiveness?

6 Have you decided if you will use any other tools in your work? Please explain.

7. Do you think there are gaps in the types of tools that are being developed to assist patients and primary care practitioners about genetic testing for late onset disorders? Please explain.

8. Are you aware of any tools that are currently under development? What are they? Who (what organization) is developing the tool?

9. Are there any other issues or observations we should consider in making recommendations to Health Canada about which tools should be used to educate patients and primary care providers about genetic testing for adult onset disorders?

10. Can you suggest any other individuals or organizations that we should contact as part of this consultation?

CONSENT FORM

Project Title: **Educational tools which relate to adult-onset disorders for which genetic testing is available.**

Purpose: To identify:

1. Educational tools currently in use, or in development, for public and professional education related to genetic testing for adult onset disorders
   ** Please note that tools' pertain to information aids and/or decision-making aids to educate patients and/or primary care practitioners about genetic testing for adult onset disorders. This may include, but is not limited to, tools that aid the processes of family history taking, risk assessment, risk communication, genetic counselling, and may include different formats such as CD-ROM, Internet, brochures, video, audio, etcetera*.
2. .Appropriate criteria to assess these educational tools to determine their effectiveness.

Procedure: A copy of the interview questions that we would like to ask you during the telephone interview has been enclosed for your review. A member of PICEPS Consultants, Inc. will contact you in the next few days to arrange a mutually convenient interview time. At this time the person will confirm that you have reviewed the information contained herein, and assess your interest in participating in the interview. We will require this form to be signed by you and returned by fax before we can conduct the interview.

The interview will require 45 minutes to complete. You may refuse to answer any questions.

Confidentiality: All information you provide will be kept strictly confidential. No identifying information will be included in any reports or summaries of this research.

I have read the information and I agree to participate in the telephone interview. I understand that I am free to withdraw at any time without any consequence to me. I understand that I may contact Dr. Fred Ashbury of PICEPS Consultants at (905) 668-8891 at any time if I have questions.

Name:_____

Signature:_____

Date:_____

PLEASE FAX THE COMPLETED FORM TO
DR. FRED ASHBURY AT 905-668-5205.
Thank you.

Appendix F - Email Survey

I am writing you to ask for your assistance in the identification of educational tools that are used to facilitate the education of patients and primary care providers regarding genetic testing for adult onset disorders.

I am contacting you as a representative of PICEPS Consultants, Inc., which is currently under contract to Health Canada to compile a representative sample of information aids and decision-making tools that are currently in use, or in development, to educate primary care providers and/or patients about genetic testing for adult onset disorders.
Given your expertise and professional background in this area, we feel that you may be able to assist us in developing an inventory of tools that is comprehensive, and that includes examples of innovations that may be in developmental stages.

To this end, it would be most appreciated if you could reply and answer the questions listed below. Please note that this information will be used to guide our efforts as we compile the inventory of educational tools for Health Canada. Your information will NOT be used for commercial purposes.

If you should have any questions about this request for information, please do not hesitate to contact Dr. Fredrick Ashbury at 905-668-8891.

Thank you very much for your assistance.

Sincerely,

Jessica Polzer
Project Coordinator for
PICEPS Consultants, Inc.

QUESTIONS:

For the following questions, 'tools' includes, but is not limited, to information and/or decision-making aids that aid the processes of family history taking, risk assessment, risk communication, genetic counselling, and may include different formats such as CD-ROM, Internet, brochures, video, audio, etcetera.

1. Do you know of any tools that are being used (by you or anyone in your organization) to educate patients and/or primary care practitioners about genetic testing for adult onset disorders? What are they? Who developed them?

2. Do you know if it is possible to receive a copy of this / these tool(s)? If so, from where can we receive a copy of the tool(s)?

3. Do you know if there is any documentation available on the processes that were used to develop these tools? If so, where can we find this documentation?

4. Do you know if these tools have been evaluated? If so, do you know if there is any documentation on the evaluation of these tools? Where can we find this documentation?

5. Would you like to receive a copy of the final report that we submit to Health Canada?

6. Is if ok to contact you again should we require any clarification of your responses?

7. Do you know of any other individuals, organizations or professional associations we should contact as part of our efforts to identify educational tools regarding genetic testing for late onset disorders?

Appendix G
Members of Canadian Association of Genetic Counsellors who Practice in Cancer Genetics or Adult Onset Disorders

Melyssa Aronson
Mount Sinai Hosp., Toronto
416-586-3154
maronson@mtsinai.on.ca

Craig Campbell
Saskatoon Cancer Centre
306-655-6717
ccampbell@scf.sk.ca

Mary Connolly-Wilson
Genetics Memorial Univ. NF
709-777-6223
mwilson@mun.ca

Heather Dorman
North York Gen. Hosp.
416-756-6000 x 4313
hdorman@nygh.on.ca

Alice Gibson
Royal Univ. Hosp., Saskatoon
306-655-1692
alice.gibson@usask.ca

Cathy Gilpin
CHEO, Ottawa
613-738-3979
gilpin@cheo.on.ca

Colleen Guimond
UBC Hosp. & HSC
604-822-7874
cguimond@helix.medgen.ubc.ca

Lidia Kasprzak
Royal Victoria Hosp, Montreal
514-842-1231 x 5745
lidia.kasprzak@muhc.mcgill.ca

Stephanie Kieffer
U of Alberta Hosp.
780-407-7336
skieffer@ualberta.ca

Jillian Murphy
Schizophrenia Res. Prog, CAMH
416-535-8501 x 2734
jillian_murphy@camh.net

Karen Panabaker
BC Cancer Agency
604-877-6000 x 2118
kpanabak@bccancer.bc.ca

Helene Perras
Eastern Ont. Genetics Program, Ottawa
613-738-3259
hperras@cheo.on.ca

Susan Randall
Familial Ovarian Ca clinic, PMH
416-946-2286
susan.randall@uhn.on.ca

Laura Robb
CHUM Familial CA clinic, Montreal
514-843-2622 x 4359
robbl@magellan.umontreal.ca

Gayle Sheridan
London Reg. Cancer Centre
519-685-8600 x 53252
gayle.sheridan@lrcc.on.ca

Susan Creighton
BC Children's & Women's Hosp.
604-875-3023
screighton@cw.bc.ca

Jenna Scott
BC Cancer Agency
604-877-6000 x 2197
jscott@bccancer.bc.ca

Tracy Robertson
Clinical Research Nurse
Hereditary Prostate Cancer Clinic
Tom Baker Cancer Centre
tracyrob@cancerboard.ab.ca

Appendix H - Genetic Risk Assessment Centres

Genetic Testing Centres
http://internaf.org/ataxia/genetest.html
List of genetic testing centres in UK and US

Moses Cone Health System's Regional Cancer Center, Chapel Hill, North Carolina
http://www.assoc-cancer-ctrs.org/pubs/julaug/genrisk_ja99.html

GENES - Genetics Network of New York, Puerto Rico, Virgin Islands
**Katharine B. Harris, MBA (Co-Coordinator)
kbh02@health.state.ny.us
Karen Greendale, MA (Co-Coordinator)
kxg03@health.state.ny.us

GLaRGG - Great Lakes Regional Genetics Group
Louise Elbaum, Coordinator
328 Waisman Center
1500 Highland Avenue
Madison, WI 53705-2280
Phone: (608) 265-2907
Fax: (608) 263-3496
e-mail: elbaum@waisman.wisc.edu

GPGSN - Great Plains Genetics Service Network
Dolores Nesbitt, PhD, Coordinator
Pediatrics/Medical Genetics
University of Iowa
Iowa City, IA 52242
Phone: (319) 356-4860
Fax: (319) 356-3347
e-mail: Dolores-Nesbitt@uiowa.edu (undeliverable)

MARHGN - Mid-Atlantic Regional Human Genetics Network
Gisela Rodriguez, MSW
Center for Human and Mol. Genetics
UMDNJ: New Jersey Medical School
Doctors Office Center, Ste. 5400
90 Bergen Street Newark, NJ 07103
Phone: (973) 972-3302
Fax: (973) 972-3310
e-mail: rodriggi@umdnj.edu

MSRGSN - Mountain States Regional Genetic Services Network
Joyce Hooker, Coordinator
Colorado Department of Health
FCHS-MAS-A4
4300 Cherry Creek Drive South
Denver, CO 80222-1530
Phone: (303) 692-2423
Fax: (303) 782-5576
e-mail: **joyce.hooker@state.co.us**

NERGG - New England Regional Genetics Group
Mary C. Aten will pass on email to NERGG BOARD OF DIRECTORS - 30/05/01 - WRITE BACK IF HAVE NOT HEARD ANYTHING IN 10 DAYS
New England Regional Genetics Group
P.O. Box 670

Mt. Desert, ME 04660
Phone: (207) 288-2704
Fax: (207) 288-2705
e-mail: **nergg@acadia.net**

PacNoRGG - Pacific Northwest Regional Genetics Group
Kerry Silvey, MA, Coordinator
CDRC - Clinical Services Building
901 E. 18th Avenue
Eugene, OR 97403-5254
Phone: (541) 346-2610
Fax: (541) 346-2624
e-mail: **kerry_silvey@ccmail.uoregon.edu** (undeliverable)

PSRGN - Pacific Southwest Regional Genetics Network
Pamela Cohen, M.S., C.G.C. , Coordinator
California Department of Health Services
2151 Berkeley Way
Annex 4
Berkeley, CA 94704
Phone: (510) 540-2852
Fax: (510) 540-2095
e-mail: **pcohen@dhs.ca.gov**

SERGG - Southeastern Regional Genetics Group
Mary Rose Lane, BS, Coordinator
Emory University
Pediatrics/Medical Genetics
2040 Ridgewood Drive
Atlanta, GA 30322
Phone: (404) 727-5844
Fax: (404) 727-5783 e-mail: **mrl@rw.ped.emory.edu**

TEXGENE - Texas Genetics Network
Diana Rosas, Coordinator
7703 Floyd Curl Dr
San Antonio TX 78284-7802
Phone: (210) 567-5194
Fax: (210) 567-5847 e-mail: **rosas@uthscsa.edu** (undeliverable)

Appendix I - Disease-Specific Organizations and Associations

Alzheimer's Disease

http://www.alz.org/	Alzheimer's Association
http://www.alzheimers.org/	Alzheimer's Disease Education and Referral Center
http://www.alzheimers.org.uk/	Alzheimer's Dementia Care and Research
http://www.alzforum.org/	Alzheimer's Research Forum

Cancer Associations

http://www.graylab.ac.uk/cancerweb/orgs/cancer.html	List of Cancer Organizations
http://cancernet.nci.nih.gov/	CancerNet
http://cancer.med.upenn.edu/about_oncolink/	OncoLink
http://www.mskcc.org/	The Memorial Sloan-Kettering Cancer Centre

Familial Melanoma

http://www.mayo.edu/research/melanoma/topic_625.html	Mayo Clinic (Rochester) Familial Melanoma Program

Polycystic Kidney Disease

http://www.niddk.nih.gov/health/kidney/pubs/polycyst/polycyst.htm	Information Clearinghouse
http://www.pkdcure.org/	The PKD Foundation

Myotonic Dystrophy

http://www.myotonicdystrophy.com/	International Mytotonic Dystrophy Organization

HNPCC

http://medicine.creighton.edu/medschool/PrevMed/hc.html	Hereditary Cancer Prevention Clinic, Creighton University Cancer Centre

Genome Research Institutes

http://www.nhgri.nih.gov/Data/	National Human Genome Research Institute: Researcher's Resources
http://www.nhgri.nih.gov/ELSI/	Ethical, Legal and Social Implications of Genetics Research

Huntington's Disease

http://www.hdsa.org/	HD Society of America
http://www.hda.org.uk/	HD Association On-line
http://www.hdfoundation.org/	Hereditary Disease Foundation
http://www.lkwdpl.org/hdsa/hdtest.htm	Genetic Testing for Huntington's Disease

Appendix J - Professional Genetics Associations Contacted

Canadian College of Medical Geneticists - B of Directors
Canadian Association of Genetic Counsellors
Canadian Collaborative Group for Cancer Genetics (CCGCG)
Canadian Directory of Genetic Support Groups
American College of Medical Genetics (ACMG)
National Society of Genetic Counselors (NSGC)
American Board of Genetic Counseling (ABGC)
American Board of Medical Genetics (ABMG) - just president since no emails
International Society of Nurses in Genetics (ISONG)
GenRISK (TM) Program
National Coalition for Health Professional Education in Genetics (NCHPEG)
Association of Professors of Human or Medical Genetics (APHMG)

Appendix K - Cancer Genetics Clinics in Canada

Province	Clinic Name	Clinic Staff
British Columbia		
Vancouver	BC Cancer Agency 600 West 10th Ave. Vancouver, BC, V5Z 4E6 Website: http://www.bccancer.bc.ca	Provincial Program
	Hereditary Cancer Program B.C. Cancer Agency - PFC 600 West 10th Ave Vancouver, BC, V5Z 4E6 Tel: (604) 877-6000 Ext. 2118 Fax: (604) 872-4596	Dr. Barbara McGillvray Karen Panabaker Jenna Scott
Victoria	Medical Genetics Victoria General Hospital 1 Hospital Way Victoria, BC, V8Z 6R5 Tel: (250) 727-4212 Fax: (250) 370-8750	Dr. Patrick MacLeod Myra Micek
Alberta	Alberta Cancer Genetics Program Division of Epidemiology Rm. AE173B, Tom Baker Cancer Centre 1331-29 St. NW Calgary, AB, T2N 4N2 Website: www.acgp.ca	Provincial Program
Calgary	Cancer Genetics Research Clinic Tom Baker Cancer Centre Rm. CC110, 1331 – 29 St. NW Calgary, AB, T2N 4N2 Tel: (403) 670-2438 Fax: (403) 283-1651	Dr. Rhiannon Hughes
Edmonton	Cancer Genetics Clinic Rm. 8-53 Medical Sciences Bldg University of Alberta Edmonton, AB, T6G 2B7 Tel: (780) 407-7333 Fax: (780) 407-6845	Dr. Dawna Gilchrist Stephanie Kieffer

Saskatchewan

Saskatoon

High Risk Breast Cancer
Assessment Clinic
Saskatoon Cancer Centre
20 Campus Drive
Saskatoon, SK , S7N 4H4
Tel: (306) 966-2113
Fax: (306) 655-2639
Email: highrisk.clinic@usask.ca

Dr. E. Lemire
Dr. S. Kanthan
Craig Campbell

Division of Medical Genetics
University of Saskatchewan
Royal University Hospital
Saskatoon, SK, S7N 0X0
Tel: (306) 655-1692
Fax: (306) 966-1736

Dr. E. Lemire
Wendy Stoeber
Sharon Cardwell

Manitoba

Winnipeg

Hereditary Breast Cancer Clinic
WHRA Breast Health Centre
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Dr. Bernie Chodirker
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Ontario

Ontario Cancer Genetics Network
Division of Preventive Oncology
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620 University Avenue
Toronto, ON, M5G 2L7
Website: http://www.cancercare.on.ca/prevention/ocgn.html

Provincial Program

Hamilton	Cancer Risk Assessment Clinic Hamilton Regional Cancer Centre 699 Concession Street Hamilton, ON, L8V 5C2 Tel: (905) 387-9495/971, x 65920 Fax: (905) 575-6326	Dr. Andrea Eisen Dr. Edmond E. Chouinard Ellen Irwin
	McMaster University Medical Centre Hamilton Health Sciences Rm 3N20 Genetic Services 1200 Main Street West Hamilton, ON, L8S 4J9 Tel: (905) 521-5085 Fax: (905) 521-2651	Dr. Ron Carter Laura Hunnisett, Gen. Couns. Kathleen Smyth
Kingston	Familial Oncology Program Kingston Regional Cancer Centre 25 King Street West Kingston, ON, K7P 2N7 Tel: (613) 544-2631 Ext. 4124 Fax: (613) 544-9708	
London	Cancer Genetics London Regional Cancer Centre 790 Commissioners Rd. London, Ontario, N6A 4L6 Tel: (519) 685-8727 Fax: (519) 685-8534	Dr. J. Jung Gayle Sheridan
Ottawa	Department of Genetics Children's Hospital of Eastern Ontario 401 Smyth Rd Ottawa, ON, K1H 8L1 Tel: (613) 738-3979 Fax: (613) 738-4822	Dr. Judith Allanson Cathy Gilpin

	Hereditary Colon Cancer Programme Loeb Health Research Institute Ottawa Hospital (Civic Site) 725 Parkdale Avenue Ottawa, ON, K1Y 4E9 Tel: (613) 798-5555 x 7805 Fax: (613) 761-5365	Dr. Alasdair Hunter Helene Perras
Sudbury	Familial Cancer Familial Cancer Risk Northeastern Ontario Regional Centre #116, 41 Ramsey Lake Road Sudbury, ON, P3E 5J1 Tel: (705) 522-6237 x 2060 Fax: (705) 523-7328	
Thunder Bay	Thunder Bay District Health Unit Northwestern Ontario Regional Cancer Centre 290 Munro Street Thunder Bay, ON, P7A 7T1 Tel: (807) 343-1610 Fax: (807) 345-2630	Dr. Judith Allanson Linda Spooner
Toronto	Genetics Department Credit Valley Hospital #1860, 2200 Eglinton Avenue West Mississauga, ON, L5M 2N1 Tel: (905) 813-4104 Fax: (905) 813-4347	On-call Counsellor
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Quebec

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	Department of Genetics Jewish General Hospital Rm. A-803 3755 Cote Ste. Catherine Road Montreal, QC, H3T 1E2 Tel: (514) 340-8222 Ext. 3851 Fax: (514) 340-7510 Ext. 2116	Dr. William Foulkes Nora Wong
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