

**A Survey of Heritable Cancer Risk Information Providers (CRIP) in North America:  
Phase II**

**Peggy Ng**

**For CRIP II co-investigators**

## Abstract:

**Background/Purposes of the Study:** The provision of accurate heritable cancer risk information in breast, ovarian, and colon cancer genetics is of great importance. No single, useful, theoretical model addresses (1) who actually provides this information at this time in North America and (2) how the information is being transmitted. Objectives: To examine the responses of a range of North American CRIP, provide meaningful categorization beyond traditional demographics such as age, gender, profession, or country of practice. Basic Procedures: Using a snowball sample technique from 12 sites across the US and Canada, 225 CRIP completed a mailed questionnaire and a one hour semi-structured telephone interview. Data were transcribed verbatim and content analyzed. **Main findings:** Using a grounded theory approach, we used the transcribed data to distinguish three CRIP categories: i) Formal Providers (20%) defined their activities related to the provision of heritable cancer risk as explicit, rather than ad hoc (e.g. genetic counselors), ii) Semi-Formal Providers (70%) defined their provision of genetic information as occasional (e.g. family physicians, nurses). They did not define the provision of risk information as part of their specific job responsibilities at this time, though many were indeed providing this information, iii) Informal Providers (10%) provided information to the public rather than to individuals (e.g. popular press, television programs, pamphlets left in waiting rooms). Ironically this group had the widest impact since it reached persons who might not otherwise access the health care system. **Principal Conclusions:** These results have solemn implications for how CRIP are educated, how they communicate, and how they can be encouraged to interact amongst themselves using an evidence-based approach. Our CRIP categories might streamline the efficacy of CRIP to anticipate emerging needs of persons at low, medium and high risk of heritable cancer now and in the future. Comparisons between CRIP in Canada and the United States are also made.

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## Key words

Cancer Risk Information, Cancer genetics, Risk provision, Breast / ovarian cancer, Ethical, Clinical practice

## INTRODUCTION

Over the past decade, advances in medical science have revolutionized man's ability to predict disease. With the development of index and reference marker maps of the human genome, the pace of gene localization and test development has accelerated rapidly. As mapped genes are cloned, genetic testing for breast, ovarian and colon cancer has become more technically feasible and commercially available for use in wide populations (NEW Beckwith, 1991; Elmer-DeWitt, 1994; Jordan, 1992; Sawicki et al., 1993), yet these predictive tests are typically available in advance of therapeutic/curative measures or appropriate legislation.

In reviewing extensive basic science, it is evident that a shift has taken place with regard to penetrance of genetic mutations and their links to cancer. While initial studies found and estimated high penetrance risk among 'high-risk' specialized populations (Ford et al, 1994;

Easton et. al, 1995, Easton et. al., 1997); further studies delineated much lower risk when utilizing population-based samples (Struewing et.al,1997). High risk has been attributed to a family history of both breast and ovarian cancers, Ashkenazi Jewish descent, younger age at initial diagnosis of breast/ovarian cancer (Couch et.al, 1997;Krainer et.al, 1997; Shattuck-Eidens et.al, 1997).

Clinically, practices of heritable cancer risk information providers range from some providers impeding or influencing clients' choices (NEW Geller, 1993) to perhaps labeling patients "high risk" on the basis of poor criteria (NEWGlanz & Lerman, 1992; Lerman et al., 1993; Shapiro & Shapiro, 1989; Siminoff, 1989). There is widespread concern over the fact that our ability to predict heritable cancer surpasses our ability to treat, or effectively mandate the process of predictive testing. The need for setting out optimal standard guidelines with an emphasis on how genetic information is provided, to whom it is provided, and the resulting ethical and legal parameters, is evident in the development of many professional organization practice guidelines (ASHG, Cancer Care, ASCO, CCGC etc). The key importance has been the diversity of practices dependent on the location of the hospital/clinic and the specific type of cancer/genetic mutation that is being screened.

While noteworthy studies have focused on individuals receiving cancer genetic information (Lerman et al, 1997, Lerman et al, 1998, Audrain et al., 1998), few studies have attempted to collect data from the actual individuals providing the cancer risk information. It is this gap in the literature of knowing who is providing risk information, their attitudes or behaviours or the range of models by which information is provided that the author is most interested in.

Cancer Risk Information Provision (CRIP)~ Phase I (1993) was one of the first studies that attempted to research who was providing cancer risk information. This study was conducted by researchers within the Behavioural Science Research Group in Toronto and consisted of a critical review of existing literature, as well as an exploratory study using an open-ended interview approach to purposively sample 60 key informants. The unstructured interviews provided data from which a semi-structured interview guide the 'Provider Telephone Interview Guide' (P-TIG) was developed.

Critical results from CRIP I began to illuminate the researchers about how wide the discipline pool was when one began to sift and sort through who was providing cancer risk information. In order to narrow the disciplines, the researchers created categories in order to designate individuals' role in cancer risk provision. It was evident that cancer risk included: formal risk providers (oncologists, genetic counselors) who provided risk information as a formal part of their job; semi-formal risk providers (family physicians, nurses, social workers) who provided risk information as a secondary part of their job in interacting with patients under a specific guise; and informal risk providers (media-radio, television etc) who provide cancer risk information indirectly to the public. In creating the P-TIG, it was thought that a second phase, CRIP II would enable the researchers to conduct a wider study that attempted to encompass the formal and semi-formal providers who were involved in cancer risk information and also allowed the researchers to create a rational and sound sampling frame that could be developed to test the generalizability of the preliminary data collected in CRIP I.

## **MAJOR AREAS OF FOCUS ~ CRIP II**

The CRIP II study has three principle goals. First is to identify those responsible for providing heritable cancer risk information. Providers are then grouped according to a variety of criterion, including amongst others: profession, gender, type of cancer risk information provided, clientele served, degree of education in genetics and/or counseling, and source of income. Second, to determine the means of dissemination and the settings within which this information is provided. Third, to ascertain what the resultant ethical, legal and sociobehavioural implications were and how they were dealt with. Specifically, what role do cancer risk information providers perceive for themselves in the informed consent process, and what is their relationship with "third party payers" such as health insurance companies?

## **STUDY INTRODUCTION**

The primary focus in CRIP II is to know who the cancer risk information providers are and to ascertain whether there is any consistency in their perceptions, views or methodology according to profession and other characteristics. Also of critical importance is where risk

information being provided, how clients are referred and what percentage and type of clients seek hereditary risk information. Similarly, due to a gap in the literature, what type of eligible clients tend to pursue genetic testing after receiving genetic information.

While in the past, only those with a strong family history of cancer had come to specialized family clinics, since the association of the 185delAG mutation with Ashkenazi Jewish heritage, there is a recognized population who are potentially at risk due to their ethnic descent alone (Struewing et al., 1995; Goldgar & Reilly, 1995). This has led us to the question of how ethnic minorities with a hereditary risk factor (such as members of the Ashkenazi Jewish community or certain persons of French Canadian descent) were perceived by cancer risk information providers. Specifically, whether the method of informing these clients or placing these clients in risk categories varies with people who have a strong family history of cancer.

The examination of the reported racial/ethnic/religious backgrounds of clients as perceived by cancer risk information providers combined with the ethnic origin of their clients led to the question of whether those with a strong family history alone were given similar or different information from those with an ethnic predictive factor alone. Additionally, we wanted to assess the reported levels of education and socioeconomic grades of clients for the purpose of examining what if any effect this had on interest in heritable cancer risk information and genetic testing.

It was important for the purposes of the study to ask and understand how or if providers varied according to a number of criteria and to what degree these attributes and characteristics differed or compared between selected sites in the U.S. and Canada. Criteria of interest include demographic characteristics (ethnicity, gender, religious background), knowledge (education in genetics and/or counselling, knowledge of genetics) and attitudes (primarily concerning who should pay for genetic services).

Sites of inquiry were chosen from both the United States and Canada, in part for the demographic purpose of comparing the impact of Medicare to a privatized health insurance system, on the outlook and attitudes of providers. Within this framework the goal was to ascertain the payment refunding policies that currently exist for cancer risk information and hereditary cancer risk information providers, for genetic testing and genetic counseling.

A main focus behind this survey, given the growing body of literature in this area is the identification of key ethical, legal, and sociobehavioural issues within the area of cancer risk provision. Attitudes and practices surrounding confidentiality and policies and procedures towards informed consent procedures are two main areas that were solicited.

To bridge the gap in our knowledge of how, what and to whom hereditary cancer risk information was provided in North America, the CRIP II study conducted an interview study of 225 cancer risk information providers across North America.

## **METHODS**

Through snowball sampling, information was obtained from 225 heritable cancer risk information providers across Canada and the United States. Each respondent completed a self-administered mail-back questionnaire and participated in a follow-up telephone interview.

### **Setting**

Twenty-six breast, ovarian, and colon cancer risk information provision collection sites were identified across the U.S. and Canada; twelve of which were selected for participation this study. The twelve sites were: Tampa, Florida; Los Angeles, California; Philadelphia, Pennsylvania; Independence, Ohio; New York, New York; Salt Lake City, Utah; St. John's, Newfoundland; Ottawa, Ontario; Calgary, Alberta; Montreal, Quebec; Toronto, Ontario; and Vancouver, British Columbia. The selected collection sites had substantial numbers of specialties and disciplines, a variety of models of information delivery, and efforts were made to ensure the inclusion of further specific criteria: rural/urban settings; settings that had formal genetic clinics and those that did not; settings whose personnel worked primarily in research areas and those that worked primarily in clinical areas.

### **Study Population and Recruitment**

The ability to accurately capture the universe of information providers is limited, however, it was feasible to create an initial list of information providers who would then be asked to identify others in their setting (Kuzel, 1992). At the time that the study was carried out, there were no published lists of heritable cancer risk information providers to sample from.

The goal was to capture the subtleties of the social process surrounding risk notification, and random sampling would not have accommodated the coherence and sequence of these social processes (Morse, 1989). We selected a sampling frame that was designed to permit progressive grounded theory development (Firestone, 1993). As a result, the sample was gathered using a snowball sampling technique (Johnson, 1990). This is a useful approach when the difficulty of identifying members of a population (Robson, 1993) arises. Snowball sampling was used to ensure site saturation, and a modification of Dillman's recommendations (Dillman, 1963) was used to ensure a high response rate. Each designated cancer risk information provision data collection site had a study coordinator identified by the PI of the study. This was necessary in order to start the snowball effect. Each coordinator then identified ten persons believed to be providing heritable cancer risk information in any form to any person perceived to be at increased risk for heritable breast, ovarian, or colon cancer.

An introductory letter regarding the study was sent to each potential respondent, and 30 days after the initial contact, a follow-up letter, and copy of the self-administered mail-back questionnaire was sent along with a consent form. If they agreed to participate, they were asked to complete the questionnaire, mail it back, and a telephone interview meeting time was established. After completing both the questionnaire and the phone interview, each respondent was asked to provide the names of 10 additional cancer risk information providers that they were acquainted with. The saturation point was reached when no new names were provided by the interviewees; in total, a list 897 heritable cancer risk information providers was compiled, and a total of 225 information providers completed both the questionnaire and interview. Based on the three-time call back as recommended by Dillman (1963), the response rate was 87%.

## **THE MEASURING INSTRUMENT**

The self-administered mail-back questionnaire was initially reviewed by six focus groups (n=42) in Phase I of the Cancer Risk Information Provider (CRIP) Study, and pilot tested on a convenience sample (n=25) of heritable cancer risk information providers.

It consisted of twenty demographic questions, open-ended questions in six sections touching on: views of information providers, avenues to risk information, availability of risk information, risk

information services, how risk information is provided, and the roles and responsibilities of information providers.

There were twenty items with a 4 point Likert scale dealing with four distinct ethical, legal, and sociobehavioural implications of heritable cancer risk information provision. The final draft of the self-administered mail-back questionnaire was to be completed in about 25 minutes. The telephone interview was designed to further explore the respondent's knowledge, attitudes, behaviours, practices and perceptions of heritable cancer risk information provision through a series of representative questions. The interview also solicited data regarding the diverse models of information provision that exist presently in North America, as well as the social and behavioural consequences of providing information.

## **DATA ANALYSIS**

The mailed-back questionnaires were entered into Microsoft Excel. The data was then analyzed in the Statistical Analysis System (SAS), and the written portions were transcribed and coded. The follow-up telephone interview was tape-recorded and transcribed verbatim, then coded for main content themes.

Demographic responses were coded and categorized. These include: category of information provider-type, gender, age, ethnocultural classification, religious preference, type of health care system (country where practicing), and primary income-source, among others. Frequencies, percentages, cross-tabulations, and contingency table analyses were used to describe the demographic profiles of our responding group, the environment they serve, the patient population and profile, similarities between the American and Canadian health care systems, and between the different information providing professions.

There were three indices of the Likert responses that were empirically determined based on reliability and factor analysis to summarize the individual questions that measured knowledge and attitudes towards genetics and provision of genetic services.

Data from the completed interviews were collected and stored as a comprehensive database in Microsoft Access. The high-quality descriptions from the telephone interviews were useful for documenting uniqueness, and commonality across participants, and were easily

filtered and sorted through discipline, type of clinic setting, location of setting, as well as the specific type of risk provided. This data was available for the project co-investigators for further separate secondary data analysis, for presentations and articles. This particular manuscript represents an overview of the main survey findings.

## **RESULTS**

### **1. Differing Professions/Differing Information Provision**

The completed questionnaires were collected from a total of 225 heritable cancer risk information providers. The average age of participants in our sample was 41 years of age, 151 were female and 73 were male. Forty seven percent of respondents were American, 53% were Canadian. The breakdown of demographics for respondents and information provision settings can be seen in Table 1. The majority of respondents were physicians, followed by genetic counselors, and the difference in genetic service provision professions was evident between genders ( $p < 0.01$ ).

The unique distribution of professions across respondents was obtained because of the snowball sampling technique. We reached a saturation with our list of providers (no new names were given), and therefore believe that we obtained a good sample of the professions in the field of heritable cancer risk information provision. The following results are representative of that population. From the distribution of information providers, we were able to create further specific categories of formal, semi-formal, and informal information providers. Formal heritable cancer risk information providers consist of those persons practicing in any profession or occupation whose job description includes the provision of heritable cancer risk information (e.g. geneticists, genetic counselors, psychologists and others); semi-formal providers include those who provide genetic cancer risk information as part of their job description, but whose work in this area is not necessary formally recognized (e.g. medical oncologists, surgical oncologists, family physicians). Informal providers include alternative information sources (e.g. the media, charitable organizations, support/activist groups, and others).

Table 1. Demographics of 225 Heritable Cancer Risk Information Providers in North America

<b>PROFESSION</b>	<b>FREQUENCY</b>	<b>PERCENT</b>
Physician	108	48
Genetic Counsellor	54	24
Nurse	34	15
Combination (also other)	25	11
Psychologist	3	1
Social Worker	1	0.5
<b>RACIAL/ETHNIC BACKGROUND</b>	<b>FREQUENCY</b>	<b>PERCENT</b>
Caucasian	185	82
Ashkenazi	14	6
Other	6	3
Hispanic	3	1.3
Native Canadian	3	1.3
Black/African American	2	0.9
Prefer not to respond	2	0.9
<b>RELIGIOUS BACKGROUND</b>	<b>FREQUENCY</b>	<b>PERCENT</b>
Protestant	74	33
Catholic	63	28
Jewish	40	18
None	25	11
Other	19	8
Prefer not to respond	2	1

The respondents in the study were, on the most part, providing risk information for more than one tumour site, in an urban centre teaching hospital (see Table 2). Fifty-one percents of respondents were providing this information in both research and service oriented programs, 34% were primarily in a service program, and 14% were primarily in a research program.

The majority (71%) of the respondents were from urban communities. Respondents who worked primarily in group/team (84%) tended to provide genetic information in a

combination of services and research programs(56%) while 64% of those who worked primarily by him/herself provided the information in service programs alone ( $p<0.01$ ).

Less than one third (59 out of 225) of the respondents have taken genetics training degree courses and 66% of this group had taken only one course. Twenty two percent had taken continuing education courses and among these, 61% had taken only one course. Almost all respondents had some in-service training on genetics. With respect to counseling, (only) 15% had university degree course training. Some respondents had in-service or other training in counseling but 47% did not report receiving any training at all on counseling. Eighty one percent of the respondents reported income from genetic service provision were salaried, including research grants, and others claimed that they were fee-for service.

Table 2. Setting for Heritable Cancer Risk Information Provision

<b>PRIMARY CLINICAL AFFILIATION</b>	<b>FREQUENCY</b>	<b>PERCENT</b>
Teaching Hospital	147	66
Non-Teaching Hospital	16	7
Other	44	
Not Applicable	11	5
<b>POPULATION OF COMMUNITY IN WHICH INFORMATION IS GIVEN</b>	<b>FREQUENCY</b>	<b>PERCENT</b>
< 20,000	3	1
20,000 - 50,000	30	14
150,000 - 500,000	31	14
> 500,000	154	71
<b>FORM OF hCRIP ACTIVITY IN YOUR SETTING</b>	<b>FREQUENCY</b>	<b>PERCENT</b>
Formal Activity	138	63
Ad-hoc Activity	75	34
Combination	6	3

Respondents said that 38% of their total patient case load were consumers of heritable cancer risk information, and that their patients were primarily female. Eighty-two percent of those patients are females between the ages of 35-50 years; 33% of whom had a cancer diagnosis and a family history of cancer, 75% had a family history but no cancer diagnosis

themselves. This accounts for approximately half (46%) of their total patient population. Twenty percent were male patients, the majority of whom are also between the ages of 35-50 years. Thirty seven percent of the male patients had a cancer diagnosis and a family history of the disease, while 51% had a family history but no cancer diagnosis. Most patients (68%) were referred for risk information by other health care professionals, while other consumers were referred either by other professional sources or self-referred. See Table 3.

Regarding literacy and socioeconomic status of patients of the respondents, 62% of the people seeking heritable cancer risk information had an education past high school level, 16% had a high school diploma only, and 2% had less than a high school education. Genetic testing has been identified as a procedure that individuals of higher socioeconomic status (SES) are concerned with, more often than their less educated, lower SES peers. It appears that at a lower income level, there are other life concerns that take precedence over knowing what one's risk for heritable cancer is.

Table 3. Types of heritable Cancer Risk Information

<b>TYPES OF CANCER INFORMATION GIVEN</b>	<b>FREQUENCY</b>	<b>PERCENT</b>
Breast only	33	15
Breast	185	83
Ovarian only	7	3
Ovarian	147	66
Colon only	24	11
Colon	144	65
Other site only	6	3
Other	70	
A combination of (but not all) the above	53	
All of the above tumour sites	48	22

The respondents were asked to estimate, in regards to the patients for whom testing is available, how many would choose to get tested. Respondents said that they believed 55% of female information consumers would choose to be tested for breast/ovarian cancer, 57% of

females would be tested for colon cancer, and 53% of male consumers would choose testing for colon cancer. The respondents estimated that the number of patients, for whom testing is available, that would actually follow through and have testing after receiving genetic counseling would be 44% of females, and 42% of males. Similar findings have been noted with the predicted and actual use of the genetic test for Huntington's disease.

The majority of respondents identified themselves as ethnically Caucasian, followed by Ashkenazi. Most frequently reported religious backgrounds were Protestant, Catholic, Jewish, and Other. The reported racial/ethnic background of the majority of consumers receiving heritable cancer risk information was Caucasian, a combination of ethnicities, and Ashkenazi. The majority of these patients (84%) were seeking information based on their family history, while the other 18% were seeking information based on their ethnicity only (i.e.: Ashkenazi).

## **2. Knowledge and attitudes for cancer risk information providers**

Three indices were empirically determined based on reliability coefficients and factor analysis to summarize the Likert scale questions that measure knowledge and attitudes towards genetics and provision of genetic services. The first index was for knowledge of genetics (denoted by KNOW), the second index was the attitude towards payment for the provision of genetic information, counseling, and testing: Should person(s) requesting these services pay, denoted by ATT-PAY); and the third index was for attitude towards availability of genetic services (should the services only available to high risk groups and limited age groups, denoted by ATT-AVAIL).

Cronbach alpha for KNOW (5 items) was 0.52, for ATT-PAY (3 items) was 0.81, and for ATT-AVAIL (4 items) was 0.54. The indices were calculated by, after adjusting for item polarity, taking the average of the item scores within each concept. The numeric values for these indices ranged from 1 to 4, where the larger the value for KNOW meant more correct answers to the knowledge of genetic information asked, larger values for ATT-PAY meant more disagreeable to the belief that genetic services should have to be paid for by the person(s) requesting it; and greater values for ATT-AVAIL reflected more support for the provision of

genetic testing and counseling for all, including those at low, moderate, and high risk and people of all ages (including children).

There was statistical evidence of difference on attitude towards availability of genetic services: respondents who spent at least four hours providing genetic services each week felt more positive towards provision of services to low, moderate, and high risk groups, and persons of all ages, including children (average =3.1,  $p<0.01$ ). Among those who spent less time, the average =2.8. Difference in attitude towards availability of genetic services was also observed between those who worked in an environment with a formal procedure (mean =3.1) than those without (mean =2.7,  $p<0.01$ ).

### **3. U.S./Canadian Similarities and Differences**

The distribution of ethnicity, religion background, professional specialty, the range of services provided, and ethnic background of patient population did not differ between the United States and Canada. A higher proportion of American respondents reported being primarily salaried (88%, including research grants), spent at least four hours of provision of genetics services (61%), worked in teams (86%), and had informed consent procedures in their work settings (41%) in comparison to the Canadian counterpart (82%; 31%,  $p<0.001$ ; 83%; 39%) respectively.

One of the main differences between Canadian and American information providers involved the manner in which they are reimbursed for their work. With respect to providers' attitude towards payment, the country in which they work was quite revealing. The Americans felt more readily than the Canadians that those who requested genetics services should pay for the services themselves. Regarding the attitude towards availability of services, the providers who spent more time on service provision, and those who worked in settings with formal activity on genetics service provision were more agreeable to provide the genetic services to low, moderate, and high risk groups and persons of all ages.

Table 4. Reimbursement Practices for Information Provision, Genetic Counselling and Testing

<b>REIMBURSEMENT OF HCR INFO PROVISION</b>	<b>FREQUENCY</b>	<b>PERCENT</b>
Public Insurance Plans (Government Funded)	112	55
Private Insurance Plans	61	30
Individual being informed pays	62	30
Research Grants	98	48
Other	31	15
<b>REIMBURSEMENT OF GENETIC COUNSELLING</b>	<b>FREQUENCY</b>	<b>PERCENT</b>
Public Insurance Plans (Government Funded)	102	52
Private Insurance Plans	56	28
Individual being informed pays	58	29
Research Grants	97	49
Other	26	13
<b>REIMBURSEMENT OF GENETIC TESTING</b>	<b>FREQUENCY</b>	<b>PERCENT</b>
Public Insurance Plans (Government Funded)	52	28
Private Insurance Plans	35	19
Individual being informed pays	62	34
Research Grants	120	65
Other	22	12

Out of those heritable cancer risk information providers that work on a fee-for-service basis, most are paid by a 3<sup>rd</sup> party payer. The primary income source for genetic counselling and testing specifically is spread out fairly evenly. Fifteen percent are paid by fee-for-service; and from that 15%, half are paid by 3<sup>rd</sup> party payers, a quarter by clients, and a quarter by a combination of clients and 3<sup>rd</sup> party payers. The majority of all heritable cancer risk information providers are paid by salary, the rest by research grants, and from a combination of other sources.

The largest portion of respondents work in a non-profit organization (86%), while the remaining 13% work in an “other” or for-profit organization (Oncormed). For heritable cancer risk information provision presently, the largest number of programs (in Canada?) are funded by the government, others by private insurance plans, the patient, research grants, and “other”

sources. Refer to Table 5 for a detailed breakdown of payment practices for information provision.

For the reimbursement of genetic counseling, about half of respondents are reimbursed through public insurance plans (government funding in Canada). About thirty percent of the others are reimbursed through private insurance, or directly by the individual who receives the genetic counseling (the patient). Approximately half of the respondents said that they get paid through research grants, and the smallest number are paid through “other” sources.

Genetic testing is reimbursed in the following manner: About a third of respondents are paid by public insurance (government funding in Canada), one fifth are paid through private insurance, a third are paid by the patient directly (the individual having the testing done pays independently), more than half receive reimbursement through research grants, and the smallest number are paid through “other” sources.

There were differences between the two countries on attitude towards payment of genetic services and knowledge of genetics. The average attitude towards payment among American respondents was 2.0 and among Canadian was 3.0, demonstrating that Americans were more readily agreeable to the fact that persons requesting genetic services should pay for the services themselves ( $p < 0.01$ ). From the data, the Americans demonstrated a higher level of knowledge of genetics (average = 3.7) than the Canadians (mean = 3.4,  $p < 0.01$ ). This significant difference was removed after adjustment was made on the amount of time respondents spent on genetic services. Among those who spent at least four hours on genetic services provision, Canadians had an average score of 3.7 on knowledge of genetics while Americans had an average score of 3.8. Among those who spent less than four hours on genetic services provision, Americans had an average knowledge of genetics score of 3.5 and Canadians 3.4. Note that in both countries, those who spent more time on service provision were more knowledgeable ( $p < 0.01$ ). Respondents who provided their services in urban communities tend to be more knowledgeable (average = 3.6) than those who practiced in rural areas (average = 3.4,  $p < 0.01$ ).

When Canada and the United States were compared for the following: provider specialties, work environment with/without informed consent procedures, providers with more/less working hours on genetics services, those who worked individually or in team/groups,

the two different primary income source groups, rural and urban communities, formal settings and those that were ad-hoc, and work environments that provided heritable related services only and those that provided a range of services, the following were found to be statistically significant.

There was no significant difference on attitude towards availability of genetic services between the United States and Canada (Canadian average =2.9, American average =3.1). Among the specialty groups: counselors, physicians, and others, the counselors were among those who have most knowledge on genetics (average =3.7), nurses (and others) and the physicians were less knowledgeable (average =3.5 for both). When comparison were made among these three groups, significant difference was found between the counselors and the other two ( $p<0.01$ ).

To summarize the analyses on the indices of genetics knowledge, the providers in the United States had a higher average score on the genetics questions than the Canadians, and the genetic counselors scored better than other professionals. It should be noted that counselors in both countries were similar in knowledge. Those who worked in settings with informed consent procedures ( $p<0.01$ ), spent more time on the services per week ( $p<0.01$ ), focused in hereditary cancer ( $p<0.01$ ), serviced in urban communities ( $p<0.01$ ), and provided the service as a formal activity ( $p<0.01$ ) tended to be more knowledgeable. After considering all the above factors in a multi-way analysis of variance, it was the amount of time providers spent on genetics services provision and if the services provision was a formal activity that related to the providers exhibit of knowledge.

#### **4. ETHICAL, LEGAL, AND SOCIOBEHAVIOURAL ISSUES**

Given the fear that many patients feel regarding breaches of confidentiality, providing information to family members, other people, and insurance companies is a sensitive issue for many risk information providers. In response to the question: *Beyond the initial client that you provide heritable cancer risk information to, what other persons do you counsel?*; only 16% of respondents said that they would not share a patient's genetic information with any other person seeking similar counselling (i.e. family members, spouses, etc.). 77% of

respondents said that they would also provide counseling to first degree relatives (siblings, parents, children). 50% said that they would give information to extended family members related by blood, 54% to the spouse or significant other, and 12% to “other” persons seeking information. This information shows how communication and information sharing is essential in families going through genetic testing and counseling. For the family medical history information to be gathered completely, different family members must become involved. About half of the informed consent procedures related to genetic counseling for heritable cancer procedures used by information providers were written informed consent; 10% had verbal procedures, 29% had no informed consent procedures, and 13% used a combination of written and verbal consent procedures.

Informed consent procedures for genetic testing differed only slightly from those for genetic counseling: 57% of respondents had written informed consent procedures related to genetic testing; 5% had verbal consent procedures, 18% had no procedures, 11% used a combination of written and verbal consent procedures, and 9% used an “other” informed consent procedure.

Table 5. Alternative Heritable Cancer Risk Information Sources

<b>ALTERNATIVE INFORMATION SOURCE</b>	<b>FREQUENCY</b>	<b>PERCENT</b>
The Media	173	87
Funding Agencies	35	18
Biotech/Drug Industries	57	29
Charitable Organizations (e.g.: Cancer Societies)	133	67
Support/Activist Groups	118	59
Religious Groups (e.g.: Synagogues)	37	19
Other	44	22

For the formal and informal information providers in our survey, one fact that came up repeatedly, was the fear that patients tend to receive misleading information from alternative sources. This information often leads to excessive anxiety, and an increase in the work load of the information provider. Telephone calls and visits to clinics increase dramatically in the few days after a television special or news article focusing on heritable cancer hits the newsstands.

Table 5 outlines the alternative sources of information that the responding information providers must compete with.

## **CONCLUSION**

The survey results have indicated that North American cancer risk information providers have been, in their own report, limited source of acquired formal knowledge for their service provision. There is mixed opinions regarding who should pay for such services and to whom should these services be provided. The differences in attitudes towards the service provision between Canada and United States, which could be a result of the different health systems, have been observed.

It is important to note that these results were collected from only 225 completed questionnaires. Inference drawn should not be over generalized. Yet, the results provide solemn implications that risk target population should be identified, whether it should be family or individuals. There is a call for development of guidelines to address equity issues and to whom the services should be provided. As the results have shown, there is a lack of informed consent in both of the countries.

There is clearly a need for such procedure. The third phase of this research project CRIP III has addressed some of these issues. Investigations have also been made on the availability of counseling before genetic risk assessment and testing. Detailed ethical, legal, and psycho-social issues will be addressed.

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