

# Predicting interest in genetic counseling and testing for cancer susceptibility: The British Columbia Family Cancer Survey Pilot Study

Results from this study suggest that interest in genetic testing may be lower than previous studies indicated.

## ABSTRACT:

**Background:** Our objective was to explore interest in genetic counseling and testing for cancer susceptibility among adults living in British Columbia, Canada.

**Methods:** A self-administered questionnaire was mailed to 104 men and women between the ages of 40 and 59 years living in the Greater Vancouver Regional District. Descriptive statistics and logistic regression analyses were used to measure sociodemographic, clinical, and psychosocial factors that may influence interest in genetic counseling and testing.

**Results:** Interest in genetic counseling (56.5%) was slightly greater than interest in testing (52.2%). Interest in both was significantly higher among older respondents, particularly those older than 50 years of age. A desire to prevent cancer, a concern for personal health, and awareness of a family history of cancer (real or perceived) motivated interest in both services.

**Conclusions:** Understanding public attitudes and interest in genetic counseling and testing for cancer susceptibility will help to predict demand in anticipation of expanding genetic services.

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## Background

Genetic counseling and testing for recognized cancer-related gene mutations is offered in most provinces in Canada. It is believed that only a small proportion of eligible subjects currently seek susceptibility testing, and that the demand for services will exceed available resources as public interest intensifies.<sup>1</sup> North American and European studies have suggested that interest in genetic testing for specific gene mutations ranges from 26% to 95% among different risk groups.<sup>2-12</sup> However, few researchers have examined samples from the general population, or interest within the context of a publicly funded health care system. On the basis of these considerations, we sought to identify sociodemographic, psychosocial, and clinical factors in British Columbia that may influence the public's intended use of genetic services for assessing cancer susceptibility.

## Methods

A random sample of 104 adults age 40 to 59 years and resident in the Greater Vancouver Regional District was generated from the population-based BC

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The British Columbia Family Cancer Survey Pilot Study**

Medical Services Plan client registry. The province's universal medical plan provides coverage to all BC residents, thereby ensuring a representative sampling frame.

A self-administered questionnaire was mailed to subjects in the spring of 2001. The survey included questions on sociodemographic characteristics, family history of cancer, and attitudes toward genetic counseling and testing for cancer susceptibility. Self-reported family histories of cancer were incomplete in many cases, particularly in terms of information on second-degree relatives.<sup>13</sup> No follow-up was possible with nonrespondents because of privacy restrictions.

Following criteria outlined by Durfy<sup>14</sup> and Gwyn,<sup>15</sup> all outcome variables were dichotomized as "definite interest" or "no interest/uncertain." Descriptive statistics were used to explore characteristics of the study participants, as well as factors that influenced their desire for genetic counseling and testing for cancer susceptibility. Logistic regression analyses were used to predict interest in genetic counseling and testing according to respondents' sociodemographic and clinical characteristics. Statistical testing was performed using maximum likelihood methods and significance was assessed using a 2-tailed test with 5% alpha.

## Results

Twenty-three people responded to the survey, for an overall response rate of 22.1%. Survey respondents did not differ from nonrespondents according to age or place of residence, but a significantly greater proportion of women participated than men ( $\chi^2 = 4.88$ ,  $P = 0.03$ ). Characteristics of survey respondents are shown in the **Table**.

Over half the respondents were interested in obtaining genetic counseling (56.5%) or testing for cancer

**Table. Patient and clinical characteristics of study subjects according to interest in genetic counseling and testing for cancer susceptibility.**

	Study population N (%)	Interest in genetic counseling N (%)	Interest in genetic testing N (%)
All subjects	23 (100.0)	13 (56.5)	12 (52.2)
Age			
40–49 years	9 (39.1)	3 (23.1)	3 (25.0)
50–59 years	14 (60.9)	10 (76.9)	9 (75.0)
Gender			
Male	7 (30.4)	4 (30.8)	4 (33.3)
Female	16 (69.6)	9 (69.2)	8 (66.7)
Education level			
≤ High school	12 (52.2)	6 (46.2)	7 (58.3)
> High school	11 (47.8)	7 (53.8)	5 (41.7)
Household income			
< \$60 000	14 (66.7)	9 (69.2)	9 (75.0)
≥ \$60 000	7 (33.3)	4 (30.8)	3 (25.0)
Place of birth			
Canada	14 (60.9)	9 (69.2)	8 (66.7)
Other	9 (39.1)	4 (30.8)	4 (33.3)
Cancer history			
No	20 (87.0)	11 (84.6)	10 (83.3)
Yes	3 (13.0)	2 (15.4)	2 (16.7)
Family history of cancer*			
No	15 (65.2)	7 (53.8)	6 (50.0)
Yes	8 (34.8)	6 (46.2)	6 (50.0)

\* Definition based on criteria adopted from BC Cancer Agency's Hereditary Cancer Program.<sup>13</sup> Family history of cancer defined as breast, ovarian, or colon cancer in two close relatives, or in one close relative before age 50. Close relatives include parents, siblings, grandparents, aunts, and uncles.

susceptibility (52.2%), while one-third were undecided about use of either of these services (30.4% and 34.8%, respectively). A small proportion of respondents were not at all interested in receiving either of these services (13.1% and 13.0%, respectively).

The primary influences cited for interest in both services included a desire to prevent cancer, concern for personal health, and awareness of a family history of cancer (see **Figure**). No survey respondents indicated religious beliefs as an influencing factor, and very few were dissuaded by privacy and confidentiality concerns.

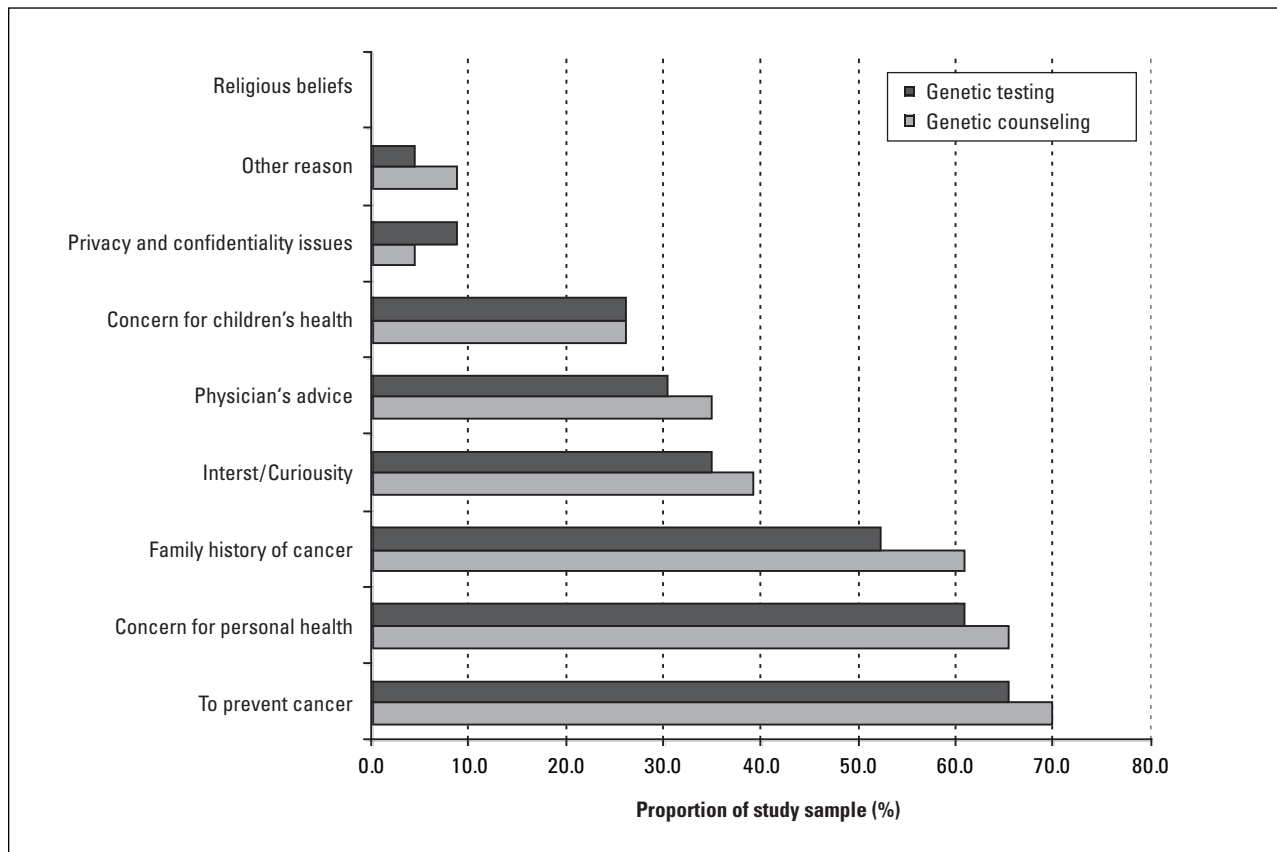
Older age was the only significant predictor of interest in genetic coun-

seling and testing for cancer susceptibility, particularly for subjects over 50 years. Respondents with a self-reported family history of cancer were more likely to show interest in genetic counseling and testing, although results did not reach statistical significance. Interest did not vary by gender, level of education, household income, or place of birth of the respondents.

## Conclusions

Our pilot study was limited by a small sample size and low response rate, and it is possible that nonresponse bias occurred. While any effects should be interpreted with caution, our study provides preliminary evidence of the

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The British Columbia Family Cancer Survey Pilot Study**



**Figure.** Factors that influence interest in genetic counseling and testing, BC residents age 40 to 59 years.

public's intentions to undergo genetic counseling and testing, and points to areas for future investigation. We found that public interest in genetic counseling and testing for cancer susceptibility may be lower than previously indicated from studies of high-risk populations.<sup>5-7,9,16-19</sup> The poor response to our survey itself may further indicate a lack of interest among the general public, which could translate to lower service utilization rates. However, the large proportion of our sample that was interested in both genetic counseling and testing suggests that similar factors, particularly perceptions of personal health, may influence the decision-making process.

Such information will become increasingly relevant as population-wide

risk notification programs for general cancer susceptibility become available. Although no single genetic test exists to assess an individual's cumulative risk of cancer, we believe that obtaining further data on a larger sample of the general population, including high-risk groups, will help to gauge potential demand for genetic counseling and testing services in anticipation of the expansion of these services.

**Competing interests**

None declared.

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demand. *Chronic Dis Can* 2000;20:21-25.

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