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Patient preferences regarding recontact by cancer genetics clinicians

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Abstract
Background Ongoing advances in cancer genetics lead to new opportunities for early disease detection, predictive genetic testing and potential interventions. Limited information exists on patient preferences concerning recontact to provide updated information. We evaluated colon cancer genetics patient preferences concerning recontact about advances in medical genetics.
Methods Information was mailed to 851 individuals seen at the Colon Cancer Risk Assessment Clinic at the Johns Hopkins Hospital and to participants in a colon cancer gene testing study seen during an 8-year period. Information provided included description of advances in gene testing technology, discovery of MSH6 and MYH genes, detailed fact sheets and a survey of patient preferences for notification and potential uses of new information.
Results Most patients wanted an ongoing relationship with genetics providers (63%), reinitiated by genetics providers (65%) and contact only with information specifically relevant to them (51%). Most preferred personalized letters as the means of contact (55%). Reasons for and against recontact and circumstances in which individuals would pursue additional genetic testing were also tabulated. There were few statistically significant differences in the responses between clinic and study participants.
Conclusion Patients evaluated in a colon cancer risk assessment clinic want updated information at a rate similar to those who participated in a colon cancer gene testing study. These findings have implications for the consultative nonlongitudinal nature of such clinics and suggest patient preferences for personally-tailored information could be labor intensive.

Keywords Colon cancer · Recontact · Genetic testing · Cancer genetics

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Introduction

The practice of clinical cancer genetics includes many related ethical issues. Examples include duty to warn at risk relatives when a patient refuses to disclose genetic information to family members [1, 2], and genetic discrimination for employment or insurability based on mutation status. Duty to recontact patients when there is new information that may affect the health care decisions of that individual is an unexplored ethical issue. Although providing patients with up to date

information might allow better healthcare decisions, the possible negative impact of such recontact on the psychological or emotional state of the patient also needs consideration [3].

Ongoing advances in cancer genetics have led to new opportunities for early disease detection, predictive genetic testing and potential interventions. While most genetics health care providers favor recontacting patients regarding new information [4], little is known about patient preferences. Additionally, many practical issues, including liability, exist with implementing a recontact policy. Previous legal decisions have held non-genetics healthcare providers liable for failing to recontact patients regarding potential complications not appreciated at the time of initial treatment [5]. Cancer genetics professionals could potentially be held to a similar standard. However, limited information exists about preferred and appropriate methods of recontacting patients to provide updated information. Previous studies have either evaluated the attitudes of genetics service providers themselves [4] or have evaluated patient populations different than cancer genetics patients [6].

While several studies report factors influencing initial interest in genetic counseling and testing for hereditary colon cancer [7–10], no information exists regarding patient interest in future contact following initial risk assessment consultation. Therefore, we provided former patients with information about recent advances in colon cancer genetics and evaluated preferences concerning recontact and method of recontact.

Materials and methods

The study population consisted of two groups. The Colon Cancer Genetics Clinic group (''Clinic group'') included 494 physician-referred or self-referred patients who were seen in the Johns Hopkins Colon Cancer Risk Assessment Clinic between 1996 and 2003. Patients were seen by a team of one of two physicians and one of four genetic counselors, and were evaluated and counseled with information available at the time of the visit. Patients were usually seen once or, if genetic testing was ordered, a second time for results disclosure; they received a written summary of the visit after each appointment. At the initial visit, each patient was assigned a diagnosis for the purpose of classification (Appendix 1) and could have been assigned more than one diagnosis. Genetic testing modalities used varied depending on the year in which patients were seen, and included protein truncation, direct genetic sequencing, and microsatellite instability testing.

The second group included 357 participants in a colon cancer genetic testing study at Johns Hopkins Medical Institutions between 1997 and 2003 (''Research group''). The purpose of the 2-year longitudinal study of adults at increased risk for colorectal cancer (CRC) was to evaluate the effect of genetic testing for hereditary colorectal cancer on psychological well-being and CRC screening behavior. A description of a subset of this cohort has been reported [11]. Analysis of genes associated with Hereditary Non-Polyposis Colorectal Cancer (HNPCC) had been performed in 33% of the original study participants. Following study closure in 2003, subjects no longer maintained regular contact with researchers.

Each study subject was mailed the following:

1) A cover letter which briefly addressed i) recent advances in gene testing technology, including the ability to identify large rearrangements undetectable using direct DNA sequencing, ii) discovery of the MSH6 and MYH genes, iii) the opportunity to schedule a follow-up genetic counseling appointment, and iv) a request to complete an enclosed survey. For clinic patients, the letter was signed by the provider(s) who had seen the patient in clinic. For research participants, the letter was signed by the coordinator and principle investigator of the original study.
2) Two 2-page fact sheets developed by our study group containing detailed information about HNPCC and the MSH6 gene, and polyposis and the MYH gene.
3) Survey (see Appendix 2). Because no validated instrument for collecting the desired information existed, we designed a survey consisting of 15 brief questions addressing the process of recontacting patients. Some questions allowed more than one response, so not all totals add up to 100%.
4) Addressed, postage-paid envelope to return the survey.

Initial packets were mailed in March 2004 and follow-up packets were sent in June 2004 to all nonrespondents. Data received by July 28, 2004 was entered into a Microsoft Access database. Differences between the two study populations were analyzed using chi-square analysis. Results for which differences are statistically significant are indicated by inclusion of the *P* value attained.

Approval for this study was obtained from The Johns Hopkins Medicine Institutional Review Board, and response to the survey indicated consent.

Results

Response rate and demographics:

In the clinic group, 40% of surveys were completed and returned, 14% were returned due to address problems and 2% were returned with notification that the subject was deceased. Diagnoses included HNPCC (59), HNPCC-like (18), Familial Adenomatous Polyposis, or FAP (17), Attenuated Familial Adenomatous Polyposis, or AFAP (13), oligopolyposis (6), Peutz-Jeghers (4), Juvenile polyposis (2), APC I1307K (43), familial colorectal cancer (10), hyperplastic polyposis (5), nonhereditary/nonsyndromic (13) and other (36). Eighty-eight percent were Caucasian, and 39% were male. Fifty-five percent were ≥50 years of age, 41% were ≤ 49 years, and 4% were not specified. In the research group, 44% of surveys were completed and returned, 15% were returned due to address problems and 1% were returned with notification that the subject was deceased. All participants had a family history suspicious for HNPCC. Ninety-two percent were Caucasian, and 43% were male. Forty-nine percent were ≥ 50 years, 35% were ≤ 49 years, and 16% did not specify.

The different response rates between males and females and between clinic and research populations were not significant. However, response rates of older (≥ 50 years) versus younger (≤ 49 years) individuals was statistically significantly different in both the clinic (47% vs. 33%, P ≤ .01) and research group (63% vs. 31%, $P \leq .01$) .

Preferences regarding recontact:

The majority of respondents (92% of both groups) reported regular contact with a primary care physician, internist or gastroenterologist, and most were seen at least yearly. Most wanted an ongoing relationship with genetics providers, though the clinic group indicated this more than the research group (69% versus 57%; $P \leq .05$). Respondents felt that primary responsibility for updating the patient belonged to the genetics provider (67% clinic, 62% research), then primary care physician (19% clinic, 22% research), then gastroenterologist (22% clinic, 15% research). Only 10% of respondents in both groups felt the patient was primarily responsible.

The preferred method of recontact was by a personalized letter only to appropriate patients. Reponses to other proposed methods are summarized in Table 1. The preferred frequency of recontact was distributed between the categories of ''only when new discoveries are made that pertain directly to the recontacted patient'' (38% clinic, 41% research), ''when any new discoveries are made'' (36% both clinic and research) and ''regularly, even if no new discoveries are made''(28% clinic, 24% research). The majority of those who preferred regular contact in the absence of new discoveries favored annual contact (89% clinic, 88% research). The desired information at the first point of recontact is summarized in Table 2.

Respondents felt patients should be asked at the initial consultation whether they wished to be recontacted (92% for both clinic and research groups). However, when queried whether a patient who indicated ''no'' at the initial visit should ever be recontacted, 47% of clinic and 41% of research respondents indicated that they should, while 26% of clinic and 30% of research respondents were uncertain. Those favoring recontact generally felt it was indicated when the new information was ''important,'' ''life-saving'' or ''life-threatening,'' or ''specific to the patient.''

Participants were provided with a list of circumstances under which they would be most likely to pursue testing if new technology were available, and asked to check all that applied. Responses are summarized in Fig. 1. We asked respondents to define ''reasonable out of pocket costs'' for genetic testing, and 45% of those who answered indicated $300 or less.

If a policy for recontacting patients were developed, most indicated they wanted to be recontacted. Of these, 36% of clinics and 41% of research respondents wanted to be recontacted only when new information arose that pertained directly to them. A similar percentage wanted to be informed when any new information was available (32% clinic, 30% research), or on a regular basis even when there are no new discoveries (30% clinic, 28% research). Only 1% thought the primary care physician/internist/gastroenterologist was the most appropriate source of such information, and 1% indicated they would recontact the genetics provider if more information was wanted. Additionally, participants were asked to specify reasons why they may or may not want to be recontacted by genetics providers. Respondents checked all that applied from a suggested list, and were also able to indicate additional reasons. These are summarized in Figs. 2 and 3.

Because each person's medical care must be individualized, particularly with genetic syndromes of varying phenotypic expression, we stated that most

Table 1 Preferred method of re-contact (both clinic and research groups)

Recontact method	Percent
Specific Letter	55
General Letter	35
Newsletter	14
Telephone	7
Updated Website	7
Media Release	2
Other	3
Do Not Re-Contact	<1

Some respondents indicated more than one method

patients would need to return to clinic to discuss any new information at length. Most respondents indicated their interest in being recontacted would not be affected by the need to be seen again (79% clinic, 75% research), although some were uncertain (12% clinic, 15% research). A few indicated this would change their interest in being recontacted (8% both groups).

Post-survey follow-up:

Only a minority of survey respondents indicated they had ever recontacted us for more information (25% clinic, 20% research). After receiving the updated information in this mailing, most participants were uncertain whether they planned to recontact us regarding improved testing techniques (38% clinic, 48% research, $P \leq .01$) although some indicated they would (31% clinic, 22% research). Similarly, most were uncertain whether they would recontact us regarding MSH6 testing for HNPCC (39% clinic, 47% research) or MYH testing for polyposis (38% clinic, 43% research), although some indicated that they would (22% clinic, 19% research for MSH6; 19% clinic, 17% research for MYH). However, in the 5 months following the survey, only 26 respondents (7.3% of those completing the survey) recontacted clinic or study staff. Twenty individuals contacted the genetic counselors or clinic coordinator by telephone, and six returned to clinic for further risk assessment.

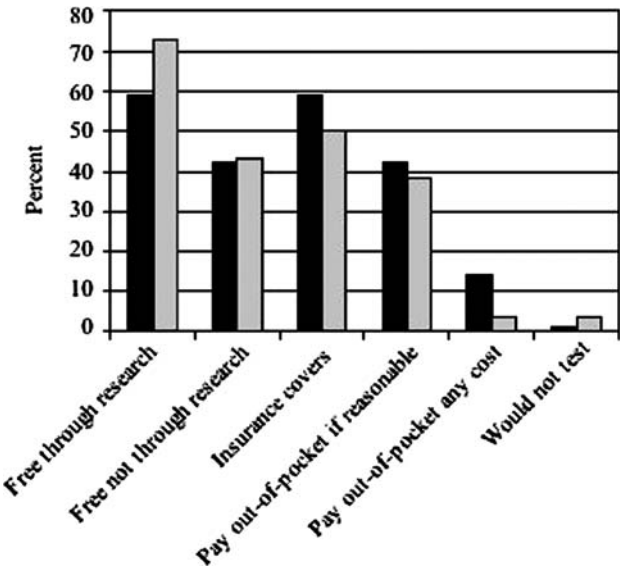

Fig. 1 Response to question "If you were told that a new genetic test were available to you, under what circumstances would you proceed with testing?" Respondents checked all that applied from a suggested list. Black bar, clinic group; grey bar, research group

Discussion

Little information exists about patient preferences regarding responsibility and mechanism for receiving updated medical information. This survey attempted to identify patient interests and expectations about recontact by cancer genetics providers. Most repondents wanted to develop a longitudinal relationship with a genetic health provider, to be recontacted with advances in genetic medicine and to receive highly personalized updates. Most often, no significant difference existed between responses by clinic patients and research participants.

We chose to update patients with information about (i) the MYH gene, a cause for a new, autosomal recessive form of adenomatous polyposis [12–14], (ii) the role of MSH6 in HNPCC since clinical testing had become available [15] and (iii) the ability to detect large genomic rearrangements and deletions in colon

Table 2 Preferred amount of information at the first point of recontact

Amount of Information:	Clinic No. (%)	Research No. (%)
There is new information; ask patient to contact Genetics	19 (7)	23 (15)
There is new information; provide a resource (website) for patient to access for details	38 (19)	33 (21)
Generally, what new information exists	44 (22)	36 (21)
Specifically, what new information exists and how it pertains to particular patient	105 (53)	76 (48)
Other (space to write in)	2 (1)	1 (1)
Genetics providers should not recontact patients	2 (1)	1 (1)

Some respondents indicated more than one method

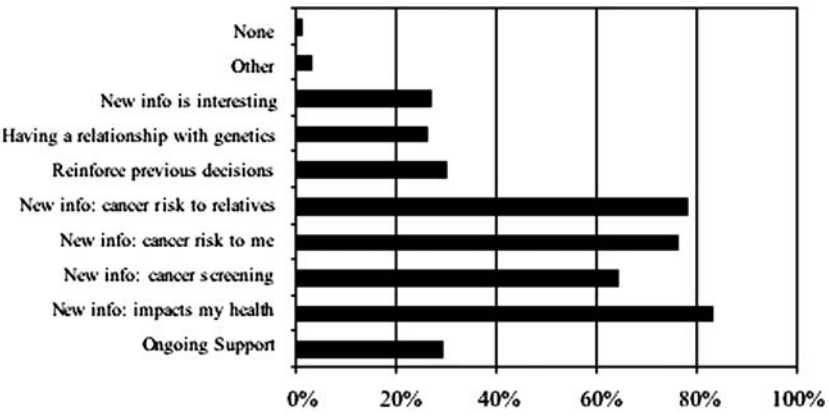

Fig. 2 Combined response from both groups to question, ''What are the reasons that you would want to be re-contacted by genetics providers?'' Respondents checked all that applied from a suggested list

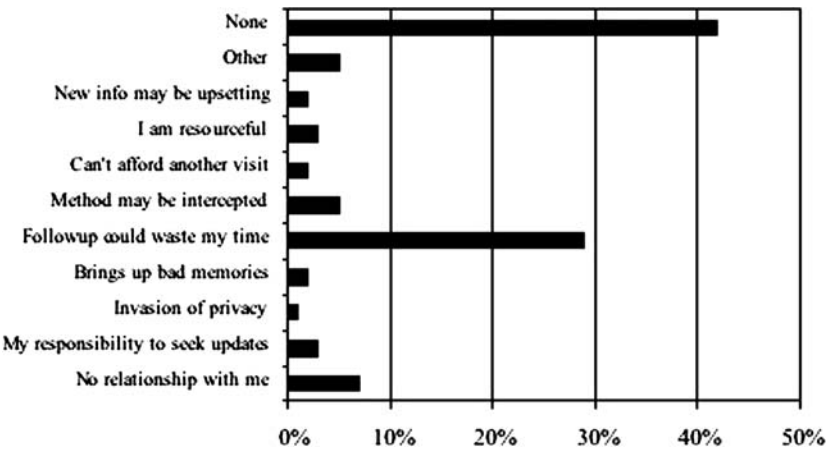

Fig. 3 Combined response from both groups to question, ''What are the reasons that you would not want to be re-contacted by genetics providers?'' Respondents checked all that applied from a suggested list

cancer-related genes [16, 17]. These discoveries could provide an explanation for families in which no gene mutation was previously found. However, despite respondents' indicating they want updated information, few clinic appointments were made in response to the information provided. This is surprising since molecular diagnosis of a genetic syndrome in a family allows identification of high- and low-risk family members, thereby directly impacting recommendations for medical management.

Recognizing the logistics involved in keeping patients informed of new genetic information, the American College of Medical Genetics (ACMG) recommends that patients notify primary care providers and/or contact the genetics provider with changes in medical history [18]. Unfortunately, the literature suggests that primary care providers are overwhelmed in keeping up with advances in clinical genetics and lack time to provide such counseling [19]. Reports also indicate that generalist providers do not obtain an adequate family history, a key component in evaluating familial cancer syndromes [20–22]. Respondents may suspect this, as only 1% felt that the recontact should come from primary care providers.

To our knowledge, the legal aspects of intitiating recontact to provide additional information relative to cancer genetic risk to a patient no longer under one's care have not been addressed directly. Hunter et al. [4] stated ''the proposed duty to recontact former patients who have been provided with information-only services is not supported by existing American or Canadian legal precedents... [However], to create the physician-patient relationship, generally speaking, the physician must offer... to see or counsel the patient, and must have made some rudimentary evaluation of the patient's complaint or condition, and the patient must rely on that evaluation and/or advice and/or offer.'' The ''duty to warn,'' which directly impacts ''duty to recontact,'' is most compelling when action can be taken to minimize harm. Yet to discern which patients might benefit most from updated information would require full review of each patient's case, along with updated personal and family history information.

Another concern is ensuring that only individuals who desire updates are recontacted. Health Insurance Portability and Accountability Act of 1996 (HIPAA) limitations suggest one would need to obtain permission for future contact at initial consultation. Despite

this, three-quarters of our survey respondents answered that there were definitely indications for recontacting patients who initially declined. The difficulty lies in determining when updated information is ''significant enough'' to warrant overriding patient instruction. Furthermore, if an individual is contacted in any way, he/she might assume that a careful review of each case has occurred, leading to a misconception that general information is actually individualized. In fact, the very act of surveying these individuals about the concept of recontact may have raised the expectation that additional information should be provided.

The logistical limitations of providing new, relevant genetic information for cancer genetics population are formidable. At a minimum, a functional database updated routinely is necessary. This is of particular importance given the relatively short retention time of medical records [23]. Not only could this become labor-intensive, but it is costly, as well. Although we could not isolate the most substantial costs, such as maintaining a database with ability to identify appropriate individuals for recontact, as well as personnel time for development of fact sheets, the printing and mailing costs of this study, alone, exceeded $2000. A recent survey of genetic services available at National Cancer Institute Cancer Centers found that most cancer genetics clinical services were partially supported by institutional or private funds [24] and suggests that additional costs may be hard to support.

There are several limitations to our study. First, we have information only from those individuals who responded, which may represent only those in favor of recontact. Second, we surveyed two highly selected populations of presumably information-seeking individuals since they presented in clinic or to a research study. However, our surveyed groups are likely to be representative of those individuals who participate in research or come to a colon cancer genetics clinic [25]. Third, we did not collect information correlating individual patient survey results with specific patient diagnoses or previous genetic test results. This information may have affected response rates and types of responses we received.

In summary, a substantial proportion of the colon cancer genetics patients we surveyed, including most who responded to our survey, want a longitudinal relationship with a genetic health provider and recontact at least annually with advances in genetic medicine. However, they desire highly personalized updates. A number of hereditary colorectal cancer registries have been established in the United States, Europe, and Asia to facilitate research on these relatively uncommon cancer syndromes. Many of the registries update pedigree information on their families and record the results of clinical surveillance for expected cancers. The registries provide an important resource for developing evidence-based clinical guidelines. A somewhat practical solution might be an annual newsletter for clinic patients, similar to those developed by these research registries for keeping their enrollees informed about new genetic discoveries and recommended surveillance practices.

Alternatively, a continually updated website may serve the same purpose. Although our survey indicated that these general informational approaches may be less desirable to patients than individualized information, they may be less labor-intensive and costly, allowing genetics professionals to provide more frequent updates to a larger number of patients.

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Appendix 1

Keywords used for diagnosis in clinic:

HNPCC (meets Amsterdam or Bethesda criteria)
HNPCC-Like (One family member with an HNPCC cancer diagnosed age 50–54 years or
Two or more family members with an HNPCC cancer diagnosed age 55–65 years)
FAP (>/= 100 adenomatous polyps)
AFAP (20–99 adenomatous polyps)
Oligopolyposis (5–20 adenomatous polyps)
Peutz-Jeghers syndrome (evaluated/suspicious for PJS)
Juvenile Polyposis (evaluated/suspicious for JPS)
APC I1307K (evaluated/suspicious for I1307K)
Familial Colorectal Cancer (Two or more family members with colon cancer; all
diagnosed >/= age 66 years)
Hyperplastic Polyposis (>10 hyperplastic polyps)
Non-syndromic/Not hereditary (Only one family member with any cancer diagnosed >/=age 55 years)

Appendix 2

«LSTNAME», «FNAME»
Unless otherwise indicated, please check only one response for each question. For the purpose of this survey, "genetics providers", "we", or "us" refers to the physician and/or genetic counselor seen during your risk assessment visit for hereditary cancer.

1) Do you see a primary care physician, internist or gastroenterologist regularly?
☐ Yes ☐ No ☐ Uncertain
If yes, how often? _____

2) Should an ongoing relationship be developed between patients and genetics providers?
☐ Yes ☐ No ☐ Uncertain

3) Whose *primary* responsibility do you think it is to keep patients updated about new genetic discoveries?
☐ Genetics provider
☐ Primary care physician/Internist
☐ Gastroenterologist (or other specialist)
☐ Patients
☐ Other: _____
☐ No one; patients should not be updated

4) If genetics providers were to re-contact patients, how often should it be done?
☐ Regularly, even if no new discoveries are made (please specify time interval _____)
☐ When *any* new discoveries are made
☐ Only when new discoveries are made that pertain directly to the re-contacted patient
☐ Other: _____
☐ Genetics providers should not re-contact patients

5) If genetics providers were to re-contact patients, what method should be used?
☐ Telephone
☐ General letter to all patients
☐ Personalized letter only to appropriate patients
☐ Newsletter
☐ Media release
☐ Continually updated website
☐ Other: _____
☐ Genetics providers should not re-contact patients

6) How much information should be provided at the first point of re-contact?
☐ Just that there is new information; ask the patient to contact genetics if interested in more details
☐ Just that there is new information; identify a resource (eg. website) that the patient can access for more details
☐ Generally, what new information exists
☐ Specifically, what new information exists, and how it pertains to the particular patient
☐ Other: _____
☐ Genetics providers should not re-contact patients

7) Should patients be asked at the initial consultation about whether or not they wish to be re-contacted?
☐ Yes ☐ No ☐ Uncertain

8) If a patient indicates "no" at the initial visit, is there ever a time that a provider should re-contact them anyway?
☐ Yes ☐ No ☐ Uncertain
If yes, under what circumstances? _____

9) Have you ever re-contacted us for more information?
☐ Yes ☐ No ☐ Uncertain

10) Do you plan to re-contact us regarding any of the following items?

Improved testing techniques	☐ Yes	☐ No	☐ Uncertain
MSH6 testing for HNPCC	☐ Yes	☐ No	☐ Uncertain
MYH testing for polyposis	☐ Yes	☐ No	☐ Uncertain

11) If you were told that a new genetic test were available to you, under what circumstances would you be most likely to pursue testing? *Check all that apply*
☐ If it were provided free of charge through a research study
☐ If it were provided free of charge, but not through a research study
☐ If my insurance would cover the cost of testing
☐ I would be willing to pay out-of-pocket if the cost were "reasonable"
(Please define "reasonable": _____)
☐ I would be willing to pay out-of-pocket, regardless of cost
☐ I would not proceed with additional genetic testing under any circumstances.

12) If we were to develop a policy for re-contacting patients, do you want to be re-contacted by us?
☐ Yes, on a regular basis, even if there are no new discoveries
☐ Yes, but only when *any* new information arises
☐ Yes, but only when new information arises that pertains directly to me
☐ No, but ask my primary care physician/internist/gastroenterologist to re-contact me
☐ No, I will contact the genetics provider if I want more information

13) What are the reasons that *you* would want to be re-contacted by genetics providers? *Check all that apply*

- ☐ Ongoing "support" from genetics providers
- ☐ Receiving new information that impacts my health
- ☐ Receiving new information about cancer screening
- ☐ Receiving new information about cancer risk to me
- ☐ Receiving new information about cancer risk to my family members
- ☐ Reinforcing decisions I made based on previous information
- ☐ Feeling like I have a "relationship" with genetics providers
- ☐ New information is interesting, even if it doesn't apply to me
- ☐ Other: _____
- ☐ None

14) What are the reasons that *you* would not want to be re-contacted by genetics providers? *Check all that apply*

- ☐ Genetics providers do not have a "relationship" with me
- ☐ It is my responsibility to seek updated information
- ☐ Re-contacting is an invasion of my privacy
- ☐ Re-contacting brings up "bad memories"
- ☐ If the new information does not apply to me, follow-up could waste my time
- ☐ The method of re-contacting may be "intercepted" by someone other than me
- ☐ I am not able to financially afford another genetics visit, so re-contacting me could be upsetting
- ☐ I am resourceful and can locate new information on my own, without re-contact from a genetics provider
- ☐ I made difficult decisions based on previous information, and new or contradictory information could upset me
- ☐ Other: _____
- ☐ None

15) Because each person's medical care must be individualized, in most cases we would need to see you again to discuss the new information at length. Does this change your interest in being re-contacted?

☐ Yes ☐ No ☐ Uncertain

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