To Bank or Not to Bank: Exploring the Current Practices of Genetic Counselors Regarding DNA Banking

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Abstract

To Bank or Not to Bank: Exploring the Current Practices of Genetic Counselors Regarding DNA Banking

A thesis presented to the Genetic Counseling Program

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Genetic counselors are uniquely positioned to discuss the option of DNA banking with patients. Personal DNA banking, a means of storing DNA for future analysis, may benefit the depositor or the depositor’s family. To date, research has primarily focused on consumer views of other types of medical banking (such as cord blood banking) and consumer opinions regarding genetic testing and/or research. The aim of this study was to assess genetic counseling practices regarding the discussion of DNA banking with patients. We recruited genetic counselors through the National Society of Genetic Counselors (NSGC) and the NSGC Cancer SIG listservs to complete an anonymous, online survey consisting of 46 multiple-choice, scaled, and open-ended questions. We presented the respondents with scenarios and asked them to indicate the likelihood they
would discuss the option of DNA banking. We received 171 completed surveys, of which 46 surveys had responses for prenatal scenarios, 51 for pediatric, and 104 for cancer. Our results suggest that DNA banking is not consistently discussed with patients. Counselors were more likely to discuss DNA banking with patients who: had multiple miscarriages or an earlier gestation loss in the prenatal setting; are suspected to have a syndrome, are expected to pass away, or had a negative test result for a test with a detection rate less than 100% in the pediatric setting; have a poor prognosis, are concerned for family members, or have not undergone testing in the cancer setting. Only twenty-seven respondents (15.8%) reported they received training regarding DNA banking in graduate school and only 12 individuals (7%) reported their current or previous employer provided a specific protocol regarding appropriate situations to discuss DNA banking with patients. These results suggest the need for training regarding DNA banking and the generation of guidelines for genetic counselors and other non-genetics health care professionals.
# Table of Contents

Introduction  
Consumers’ Views on Genetic Research, Genetic Testing and DNA Banking  
Consumers’ Views on Different Types of Banks  
Genetic Services in Palliative Care  
Personal DNA Banking  
Methods  
Results  
Response Rate  
Demographics  
Professional Information  
Graduate School Training  
DNA Banking Training and Protocols  
DNA Banking Scenarios  
Open-ended Responses  
Discussion  
Limitations  
Conclusions  
References  
Appendices
List of Tables

Table 1: Frequency of Children for Respondents Who Answered “Yes” to Having Children 11

Table 2: Respondents’ Professional Region and Clinical Setting 12

Table 3: Region of Graduate School Respondents Attended 15
List of Figures

Figure 1: Average of Percentages of Time Spent Working in Clinical Specialty 13

Figure 2: Average of Percentages of Race Making up Patient Population 14

Figure 3: Compilation of All Responses for Likelihood of Discussing DNA Banking 17

Figure 4: Responses to likelihood of discussing DNA banking for Prenatal Scenario 3 and 4 18

Figure 5: Responses to likelihood of discussing DNA banking for Prenatal Scenario 7 and 8 19

Figure 6: Responses to likelihood of discussing DNA banking for Pediatric Scenarios 1 and 2 20

Figure 7: Responses to likelihood of discussing DNA banking for Pediatric Scenarios 6 and 7 21

Figure 8: Responses to likelihood of discussing DNA banking for Pediatric Scenarios 3, 4 and 5 23

Figure 9: Responses to likelihood of discussing DNA banking for Cancer Scenarios 3 and 4 24

Figure 10: Responses to likelihood of discussing DNA banking for Cancer Scenarios 5 and 6 25

Figure 11: Responses to likelihood of discussing DNA banking for Cancer Scenarios 7 and 8 26

Figure 12: Responses for Similar Situation for Prenatal, Pediatrics, and Cancer Scenarios 27

Figure 13: Responses for Patient’s Acceptance for Prenatal, Pediatric and Cancer Scenarios 28
Introduction

Four types of DNA banking exist in the United States: academically based banks in laboratories of scientists who are studying one or more genetic disorders; state-based DNA forensic banks intended to assist in the resolution of violent crimes by comparing biological specimens from a crime scene to those collected from thousands of convicted felons; and, DNA banking by the military to assist in identification of human remains. The last type and the ones of interest are commercially based banks that offer banking as a service to individuals who may have some reason to store their DNA in anticipation of the development of a linkage test or other genetic test that might benefit their children and grandchildren (Reilly, 1992).

For the purposes of this study, a DNA bank refers to a commercial DNA bank and is defined as a facility that stores DNA for future analysis, to promote the health and well-being of the depositor and his/her relatives and descendents (Hall, 1991). DNA banking is an appropriate option for: individuals with a specific health condition who are concerned that family members might be at risk for the same problem; families for whom a specific gene change could not be identified at the time of banking but may be identified in future genetic testing; and, individuals/families being evaluated for a genetic cause for their disease for which there is currently no genetic test available. It is also appropriate for an affected family member who is terminally ill and does not have time for traditional genetic evaluation (NSGC brochure).
DNA banking offered through commercial laboratories have varying costs that can range from approximately $50 to $350. This onetime fee depends on the amount of time the DNA is stored, which ranges from 5 years to indefinitely. Once the DNA is stored, the individual or family members that the individual chooses can access it for future clinical genetic testing or research (NSGC brochure).

**CONSUMERS’ VIEWS ON GENETIC RESEARCH, GENETIC TESTING AND DNA BANKING**

Research has been done addressing consumers’ views on the subject of genetic testing in a population of adults 65 years and older in the United Kingdom. Researchers found that the participants had an altruistic approach to genetic testing, which influenced their willingness to be tested in order to benefit others in the family or the wider community. The participants felt that genetic testing was a way of preventing future suffering for children and grandchildren in the family (Skirton, 2006).

Public opinion and attitudes regarding the donation and storage of blood for genetic research have also been investigated. Wang et al. found that: 42% of respondents were in favor of both blood donation and long-term storage for genetic research; 37% were in favor of either blood donation or storage for genetic research but not both; and, 21% were not willing to donate blood or have it stored for genetic research under any circumstances. Characteristics such as higher education, white race, living in the Mountain/Pacific or mid-Atlantic regions of the United States or having a positive family history of a genetic disorder were correlated with those who favored the blood donation and long-term storage (Wang, 2001).
These studies indicate that, in general, individuals have a positive view on genetic services. Individuals may be more inclined to use genetic services if they believe that it will benefit others (either family or the community) or if they have personal experiences with a genetic disorder. Although these studies do not directly address consumers’ views on personal DNA banking, the positive views on other genetic services seen in these studies may indicate that consumers would have similar views regarding personal DNA banking.

**CONSUMERS’ VIEWS ON DIFFERENT TYPES OF BANKS**

Patient’s attitudes towards large-scale efforts to collect genetic samples for research from excess clinical blood specimens have been investigated. Researchers found that only a minority of individuals did not believe in the benefits of a DNA databank and opposed its use. They found that the majority of respondents had positive opinions about medical research and the potential for a DNA databank. Most respondents were in favor of research and were either very or somewhat comfortable with anonymous genetic information being used for research. Ninety-one percent felt that leftover blood and tissues should be used for anonymous medical research; however, this number varied by ethnicity (Pulley, 2008).

Another study examined the knowledge and attitudes of pregnant women towards cord blood banking and why they might choose public (through which stem cells are available to anyone who needs them) rather than private (whereby cord blood is stored for the exclusive use of the donor’s family) cord blood banking. They discovered that most respondents had poor or very poor knowledge of cord blood banking but the
majority of respondents felt that physicians should talk to pregnant woman about this option. Respondents indicated two main reasons for choosing public banking over private: altruism and the expense associated with private banking. Only one-third of respondents felt that the cord blood should only be used for transplantation; the other two-thirds were open to alternative uses of cord blood including research, gene therapy, and drug manufacturing (Fernandez, 2003).

Over all, these studies suggest that consumers have favorable views on other types of DNA banking, for either research or individual use, and would respond positively if these options were presented to them more frequently. These positive views could also represent how consumers feel about personal DNA banking, however, this cannot be said definitively without specific studies addressing personal DNA banking.

**GENETIC SERVICES IN PALLIATIVE CARE**

Of particular interest are studies addressing genetic services in palliative care. Many of the patients in this setting are suffering from serious, complex illnesses that may take their life and DNA banking may be beneficial for the patient’s family to provide information in the future.

The need for genetic services, including risk assessment and genetic testing, has been discussed in the context of cancer palliative care. Lillie (2006) suggests that predictive genetic testing within the palliative care setting can be considered if the family history is concerning. Predictive genetic testing can be beneficial to the patient’s family because if the family members are found to be at risk for cancer they will be able to make informed decisions about their future health risks and start regular screening. It can also
be a positive experience for the patient because it allows them to act altruistically (Lillie, 2006).

In a different study, researchers showed the importance of genetic assessment in palliative care using a case report of a patient who was dying imminently of gastrointestinal cancer. The experience of this patient and the benefits the genetic assessment and DNA banking provided for the patient’s family illustrated the importance of this service in palliative care. Researchers emphasized the fact that quality palliative care addresses the concerns of patients and families. Offering genetic services will not help the patient’s health but can help to reassure the patient of a better life for their loved ones (Quillin, 2008).

**PERSONAL DNA BANKING**

The type of DNA banking that is of most interest to genetic counselors is personal DNA banking. Individuals who decide to bank their DNA do so to preserve their genetic legacy in hopes of benefiting current family members and future generations. Personal DNA banking is becoming more widespread in certain clinical situations, though little research has been done regarding personal DNA banking. The research described above may provide insight into consumers’ interest in personal DNA banking; these views may be similar to the ones they have on other types of DNA banks and other types of genetic services. To the authors’ knowledge, no published studies exist on how often and in what situations certain health care professionals (including oncologists, neonatologists, obstetricians and genetic counselors) discuss DNA banking with patients.
The aim of this study is to start with one population, genetic counselors, and investigate when they discuss the option of DNA banking, and whether they received training in graduate school, or have protocols at their current jobs specifying situations in which the option of DNA banking should be discussed with patients. This information would be advantageous in filling in the existing gap in the literature. Studies addressing this issue would be valuable in determining how often the option of DNA banking is being discussed; and, therefore, how often consumers are being exposed to the option. These studies may also indicate whether genetic counselors are consistent in their decisions to discuss the option, and if there is a need for training on situations in which genetic counselors should discuss the option of DNA banking. The results from the survey may also be used to generate guidelines about the discussion of DNA banking for use by other non-genetic health care professionals.
Methods

STUDY DESIGN

The study design was an anonymous survey directed at genetic counselors using an online survey. The survey tool was formulated to ascertain the practices of genetic counselors regarding DNA banking. It consisted of 46 questions that were multiple choice, scaled, and open-ended.

STUDY PROCEDURES

Recruitment procedures and materials

We recruited genetic counselors for participation in our project by posting on the National Society of Genetic Counselors (NSGC) listserv and the NSGC cancer Special Interest Group (SIG) listserv. The posting was linked to an anonymous online survey via Survey Monkey. Our sample consisted of those genetic counselors who subscribed to the NSGC listservs and who chose to click on the link and fill out the survey after seeing the invitation to participate in the study (Appendix I).

Data Collection

The survey consisted of various demographic questions including: region where the genetic counselors work; region where they went to graduate school; years of clinical experience; age, and sex. We also asked if they had any training in graduate school regarding when to discuss DNA banking; and, if they have worked or are currently working in a clinic that has protocols for when to discuss the option of DNA banking.
The survey had three different sets of clinical scenarios: one for prenatal, pediatric, and cancer. At the beginning of each section, we asked how many cases per week the counselor sees of each type. For the scenarios within each section, we asked both “would you discuss the option of DNA banking?” and if the counselor had been in that situation before, if he/she discussed DNA banking then. We also asked the respondents what their reasons would be for discussing or not discussing DNA banking for each scenario. Finally, if the respondent had been in the situation described by the scenario and discussed DNA banking with the patient; we asked whether or not the patient accepted and if the patient declined, what the reason was for declining (Appendix II).

**Data Analysis**

Data from the online survey were entered into Survey Monkey. After data collection was complete, responses were exported from Survey Monkey to a spreadsheet in Microsoft Excel 2007. From there, data was stored, coded and analyzed using Predictive Analytic SoftWare (PASW) Statistics version 18.0. Frequency data were reported for demographic information and scenario questions. Chi-squared tests were performed on select demographics to compare the survey population with the population of genetic counselors who responded to the 2008 NSGC Professional Status Survey (Smith et al, 2009). Paired t-tests were used to determine if there were any significant differences in responses between the pairs of scenarios. Lastly, open-ended questions were analyzed using Atlas.ti version 5.0 and reported for common themes.

**COMPENSATION**

We offered two $50 gift certificates as an incentive to fill out the survey which were raffled off after all of the survey responses had been received. After completion of
the survey, a link directed subjects to another website where they had the option to submit an email address to participate in the raffle. Participation in the raffle was optional. The only identifying information required of raffle participants was the email that they provided. The emails for the raffle were not linked to the subject’s responses from the survey, so that the survey remained anonymous.
Results

A total of 180 surveys were started, of which 9 were not completed with sufficient data to include in the analysis. Twenty-eight of the remaining 171 surveys had varying degrees of completion. We decided that these surveys were completed sufficiently enough to include. Therefore, 171 surveys were used in our analysis.

DEMOGRAPHICS

One hundred thirty seven of the respondents were female (80.1%), 5 were male (2.9%), and 1 was unspecified (0.6%). The remaining 28 individuals chose not to answer the question (16.4%). Respondents’ ages fell within the categories ranging from 21-60 years old. The greatest percentage of respondents were age 21 to 30 years old (N=65, 38%), followed by 31 to 40 years old (N=57, 33.3%). The largest percentage of respondents did not have children (N=80, 46.8%), although some respondents (N=53, 31%) did have children or were currently pregnant (N=9, 5.3%). The remaining 29 respondents chose not to answer the questions about age and children (17%). Of the respondents who had children, the most had two children (N=24, 45.3%), followed by one (N=20, 37.7%) (Table1).
<table>
<thead>
<tr>
<th>N</th>
<th>Percentage (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>20</td>
</tr>
<tr>
<td>2</td>
<td>24</td>
</tr>
<tr>
<td>3</td>
<td>8</td>
</tr>
<tr>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>53</strong></td>
</tr>
</tbody>
</table>

*Table 1: Frequency of Children for Respondents Who Answered “Yes” to Having Children*

**PROFESSIONAL INFORMATION**

Respondents on average have worked in a clinical setting for 6.59 years (SD=5.98). Clinical work experience for the respondents ranged from 3 months to 28 years. Years of clinical work experience of respondents was not significantly different from years of clinical work experience reported by respondents of the NSGC professional status survey (PSS) ($\chi^2 (5)=9.860$, $p=0.079$).

The greatest percentage of respondents worked in region IV (N=32, 18.7%) of the United States although the respondents were spread out among the regions and all regions were represented in the results of the survey (Table 2). The distribution of professional region was not significantly different from the distribution found in the NSGC PSS ($\chi^2(5)=6.853$, $p=0.232$). The greatest percentage of respondents worked in a university medical center (N=69, 40.4%), with the second largest being hospitals (N=52, 30.4%) with an equal split between public and private hospitals (Table 2). Respondents who answered “other” indicated that they worked in a non-profit setting, public health, laboratory, HMO, telephone genetic counseling company, and a National Cancer Institute comprehensive cancer center. There was no significant difference in the distribution of
professional setting between this sample of respondents and those included in the NSGC PSS ($\chi^2(3)=5.242$, p=0.155). The “other” category was excluded from the chi-squared analysis because it was defined differently in the two surveys. Twenty-nine respondents (17%) chose not to answer the region employed question and 31 respondents (18.1%) chose not to indicate clinical work setting.

<table>
<thead>
<tr>
<th>Region Employed</th>
<th>Current Survey data</th>
<th>2008 Survey data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Region I (CT, ME, MA, NH, RI, VT)</td>
<td>11.7%</td>
<td>9%</td>
</tr>
<tr>
<td>Region II (D.C., DE, MD, NJ, NY, PA, VA, WV)</td>
<td>17.5%</td>
<td>24%</td>
</tr>
<tr>
<td>Region III (AL, FL, GA, KY, LA, MS, NC, SC, TN, PR)</td>
<td>10.5%</td>
<td>13%</td>
</tr>
<tr>
<td>Region IV (AR, IL, IN, IA, KS, MI, MN, MO, NE, ND, OH, OK, SD, WI)</td>
<td>18.7%</td>
<td>24%</td>
</tr>
<tr>
<td>Region V (AZ, CO, MT, NM, TX, UT, WY)</td>
<td>11.7%</td>
<td>11%</td>
</tr>
<tr>
<td>Region VI (AK, CA, HA, ID, NV, OR)</td>
<td>12.9%</td>
<td>19%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Clinical Work Setting</th>
<th>Current Survey data</th>
<th>2008 Survey data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public Hospital</td>
<td>15.2%</td>
<td>14%</td>
</tr>
<tr>
<td>Private Hospital</td>
<td>15.2%</td>
<td>19%</td>
</tr>
<tr>
<td>University Medical Center</td>
<td>40.4%</td>
<td>37%</td>
</tr>
<tr>
<td>Private Practice</td>
<td>2.9%</td>
<td>6.4%</td>
</tr>
<tr>
<td>Non-Medical Setting</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>8.2%</td>
<td></td>
</tr>
</tbody>
</table>

**Table 2:** Respondents’ Professional Region and Clinical Setting

Respondents were asked to indicate what percentage of time was spent working in each of six clinical specialties including adult, cancer, prenatal, pediatrics, specialty
disease, and other. The average percentage of time spent working in cancer genetics was largest at 50%. Respondents spent the second largest amount of time working in prenatal genetic counseling (19%), with pediatrics close behind (18%) (Figure 1). If a respondent spent any time working in a clinical specialty not listed, they had the option of “other”. If they put any percentage in the “other” option, they were then asked to specify. The other clinical specialties that some respondents spent time working in were public health, laboratory, research, teaching, clinic coordination, non-clinical administration, hematology, pediatric oncology, maternal serum screening coordination, clinical molecular diagnostics, newborn screening, and IVF.

![Figure 1: Average of Percentages of Time Spent Working in Clinical Specialty](image)

Respondents were also asked to indicate the percentages of the make-up of their patient population by race. The average patient population was mostly Caucasian (69%)
with African American and Hispanic both being the next largest percentages (11%). Also making up some respondents’ patient population were individuals from Asia and the Middle East (Figure 2). Respondents were also given the option of “other” if they see patients from a race that was not included as an option. Respondents who put a percentage in the “other” category were then asked to specify. Respondents indicated that the individuals were Native American and Haitian Creole.

![Figure 2: Average of Percentages of Race Making up Patient Population](image)

**GRADUATE SCHOOL TRAINING**

Respondents on average have been out of graduate school for 7.05 years (SD=6.19). Years since graduate school for the respondents ranged from 8 months to 29 years. The greatest percentage of respondents attended graduate school in region II of the United States (N=48, 28.1%), with the second largest being region IV (N=42, 24.6%).
All of the regions of the United States were represented in the responses given by respondents. Thirty-four individuals (19.9%) chose not to answer this question.

<table>
<thead>
<tr>
<th>Graduate School Region</th>
<th>Percentage (%)</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Region I (CT, ME, MA, NH, RI, VT)</td>
<td>5.8</td>
<td>10</td>
</tr>
<tr>
<td>Region II (D.C., DE, MD, NJ, NY, PA, VA, WV)</td>
<td>28.1</td>
<td>48</td>
</tr>
<tr>
<td>Region III (AL, FL, GA, KY, LA, MS, NC, SC, TN, PR)</td>
<td>9.9</td>
<td>17</td>
</tr>
<tr>
<td>Region IV (AR, IL, IN, IA, KS, MI, MN, MO, NE, ND, OH, OK, SD, WI)</td>
<td>24.6</td>
<td>42</td>
</tr>
<tr>
<td>Region V (AZ, CO, MT, NM, TX, UT, WY)</td>
<td>7.6</td>
<td>13</td>
</tr>
<tr>
<td>Region VI (AK, CA, HA, ID, NV, OR)</td>
<td>4.1</td>
<td>7</td>
</tr>
</tbody>
</table>

Table 3: Region of Graduate School Respondents Attended

**DNA BANKING TRAINING AND PROTOCOLS**

Respondents were asked both if they had training in graduate school and if they have ever had a protocol at work (current or past job placement) regarding when to discuss the option of DNA banking with a patient. The majority of individuals answered that they did not receive training in graduate school (N=113, 66.1%) regarding DNA banking. The twenty-seven individuals (15.8%) who responded that they did receive training went to graduate school at 21 different schools. The majority attended graduate school in regions II and IV (N=9 for each). Schools of attendance were also located in regions I, III, and VI. Thirty-one individuals (18.1%) chose not to answer the question about training in school.
The majority of respondents answered that they have never had a protocol at work regarding when to discuss the option of DNA banking with a patient (N=127, 74.3%). Of the 12 individuals (7%) who indicated that they currently have a protocol or have had one in a past job, five specified the location. One respondent had a protocol at two separate locations. The six locations where there was a protocol regarding DNA banking were mostly private hospitals (N=3) and university medical centers (N=2). The other location was a Health Maintenance Organization (HMO). Thirty-two individuals (18.7%) chose not to answer this question.

**DNA BANKING SCENARIOS**

Respondents were asked if they saw at least one patient per week on average for each of the three following areas of genetic counseling: prenatal, pediatrics, and cancer. Forty-six respondents indicated that they saw at least one prenatal patient per week, 51 saw at least one pediatric patient per week, and 104 saw at least one cancer patient per week. Those individuals were then asked to indicate how many patients they saw per week in these areas. Respondents answered that they saw an average of 8 prenatal patients (M=7.62, SD=6.07) per week, 5 pediatric patients (M=5.18, SD=4.15) per week, and 5 cancer patients (M=4.98, SD=3.43) per week. Respondents were then directed to a series of scenarios for each of the types of patients that they saw.

For each scenario, the respondents were asked to indicate on a 5 point Likert scale (definitely not, probably not, undecided, probably, or definitely) if they would discuss the option of DNA banking in that scenario. When looking at the compilation of responses for all the scenarios in each section, the majority of responses given by individuals that
answered the pediatric section were that they would definitely (N=197, 45.29%) or probably (N=148, 34.02%) discuss DNA banking in those scenarios. For the prenatal scenarios, the answer given the most frequently was probably not (N=128, 39.51%) with probably (N=87, 26.85%) being the second most common. The majority of responses given by individuals answering the cancer scenarios were that they would probably not (N=387, 34.96%) discuss DNA banking in those scenarios with the second largest percentage being definitely (N=315, 28.46%) (Figure 3).

Figure 3: Compilation of All Responses for Likelihood of Discussing DNA Banking
Prenatal Scenarios

Included in this section were eight prenatal scenarios that were divided into pairs to assess whether respondents answered differently regarding the likelihood of discussing the option of DNA banking with a patient based on four patient characteristics: age, previous miscarriage status, prognosis of the pregnancy, and gestational age at time of termination.

Respondents answered differently based on the patient’s previous miscarriage status (Figure 4). On average, respondents answered 0.85 points higher or more likely on a 5-point Likert scale of how likely the respondent would discuss DNA banking in the scenario when the patient had multiple previous miscarriages versus when the patient had no previous miscarriages (t(39)=4.999, p<.001).

![Figure 4: Responses to likelihood of discussing DNA banking for Prenatal Scenarios 3 and 4](image-url)
Respondents also answered marginally differently based on the gestational age at the time of termination (Figure 5). On average, respondents answered 0.13 points higher or slightly more likely to discuss the option of DNA banking when the patient was 20 weeks gestation versus 30 weeks gestation and undergoing a termination because of fetal anomalies \((t(39)=1.707, p=.096)\).

No difference in response was seen based on the patient’s age or the prognosis of the pregnancy. Respondents answered similarly on a 5-point Likert scale of how likely they would discuss DNA banking with a 25-year-old patient versus a 40-year-old patient who has had a 22-week fetal demise with no other fetal anomalies seen on ultrasound \((t(39)=1.00, p=.323)\). Respondents also answered similarly on how likely they would discuss DNA banking with a 28-year-old patient at 18-weeks gestation with fetal anomalies detected on ultrasound and whose pregnancy prognosis is unknown versus poor \((t(39)=1.657, p=.105)\).

**Figure 5**: Responses to likelihood of discussing DNA banking for Prenatal Scenarios 7 and 8
**Pediatric Scenarios**

Included in this section were nine pediatric scenarios that were divided into 3 pairs as well as a grouping of three scenarios to assess whether respondents answered differently about the likelihood of discussing the option of DNA banking with a patient based on four characteristics: suspicion of a the presence of a syndrome in the patient, detection rate of the testing, future of the child, and age of the patient.

Respondents answered differently based on the suspicion of the presence of a syndrome in the patient (Figure 6). On average, respondents answered 0.94 points higher or more likely on a 5-point Likert scale of how likely the respondent would discuss DNA banking in the scenario when the baby was in the NICU, not expected to live, and had dysmorphic features versus when the baby was in the NICU, not expected to live, and had an isolated heart defect ($t(48)=5.744$, $p<.001$).

![Figure 6: Responses to likelihood of discussing DNA banking for Pediatric Scenarios 1 and 2]
Respondents also answered differently based on the future of the child (Figure 7). On average, respondents answered 0.79 points higher or more likely to discuss the option of DNA banking when the baby was in the NICU, had dysmorphic facies and limb abnormalities, and was not expected to live versus when the baby was in the NICU, had dysmorphic facies and limb abnormalities, and was being put up for adoption ($t(47)=6.107, p<.001$).

![Figure 7](image)

**Figure 7**: Responses to likelihood of discussing DNA banking for Pediatric Scenarios 6 and 7

No difference in response was seen based on the age of the patient. Respondents answered similarly on a 5-point Likert scale of how likely they would discuss DNA banking with the parents of a baby versus a 11-year-old patient with a rare metabolic
disorder for which there is no treatment and life expectancy is less than a year 
\( t(47) = 1.231, p = .224 \).

The set of three scenarios that were used to see if respondents answered 
differently on whether they would discuss DNA banking with a patient based on the 
detection rate of the testing for the clinically diagnosed syndrome showed that 
respondents answered differently if the testing had a 100% detection rate versus if the 
testing had been done but the syndrome still had unidentified genes associated with it. 
Respondents also answered differently if the testing had a 100% detection rate versus if 
no testing was done because the gene has not been identified (Figure 8). However, 
respondents did not answer differently if testing had been done but the syndrome still had 
unidentified genes associated with it versus if the testing had not been done because the 
gene has not been identified \( t(47) = .256, p = .799 \). On average, respondents answered 
0.396 points higher or more likely on a 5-point Likert scale when testing was done but 
the syndrome still had unidentified genes associated with it versus when the testing had a 
100% detection rate \( t(47) = 3.587, p = .001 \). When comparing the scenarios with testing 
not being done because the gene associated with the syndrome has not been identified 
versus the testing having a 100% detection rate, respondents, on average, answered 0.375 
points higher or more likely to discuss the option of DNA banking \( t(47) = 2.918, p = .005 \).
Cancer Scenarios

Included in this section were twelve cancer scenarios that were divided into pairs to assess whether respondents answered differently regarding discussing the option of DNA banking with a patient based on four characteristics: face-to-face contact, patient survival, concern for family, and testing status.

Respondents answered differently based on patient survival (Figure 9). On average, respondents answered 1.19 points higher or more likely on a 5-point Likert scale of how likely the respondent would discuss DNA banking in the scenario when a patient with a family history suspicious of a hereditary cancer syndrome did not get testing because of insurance denial and the patient was not expected to live versus where the life expectancy was not known (t(93)=9.533, p<.001).
Respondents also answered differently based on the patient’s concern for their family (Figure 10). They answered, on average, 0.656 points higher or more likely to discuss the option of DNA banking when the patient with a family history suspicious of a hereditary cancer syndrome was concerned about the implications for his/her family versus not being concerned for his/her family (t(89)=5.858, p<.001).

There was no difference seen for answers based on face-to-face contact with the patient. Respondents were no more likely to discuss the option of DNA banking for a hospice patient who was likely to die before genetic counseling or testing could be done than with a hospice patient who was likely to die but was able to be seen by a genetic counselor (t(100)=.961, p=339).
The last set of six scenarios was used to examine whether respondents answered differently based on testing status (not tested vs. negative testing) for different types of patients. Respondents answered differently for the first pair of scenarios looking at a 35-year-old female patient with breast cancer, no significant family history, and a BRCAPRO score of 2.2% (Figure 11). On average, respondents answered 0.236 points higher or more likely to discuss the option of DNA banking when the patient did not undergo testing versus when the patient had testing and was found to be negative for a BRCA1/2 mutation ($t(88)=2.177$, $p<.05$).
Respondents did not answer differently in their likelihood of discussing the option of DNA banking based on testing status for the other two pairs of scenarios: a 65-year-old female patient with breast cancer at age 50, with a paternal aunt who was diagnosed with breast cancer at age 65, and a BRCAPRO score of 2.1% ($t(87)=.568$, $p=.572$) and a 45-year-old female patient with breast cancer at age 40, with a mother with ovarian cancer at age 70, and a BRCAPRO score of 13.3% ($t(85)=1.436$, $p=.155$).

**Similar Situation and Patient’s Acceptance**

Following each scenario, the respondents were asked whether they had been in the same or a similar scenario before and discussed the option of DNA banking with the
patient. If they had been in the same or similar scenario, they were asked whether the patient had accepted the option of DNA banking.

The majority of respondents had not been in the same or similar situation as the scenario for any of the three types of patients: prenatal (N=254, 78.4%), pediatrics (N=369, 84.8%), and cancer (N=714, 69.9%) (Figure 12). The total number of respondents who had been in a similar situation was 70 individuals for all the prenatal scenarios combined, 66 individuals for all the pediatrics scenarios combined, and 307 individuals for all the cancer scenarios combined.

![Figure 12: Responses for Similar Situation for Prenatal, Pediatrics, and Cancer Scenarios](image)

Of the respondents who had been in a similar situation, they reported that the greatest percentage of the patients did indeed want to proceed with DNA banking. Of all of the responses given, 31 (46.27%) of the prenatal patients, 38 (57.58%) of the pediatric patients, and 199 (37.66%) of the cancer patients decided that they would like to proceed
with DNA banking (Figure 13). Respondents indicated that 18 prenatal patients said that they would not like to proceed with DNA banking and respondents answered that they did not know for 18 prenatal patients. For pediatric patients, respondents indicated that 16 patients said they would not like to proceed and respondents did not know for 12 patients. Respondents indicated that 87 cancer patients did not want to proceed with DNA banking and they did not know for 110 patients.

<table>
<thead>
<tr>
<th>Scenario</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cancer</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>34.81%</td>
</tr>
<tr>
<td>No</td>
<td>27.53%</td>
</tr>
<tr>
<td>I don't know</td>
<td>37.66%</td>
</tr>
<tr>
<td>Pediatric</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>57.58%</td>
</tr>
<tr>
<td>No</td>
<td>24.24%</td>
</tr>
<tr>
<td>I don't know</td>
<td>18.18%</td>
</tr>
<tr>
<td>Prenatal</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>46.27%</td>
</tr>
<tr>
<td>No</td>
<td>26.87%</td>
</tr>
<tr>
<td>I don't know</td>
<td>26.87%</td>
</tr>
</tbody>
</table>

Figure 13: Responses for Patient’s Acceptance for Prenatal, Pediatric and Cancer Scenarios

**OPEN-ENDED RESPONSES**

After each scenario, the respondents were given the opportunity to explain their reasons for either discussing or not discussing the option of DNA banking in that scenario. If respondents indicated for any of the scenarios that they had been in the same
or similar situation and had offered testing which the patient declined, they were given
the opportunity to indicate the reason the patient gave for declining. Finally, at the end of
the survey, respondents were asked to explain the types of scenarios that would warrant
the discussion of DNA banking.

**DISCUSSING DNA BANKING**

Respondents gave a variety of answers for why they would discuss DNA banking
with a patient. The most common reasons were that the DNA would be available for
future testing and a way of providing information for the family.

“…the banked DNA could be used by the family in the future to test for any
suspected genetic condition. This could potentially provide them with
information for future reproductive decision-making and for family members”

“For future diagnosis, to know future recurrence risks and have an explanation for
their child's death”

“Having a proband who is affected with cancer is so important for informative
genetic testing in a family - if it’s not possible to do genetic testing on the patient
while he/she is living, banking DNA can enable tests that will provide
information for surviving family members”

Respondents also thought banking could be a means of comfort or hope for the patient or
the patient’s family:

“This gives the family hope for potential testing in the future if more information
about causative genes becomes available”

“If [the] patient had children and was very concerned for their well-being it may
be comforting for them to know they are doing something that may help them in
the future”

For cancer patients, respondents answered that banking may be more affordable than
testing as a means of leaving behind information for the family:
“DNA banking is much cheaper than performing a genetic test. Thus, at this time storing the DNA is a wise decision. This way the most informative testing can be done later if a family member has money or if a research study opens”

“If the patient's personal history is suspicious and they are [the] ‘best testable’ person in the family, this is a much less expensive way for them to provide future information to their family members”

Finally, respondents thought that DNA banking could decrease the amount of blood draws that a child needed for testing:

“I would offer to bank some DNA while we are in the pursuit of diagnosis, both to limit future blood draws and to have it available should the child pass away”

**NOT DISCUSSING DNA BANKING**

The most common responses for why respondents would not discuss DNA banking were that banking would be unlikely to help in the future and other testing (karyotype, microarray, testing another family member with cancer) would be more informative:

“Seems like a shot in the dark”

“Low likelihood of genetic risk factor”

“It seems as though there are some options (karyotype, microarray) that could be pursued before consideration of DNA banking”

“The patient does not want to have testing. Maybe someone else in the family could consider testing instead”

The respondents also did not talk about DNA banking because they felt that there was not a need for it or the patient did not seem interested:

“Patient and or family is available for future testing--banking may have limited role”

“[It would be] unlikely to be helpful for parents in the future”
“Patient does not seem interested”

They also felt that the patients may be too overwhelmed:

“[P]atient is probably not ready for this discussion...seems like may be in denial and is dealing with enough for the moment”

“[F]amily is under a lot of stress, it would be difficult to present them with the logistics of cost, sample collection, where to store, etc, when they are in crisis”

The cost of DNA banking was also a concern for respondents:

“[N]ot worth the money”

Finally, some respondents do not offer DNA banking because they are not familiar with the service:

“Not familiar with DNA banking options and I have not previously coordinated this for a patient”

“It is not something that I routinely offer and am not familiar with the service”

**REASONS PATIENTS DECLINED**

The most common reasons given by patients to the respondents for not proceeding with DNA banking were that it was too expensive and they did not feel that there was a need for it:

“The patient was responsible for the cost of the original gene testing (as she did not meet Medicare criteria). Therefore, she was not amenable to the additional expense of DNA banking at the time”

“The patient did not feel DNA banking was needed at this time, as she is planning on living for many more years, and so would be available for future testing, should she or her family choose to pursue this”

“[The patient] did not feel the need for additional testing”

Respondents also indicated that patients did not proceed with DNA banking because they were too overwhelmed or emotional at the time of the discussion:
“They were clearly overwhelmed and I don't think they could emotionally make any more decisions at that point”

“I believe they were too emotional at the time”

Finally, the respondents said that some patients did not want to bank their DNA because they did not want to do anything further or they needed closure:

“[P]atients simply don't want to go through the logistics of another blood draw and paperwork and a fee that is not paid by insurance”

“… they just wanted some closure (in their mind) they did not want to pursue testing for a list of possible conditions”

WHEN TO DISCUSS

Respondents answered that typically they would talk about DNA banking if the patient was dying, if there is no testing available at the moment, or if testing has been done but has been negative:

“If they decide not to pursue genetic testing, if they have pursued genetic testing and we have not found a genetic etiology and if there is a chance that they may not live to see the results of the genetic testing then we'll offer DNA banking and testing at the same time”

“Terminal illness, when DNA testing has not been done, or no diagnosis”

Other less commonly given factors that would initiate the discussion were the ability to provide information for the family, if the family is especially driven to find an answer, if insurance will not pay for testing, or to lessen the amount of blood draws for patients:

“When the family expresses interest or if there is a potential benefit for the family”

“[In] cases with families driven to find an answer”
“When patients do not want genetic testing (either by choice or because insurance won’t cover)…”

“[O]ften now in peds so we don't have to draw blood repeatedly as we work thru a differential”
Discussion

This study was designed to elicit current genetic counseling practices on discussing DNA banking with patients. There has been very little research done in the area of consumer views on utilization of personal DNA banking; and none, to the author’s knowledge, focusing on the current practices of genetic counselors in discussing DNA banking with patients. One of this study’s aims was to determine under what circumstances the option of DNA banking was being discussed. This was investigated by using a set of scenarios that could provide a general sense of when DNA banking was being discussed; as well as if certain factors influenced the discussion. Several of the factors examined did influence whether or not DNA banking was discussed.

In the prenatal scenarios, the miscarriage status of the patient affected whether or not the genetic counselor discussed DNA banking. Genetic counselors were more inclined to discuss DNA banking with a patient who has had multiple previous miscarriages than with a patient who had suffered her first miscarriage. This was most likely because it is common for a woman to have a miscarriage with about 15% of recognized pregnancies ending in spontaneous abortion, usually during the first 12 weeks (Moore, 2008). Therefore, a woman who has just had her first miscarriage would not necessarily raise concern of an underlying genetic cause for the miscarriage that would increase her risk of having subsequent miscarriages. Genetic counselors may be more inclined to think that there could be an underlying genetic reason for the miscarriages for a woman who has had multiple miscarriages.
Although more respondents answered that they probably or definitely would discuss DNA banking with a woman who had suffered multiple miscarriages, the majority response was still that they probably would not. This hesitation is likely the result of the many possible causes of miscarriages including, but not limited to, chromosome abnormalities, maternal thrombophilia, and genetic syndromes. Of these possible causes, genetic syndromes may be the only one that would cause genetic counselors to consider discussing DNA banking. To rule out chromosome abnormalities including aneuploidies and unbalanced translocations, one would be inclined to order a karyotype on the fetus. To rule out maternal thrombophilia, a thrombophilia work-up would be performed on the mother. Some counselors may think about DNA banking only after both of these are negative and may still only discuss it if the patient’s family history seems suspicious of a genetic syndrome.

Also in the prenatal scenarios, the gestational age at termination marginally influenced whether or not genetic counselors discussed the option of DNA banking with the patient. Respondents were slightly more likely to discuss DNA banking with a woman who was terminating at 20 weeks gestation because of fetal anomalies than with a woman who was terminating at 30 weeks gestation. Responses suggest that the termination procedure may influence the decision whether to discuss DNA banking. At 20 weeks gestation, a patient will have the option of dilation and evacuation or an induction of labor. At 30 weeks gestation, the patient will most likely be undergoing an induction of labor, which would allow a fetal autopsy to be done to identify possible underlying genetic cause. In addition, most terminations at 30 weeks gestation would require travel out of state, perhaps making DNA banking more of a logistical problem.
In the pediatric scenarios, the suspicion of a syndrome in the child influenced the discussion of DNA banking with the patient’s parent(s). Respondents were more likely to discuss DNA banking if a syndrome was suspected than with the parents of a child with an isolated birth defect. Genetic counselors may believe that DNA banking will be more useful for a family if a syndrome is suspected because in this situation, more than with an isolated birth defect, they may have some suspicions of what testing should be done. An isolated defect may not have a genetic cause or may have a genetic cause that could take years to discover; this would lessen the usefulness of DNA banking for the family. Although respondents were less likely to discuss DNA banking with the parents of a child with an isolated birth defect than with a suspected syndrome, the greatest percentage of respondents still answered that they probably would discuss it in that situation. This could be because although the heart defect was the only thing noted at birth, if the baby had lived, more features suggesting a syndrome could have become apparent overtime.

Also in the pediatric scenarios, respondents were more likely to offer DNA banking to the parents of a patient who was not expected to live than when the patient was being put up for adoption. Banking the DNA for a patient who is not expected to live and has dysmorphic facies, limb abnormalities, and a heart defect would give the family a way to test the child’s DNA after the child has passed away. Banking would enable parents to pursue testing for a possible syndrome after they have grieved for the loss of their child. Testing of the affected child may also help the family address the concerns of a recurrence in future pregnancies. The difference in responses may also be due to the legal issues of the adoption. Many respondents expressed their concern that if
the couple banked the baby’s DNA, after the adoption, the couple may not be able to access the DNA for testing because they assumed that the genetic parents would be relinquishing those rights through the adoption process.

Although the respondents were more inclined to discuss DNA banking with the couple whose child is not expected to live, the majority of respondents still indicated that they probably or definitely would discuss DNA banking with the couple putting the baby up for adoption. It seems that the reasons behind these responses were the same as the ones above: for future testing and recurrence risks.

The detection rate of testing also influenced whether respondents discussed DNA banking with a patient. Respondents were less likely to discuss DNA banking with the parents of a patient with degenerative neurological problems who had testing with a 100% detection rate, than with a similar patient who had testing for a syndrome that may still have unidentified genes or one who has not had testing at all. Overall, the majority of respondents indicated that they would probably or definitely discuss DNA banking with this patient regardless of detection rate. Respondents may believe that the patients who did not have testing or had testing for a syndrome that may still have unidentified genes associated with it would benefit more from DNA banking because of the possibility that a gene or genes associated with the syndrome may be discovered in the future or the detection rate for the existing test may increase. However, genetic counselors may still discuss DNA banking with a patient who had testing that was stated to be 100% because that patient could also benefit from DNA banking; the child could have been diagnosed incorrectly or the detection rate for the testing could be incorrect. If
in the future either of these things become known, then DNA would be available for testing.

In the cancer scenarios, the prognosis of the patient influenced whether the respondents discussed DNA banking. Respondents were more likely to discuss DNA banking with a patient whose prognosis was poor and whose insurance would not cover testing than with a patient whose prognosis was unknown. This may be because an individual who is expected to pass away shortly could benefit from DNA banking because banking would allow the patient’s family the opportunity to do testing in the future, especially if insurance coverage changes or funding becomes available. If the patient is the best person to test in the family because they have been affected with cancer, this could provide valuable information for the family. If the patient has not had cancer, testing their DNA may still be of benefit for the patient’s offspring especially if a mutation is later identified in a family member (ex. patient’s sister). Respondents may be less inclined to discuss DNA banking with a patient who is not imminently dying because they might feel that the person will be around for future testing if insurance coverage changes.

The patient’s concern for their family was also a factor affecting whether or not respondents would discuss DNA banking. Respondents were more likely to discuss DNA banking with a patient who has opted out of testing for him/herself but is concerned about implications for his/her family, than with a patient who does not choose testing and is not concerned about implications for his/her family. This difference in responses emphasizes one great benefit of DNA banking: to provide information for family members. Also, when the respondents were asked to give reasons for discussing DNA
banking with a patient, the second most common response was that it was a way of providing information for the family. When the patient is not concerned about his/her family, either because they are not in contact with them or because there may not be any family members that would benefit from the information, a genetic counselor may be less inclined to discuss DNA banking. In this situation, one of the major benefits of DNA banking would not be applicable.

Finally, the testing status of the patient influenced whether the genetic counselor discussed DNA banking. Respondents were more inclined to discuss DNA banking with a patient who did not undergo testing than with a patient who had testing with a negative result. This may be because the patient has not had BRACAnalysis, which detects mutations that account for the majority of hereditary breast and ovarian cancer. A genetic counselor may think that the DNA banking yield for a patient who has undergone testing, and found to be negative, would be lower. Even though a difference in responses was seen, the majority of respondents answered that they probably would not discuss DNA banking with either patient because, based on the given scenario, the suspicion that the breast cancer was due to an underlying syndrome seemed low. Finally, more individuals responded that they definitely would discuss DNA banking with the patient who tested negative than with the patient who did not have any testing; respondents indicated that if the patient does not want testing the patient also would likely not want to bank DNA.

Results suggest that the genetic counselors who responded to the survey generally reflect the NSGC membership at large with regards to: years of clinical practice, regional representation, and workplace setting. In addition, there was a good response rate for
each of the three genetic counseling areas of practice: prenatal, pediatrics, and cancer. This suggests that the survey data may accurately represent, in a general way, how genetic counselors as a whole are currently discussing DNA banking with patients.

Generally, DNA banking in all three areas of practice is discussed in situations where the patient: is going to pass away, has not had testing, or has had testing but the testing has come back negative. A few other less common scenarios exist where genetic counselors would discuss DNA banking. These results mostly mirrored the set of scenarios, provided by the NSGC, where DNA banking would be an appropriate option: individuals with a specific health condition who are concerned that family members might be at risk for the same problem; families where a previous genetic test did not identify a specific gene change but may in the future; individuals/families being evaluated for a genetic cause for their disease where there is currently no genetic test available; and, an affected family member who is terminally ill and does not have time for traditional genetic evaluation (NSGC brochure). Although the results showed that genetic counselors discuss DNA banking in these common situations, the results also show that this discussion is not happening consistently. This lack of consistency could be affecting patients’ access to a valuable resource.

The second aim of this study was to determine whether respondents had training in graduate school or have protocols at their current jobs for when to discuss the option of DNA banking with patients. The majority of respondent had neither. Only 27 individuals (15.8%) had received training in graduate school on DNA banking and only 12 individuals (7%) indicated that they either have a protocol at their current job or had one at a past job. These numbers are very low and indicate a need for protocols in
the workplace so that DNA banking can be discussed with more consistency, as well as a need for training in graduate school so that genetic counselors are aware of this option and when they should utilize it. The need for education also is clear from this respondent’s quote:

“I don't [discuss DNA banking] at this time because I have never been educated on this option. I would like to learn more about it because I think there are many scenarios in which it would be appropriate to offer”

LIMITATIONS

Although the total number of respondents was 171 individuals, the responses for each section resulted in a small sample size. In addition, evidence showed that the results of this study may be generalizable. However, this evidence was not striking and therefore the ability to apply the results to the larger genetic counseling population is unclear. Another limitation of this study is that respondents were asked to answer questions concerning hypothetical scenarios. If respondents had never been in a similar situation, they may not know whether they would discuss DNA banking if it actually presented itself. Respondents may have also been more inclined to say that they would discuss DNA banking in a scenario because they felt that was the correct way to answer the question. Finally, respondents were asked to indicate the reason a patient gave for not pursuing DNA banking. These responses were based on recollection, which may be inaccurate especially if time has passed since seeing that patient.
Conclusions

The current study investigating genetic counseling practices regarding the discussion of DNA banking suggests that counseling practices are not uniform. Among the various scenarios in all three practice settings, responses ranged from definitely would not discuss to definitely would discuss DNA banking.

Responses indicated that certain factors influence whether or not DNA banking is being discussed. The data on the prenatal scenarios indicated the patient’s miscarriages status influenced the discussion of DNA banking and the gestational age at termination marginally influenced the discussion. The pediatric scenario data suggests that a suspicion of a syndrome in the child, the future (death vs. adoption) of the child, and the detection rate of testing all had an impact on whether or not DNA banking was discussed with the parents. The cancer scenario data indicates that prognosis and testing status of the patient as well as the patient’s concern for their family influenced whether the genetic counselors discussed DNA banking as an option.

When the respondents were asked in what situations they discuss DNA banking, their responses mostly mirrored the set of scenarios provided by the NSGC where DNA banking would be an appropriate option. The most common responses were in situations where the patient will not live, where testing is not available, or where testing was done but has come back negative. Respondents also indicated that other situations where banking should be discussed would include: if DNA banking would provide information
for the patient’s family; if the family was especially driven to find an answer; if insurance would not pay for testing; and, to lessen the amount of blood draws needed.

Responses also indicated that patients are not choosing DNA banking because they find the cost to be too much or they do not see the need for it. Other responses included that the patient was too overwhelmed or emotional at the time of the discussion, and that they just did not want to undergo anything further, or they needed closure.

All of these findings suggest that there is a need for more education on appropriate times to discuss DNA banking as well as a need for a way to ensure that patients are being exposed to the option consistently. Past studies have shown that individuals have positive views of genetic testing and DNA storage in settings other than a genetic counseling session and regarding DNA banking other than personal DNA banking. Individuals are interested in these options and would like to be presented with them more often. Although those results cannot be generalized to all types of DNA banking, it may be that these views also apply to personal DNA banking. Patients seem to appreciate the discussion of all of their options; if patients were well informed they may decide that DNA banking is appropriate for them.

Future studies are needed to investigate when DNA banking is being discussed with patients and should include a more in-depth study of actual situations where genetic counselors have discussed DNA banking, as well as a patient survey asking about their feelings on DNA banking and its usefulness.
References


Appendix I: Recruitment Notice

Research Volunteers Needed!

If you are a genetic counselor currently providing genetic services and practice within the United States, please consider participating in a brief survey concerning counseling practices on DNA banking. This study is part of a student research project at Brandeis University. This survey will be posted to both the NSGC listserv and the NSGC cancer SIG.

- You are eligible for the study if you currently have any experience with discussing the option of DNA banking with patients.
- The survey will take less than 20 minutes to complete.
- Participation is voluntary and anonymous.
- To thank you for your participation you will have the option of entering a raffle to win a $50 gift certificate for Amazon.com upon completion of the survey.

If you would like to participate, please click on the link:

- The survey will be posted until March 1st, 2010

Thank you very much for your consideration and participation. Please feel free to contact me at htmunro@brandeis.edu with any questions or concerns.

Sincerely,

Heidi T. Munro, BS
Brandeis Genetic Counseling Student
Appendix II: Survey Questions

DNA banking for the purpose of this survey is the personal storage of DNA so that it will be saved for future analysis, for promoting the health and well-being of the depositor and his/her relatives and descendents (Hall, 1991).

Prenatal Scenarios:

1. How many prenatal cases do you see per week? ______

2. You are called to see a 25-year-old female patient at 22 weeks gestation. A routine ultrasound shows no heartbeat but no other fetal anomalies are noted.
   a. Would you offer the patient a CVS or amniocentesis?
      o Definitely
      o Probably
      o Undecided
      o Possibly
      o Definitely not
   b. Would you discuss with her the option of DNA banking for the fetus’ DNA?
      o Definitely
      o Probably
      o Undecided
      o Possibly
      o Definitely not
   c. What are your reasons for discussing or not discussing the option of DNA banking?

   __________________________________________________________
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________

   d. Have you been in this situation or a similar one and discussed the option of DNA banking?
      o Yes Please describe the most recent:

   __________________________________________________________
   __________________________________________________________
   __________________________________________________________
e. If you answered yes for part d, did the patient accept?
   o I don’t know
   o Yes
   o No Please describe the reason they gave for declining (if they did not give a reason please leave blank):

3. You are called to see a 40-year-old female patient at 22 weeks gestation. A routine ultrasound shows no heartbeat but no other fetal anomalies are noted.

   a. Would you offer the patient a CVS or amniocentesis?
      o Definitely
      o Probably
      o Undecided
      o Possibly
      o Definitely not

   b. Would you discuss with her the option of DNA banking for the fetus’ DNA?
      o Definitely
      o Probably
      o Undecided
      o Possibly
      o Definitely not

   c. What are your reasons for discussing or not discussing the option of DNA banking?
d. Have you been in this situation or a similar one and discussed the option of DNA banking?
   ○ Yes Please describe the most recent:

   __________________________________________________________
   __________________________________________________________
   __________________________________________________________
   ○ No

e. If you answered yes for part d, did the patient accept?
   ○ I don’t know
   ○ Yes
   ○ No Please describe the reason they gave for declining (if they did not give a reason please leave blank):

   __________________________________________________________
   __________________________________________________________

4. You are called to see a 30-year-old female patient at 12 weeks gestation who is in the hospital because no heart beat was detected on ultrasound. She is scheduled for a dilation and curettage. This is her first miscarriage.

   a. Would you offer the patient information on support groups?
      ○ Definitely
      ○ Probably
      ○ Undecided
      ○ Possibly
      ○ Definitely not

   b. Would you discuss the option of DNA banking for the current miscarriage’s DNA?
      ○ Definitely
      ○ Probably
      ○ Undecided
      ○ Possibly
      ○ Definitely not

   c. What are your reasons for discussing or not discussing the option of DNA banking?
d. Have you been in this situation or a similar one and discussed the option of DNA banking?
   - Yes Please describe the most recent:

   - No

e. If you answered yes for part d, did the patient accept?
   - I don’t know
   - Yes
   - No Please describe the reason they gave for declining (if they did not give a reason please leave blank):

5. You are called to see a 30-year-old female patient at 12 weeks gestation who is in the hospital because no heart beat was detected on ultrasound. She is scheduled for a dilation and curettage. She has had multiple previous miscarriages.

   a. Would you offer the patient information on support groups?
      - Definitely
      - Probably
      - Undecided
      - Possibly
      - Definitely not

   b. Would you discuss the option of DNA banking for the current miscarriage’s DNA?
      - Definitely
      - Probably
      - Undecided
c. What are your reasons for discussing or not discussing the option of DNA banking?

________________________________________________________________________________
________________________________________________________________________________
________________________________________________________________________________

d. Have you been in this situation or a similar one and discussed the option of DNA banking?
   o Yes Please describe the most recent:
   ____________________________________________________________
   ____________________________________________________________
   ____________________________________________________________
   o No

  e. If you answered yes for part d, did the patient accept?
     o I don’t know
     o Yes
     o No Please describe the reason they gave for declining (if they did not give a reason please leave blank):
     _________________________________________________________
     _________________________________________________________
     _________________________________________________________

6. A 28-year-old female patient at 18 weeks gestation comes to see you regarding fetal anomalies detected on ultrasound. The prognosis for the fetus is unknown and the patient decides to have an amniocentesis.

   a. Would you offer the patient information on support groups?
      o Definitely
      o Probably
      o Undecided
      o Possibly
      o Definitely not
b. Would you discuss with her the option of DNA banking for the fetus’ DNA?
   - Definitely
   - Probably
   - Undecided
   - Possibly
   - Definitely not

c. What are your reasons for discussing or not discussing the option of DNA banking?

   __________________________________________
   __________________________________________
   __________________________________________

   d. Have you been in this situation or a similar one and discussed the option of DNA banking?
   - Yes Please describe the most recent:
     __________________________________________
     __________________________________________
     __________________________________________
   - No

e. If you answered yes for part d, did the patient accept?
   - I don’t know
   - Yes
   - No Please describe the reason they gave for declining (if they did not give a reason please leave blank):
     __________________________________________
     __________________________________________
     __________________________________________

7. A 28-year-old female patient at 18 weeks gestation comes to see you regarding fetal anomalies detected on ultrasound. The prognosis for the fetus is poor and the patient decides to have an amniocentesis.

a. Would you offer the patient information on support groups?
   - Definitely
b. Would you discuss with her the option of DNA banking for the fetus’ DNA?
   - Definitely
   - Probably
   - Undecided
   - Possibly
   - Definitely not

c. What are your reasons for discussing or not discussing the option of DNA banking?

   __________________________________________________________
   __________________________________________________________
   __________________________________________________________


d. Have you been in this situation or a similar one and discussed the option of DNA banking?
   - Yes    Please describe the most recent:
     __________________________________________________________
     __________________________________________________________
     __________________________________________________________
     __________________________________________________________
   - No

e. If you answered yes for part d, did the patient accept?
   - I don’t know
   - Yes
   - No    Please describe the reason they gave for declining (if they did not give a reason please leave blank):
     __________________________________________________________
     __________________________________________________________
     __________________________________________________________
8. A 27-year-old female patient comes to see you regarding fetal anomalies detected on ultrasound. The patient is 20 weeks gestation and decides to terminate the pregnancy.

   a. Would you offer the patient a CVS or amniocentesis?
      - Definitely
      - Probably
      - Undecided
      - Possibly
      - Definitely not

   b. Would you discuss with her the option of DNA banking for the fetus’ DNA?
      - Definitely
      - Probably
      - Undecided
      - Possibly
      - Definitely not

   c. What are your reasons for discussing or not discussing the option of DNA banking?

   d. Have you been in this situation or a similar one and discussed the option of DNA banking?
      - Yes Please describe the most recent:

   e. If you answered yes for part d, did the patient accept?
      - I don’t know
      - Yes
      - No Please describe the reason they gave for declining (if they did not give a reason please leave blank):
9. A 27-year-old patient comes to see you regarding fetal anomalies detected on ultrasound. The patient is 30 weeks gestation and decides to terminate the pregnancy.

   a. Would you offer the patient a CVS or amniocentesis?
      - Definitely
      - Probably
      - Undecided
      - Possibly
      - Definitely not

   b. Would you discuss with her the option of DNA banking for the fetus’ DNA?
      - Definitely
      - Probably
      - Undecided
      - Possibly
      - Definitely not

   c. What are your reasons for discussing or not discussing the option of DNA banking?

   d. Have you been in this situation or a similar one and discussed the option of DNA banking?
      - Yes  Please describe the most recent:
      - No
e. If you answered yes for part d, did the patient accept?
   ○ I don’t know
   ○ Yes
   ○ No  Please describe the reason they gave for declining (if they did not give a reason please leave blank):


Pediatrics:

1. How many pediatric cases do you see per week? _______

2. You are called to the NICU for a baby who is in respiratory failure and not expected to live much longer. The baby has dysmorphic features and he/she is suspected to have a syndrome. The parents do not want to pursue genetic testing at this time.

   a. Would you offer the parent(s) information on support groups?
      ○ Definitely
      ○ Probably
      ○ Undecided
      ○ Possibly
      ○ Definitely not

   b. Would you discuss with the parent(s) the option of DNA banking for the baby’s DNA?
      ○ Definitely
      ○ Probably
      ○ Undecided
      ○ Possibly
      ○ Definitely not

   c. What are your reasons for discussing or not discussing the option of DNA banking?


d. Have you been in this situation or a similar one and discussed the option of DNA banking?
   o Yes Please describe the most recent:
   o No

e. If you answered yes for part d, did they accept?
   o I don’t know
   o Yes
   o No Please describe the reason they gave for declining (if they did not give a reason please leave blank):

3. You are called to the NICU for a baby who is in respiratory failure and not expected to live much longer. The baby has only an isolated heart defect and he/she is not suspected to have a syndrome. The parents do not want to pursue genetic testing at this time.

   a. Would you offer the parent(s) information on support groups?
      o Definitely
      o Probably
      o Undecided
      o Possibly
      o Definitely not

   b. Would you discuss with the parent(s) the option of DNA banking for the baby’s DNA?
      o Definitely
      o Probably
      o Undecided
      o Possibly
      o Definitely not
c. What are your reasons for discussing or not discussing the option of DNA banking?

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

d. Have you been in this situation or a similar one and discussed the option of DNA banking?
   - Yes      Please describe the most recent:
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
   - No

   e. If you answered yes for part d, did they accept?
      - I don’t know
      - Yes
      - No      Please describe the reason they gave for declining (if they did not give a reason please leave blank):
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________

4. A 5-year-old pediatric patient comes to see you and receives a clinical diagnosis for a syndrome that involves degenerative neurological problems. You do genetic testing for the syndrome, which comes back negative. The detection rate for the test is stated to be 100%. The patient is deteriorating and is not expected to live.

   a. Would you offer the parent(s) information on support groups?
      - Definitely
      - Probably
      - Undecided
      - Possibly
      - Definitely not
b. Would you discuss with the parent(s) the option of DNA banking for the child’s DNA?
   o Definitely
   o Probably
   o Undecided
   o Possibly
   o Definitely not

c. What are your reasons for discussing or not discussing the option of DNA banking?
   ____________________________________________________________
   ____________________________________________________________
   ____________________________________________________________
   ____________________________________________________________
   ____________________________________________________________

   d. Have you been in this situation or a similar one and discussed the option of DNA banking?
      o Yes Please describe the most recent:
          __________________________________________________________
          __________________________________________________________
          __________________________________________________________
          __________________________________________________________
      o No

   e. If you answered yes for part d, did they accept?
      o I don’t know
      o Yes
      o No Please describe the reason they gave for declining (if they did not give a reason please leave blank):
          __________________________________________________________
          __________________________________________________________
          __________________________________________________________

5. A 5-year-old pediatric patient comes to see you and receives a clinical diagnosis for a syndrome that involves degenerative neurological problems. You do genetic testing for the syndrome, which comes back negative. However, the syndrome may have other unidentified genes associated with it. The patient is deteriorating and is not expected to live.
a. Would you offer the parents information on support groups?
   o Definitely
   o Probably
   o Undecided
   o Possibly
   o Definitely not

b. Would you discuss with the parent(s) the option of DNA banking for the child’s DNA?
   o Definitely
   o Probably
   o Undecided
   o Possibly
   o Definitely not

c. What are your reasons for discussing or not discussing the option of DNA banking?
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________


d. Have you been in this situation or a similar one and discussed the option of DNA banking?
   o Yes    Please describe the most recent:
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________
   o No

e. If you answered yes for part d, did they accept?
   o I don’t know
   o Yes
   o No    Please describe the reason they gave for declining (if they did not give a reason please leave blank):
   __________________________________________________________
   __________________________________________________________
6. A 5-year-old pediatric patient comes to see you and receives a clinical diagnosis for a syndrome that involves degenerative neurological problems where the associated gene is not yet known. The patient is deteriorating and is not expected to live.

   a. Would you offer the parent(s) information on support groups?
      o Definitely
      o Probably
      o Undecided
      o Possibly
      o Definitely not

   b. Would you discuss with the parent(s) the option of DNA banking for the child’s DNA?
      o Definitely
      o Probably
      o Undecided
      o Possibly
      o Definitely not

   c. What are your reasons for discussing or not discussing the option of DNA banking?

       __________________________________________________________
       __________________________________________________________
       __________________________________________________________

   d. Have you been in this situation or a similar one and discussed the option of DNA banking?
      o Yes Please describe the most recent:

       __________________________________________________________
       __________________________________________________________
       __________________________________________________________

      o No

   e. If you answered yes for part d, did they accept?
      o I don’t know
      o Yes

60
7. You are called to the NICU for a baby who has dysmorphic facies, limb abnormalities, and a heart defect. The baby is in respiratory failure and is not expected to live much longer. The parents have expressed to you that they are planning to have more children.

   a. Would you offer the parent(s) information on support groups?
      o Definitely
      o Probably
      o Undecided
      o Possibly
      o Definitely not

   b. Would you discuss with the parent(s) the option of DNA banking for the baby’s DNA?
      o Definitely
      o Probably
      o Undecided
      o Possibly
      o Definitely not

   c. What are your reasons for discussing or not discussing the option of DNA banking?

   d. Have you been in this situation or a similar one and discussed the option of DNA banking?
      o Yes Please describe the most recent:
62

8. You are called to the NICU for a baby who has dysmorphic facies and limb abnormalities. The parents have decided to put the baby up for adoption. The parents have expressed to you that they are planning to have more children.

   a. Would you offer the parent(s) information on support groups?
      o Definitely
      o Probably
      o Undecided
      o Possibly
      o Definitely not

   b. Would you discuss with the parent(s) the option of DNA banking for the baby’s DNA?
      o Definitely
      o Probably
      o Undecided
      o Possibly
      o Definitely not

   c. What are your reasons for discussing or not discussing the option of DNA banking?

   d. Have you been in this situation or a similar one and discussed the option of DNA banking?
9. You are called to the NICU for a baby who has just been diagnosed with a rare metabolic disorder. The disorder does not have any successful treatments and life expectancy for the baby is less than a year.

   a. Would you offer the parent(s) information on support groups?
      o Definitely
      o Probably
      o Undecided
      o Possibly
      o Definitely not

   b. Would you discuss with the parent(s) the option of DNA banking for the baby’s DNA?
      o Definitely
      o Probably
      o Undecided
      o Possibly
      o Definitely not

   c. What are your reasons for discussing or not discussing the option of DNA banking?
d. Have you been in this situation or a similar one and discussed the option of DNA banking?
   ○ Yes Please describe the most recent:

   ○ No

e. If you answered yes for part d, did they accept?
   ○ I don’t know
   ○ Yes
   ○ No Please describe the reason they gave for declining (if they did not give a reason please leave blank):

10. An 11-month-old pediatric patient comes to see you because he has been diagnosed with a rare metabolic disorder. The disorder does not have any successful treatments and life expectancy for the child is less than a year.

   a. Would you offer the parent(s) information on support groups?
      ○ Definitely
      ○ Probably
      ○ Undecided
      ○ Possibly
      ○ Definitely not

   b. Would you discuss with the parent(s) the option of DNA banking for their child’s DNA?
      ○ Definitely
      ○ Probably
      ○ Undecided
      ○ Possibly
c. What are your reasons for discussing or not discussing the option of DNA banking?

________________________

________________________


d. Have you been in this situation or a similar one and discussed the option of DNA banking?
   o Yes    Please describe the most recent:

________________________

________________________

   o No

e. If you answered yes for part d, did they accept?
   o I don’t know
   o Yes
   o No   Please describe the reason they gave for declining (if they did not give a reason please leave blank):

________________________

________________________

Cancer:

1. How many cancer cases do you see per week? _________

2. An oncologist calls you to tell you about his patient who is in hospice and will likely die before a genetic counseling session or testing can be done. You are not able to go see the patient.

   a. Would you tell the oncologist to offer the patient and his/her family information on support groups?
      o Definitely
      o Probably
b. Would you discuss with the oncologist the option of DNA banking for the patient’s DNA so that he/she can discuss it with the patient?
   - Definitely
   - Probably
   - Undecided
   - Possibly
   - Definitely not

c. What are your reasons for discussing or not discussing the option of DNA banking?

   ____________________________________________________________
   ____________________________________________________________
   ____________________________________________________________


d. Have you been in this situation or a similar one and discussed the option of DNA banking?
   - Yes    Please describe the most recent:
   ____________________________________________________________
   ____________________________________________________________
   ____________________________________________________________
   - No


e. If you answered yes for part d, did the patient accept?
   - I don’t know
   - Yes
   - No    Please describe the reason they gave for declining (if they did not give a reason please leave blank):
   ____________________________________________________________
   ____________________________________________________________
   ____________________________________________________________

3. An oncologist calls you to tell you about his patient who is in hospice and will likely die before testing can be done. You are able to go see the patient.
a. Would you offer the patient and his/her family information on support groups?
   o Definitely
   o Probably
   o Undecided
   o Possibly
   o Definitely not

b. Would you discuss with the patient the option of DNA banking for his/her DNA?
   o Definitely
   o Probably
   o Undecided
   o Possibly
   o Definitely not

c. What are your reasons for discussing or not discussing the option of DNA banking?

   __________________________________________________________
   __________________________________________________________
   __________________________________________________________

d. Have you been in this situation or a similar one and discussed the option of DNA banking?
   o Yes Please describe the most recent:
   __________________________________________________________
   __________________________________________________________
   __________________________________________________________
   o No

e. If you answered yes for part d, did the patient accept?
   o I don’t know
   o Yes
   o No Please describe the reason they gave for declining (if they did not give a reason please leave blank):
4. A patient comes to see you whose family history is suspicious for a hereditary cancer syndrome and he/she is not expected to live. The patient’s insurance will not pay for testing and he/she cannot afford it.

a. Would you offer the patient and his/her family information on support groups?
   - Definitely
   - Probably
   - Undecided
   - Possibly
   - Definitely not

b. Would you discuss with the patient the option of DNA banking for his/her DNA?
   - Definitely
   - Probably
   - Undecided
   - Possibly
   - Definitely not

c. What are your reasons for discussing or not discussing the option of DNA banking?

   __________________________________________________________
   __________________________________________________________
   __________________________________________________________

d. Have you been in this situation or a similar one and discussed the option of DNA banking?
   - Yes Please describe the most recent:
   - No
5. A patient comes to see you whose family history is suspicious for a hereditary cancer syndrome. His/her insurance will not pay for the testing and he/she cannot afford it.

a. Would you offer the patient and his/her family information on support groups?
   - Definitely
   - Probably
   - Undecided
   - Possibly
   - Definitely not

b. Would you discuss with the patient the option of DNA banking for his/her DNA?
   - Definitely
   - Probably
   - Undecided
   - Possibly
   - Definitely not

c. What are your reasons for discussing or not discussing the option of DNA banking?

   __________________________________________________________
   __________________________________________________________
   __________________________________________________________

   d. Have you been in this situation or a similar one and discussed the option of DNA banking?
      - Yes Please describe the most recent:
6. A patient comes to see you whose family history is suspicious for a hereditary cancer syndrome. However, the patient does not want testing for him or herself. After discussion of the possible implications for his/her family, he/she is concerned about the implications for them.

   a. Would you offer the patient and his/her family information on support groups?
     - Definitely
     - Probably
     - Undecided
     - Possibly
     - Definitely not

   b. Would you discuss with the patient the option of DNA banking for his/her DNA?
     - Definitely
     - Probably
     - Undecided
     - Possibly
     - Definitely not

   c. What are your reasons for discussing or not discussing the option of DNA banking?
d. Have you been in this situation or a similar one and discussed the option of DNA banking?
   o Yes  Please describe the most recent:
   o No

e. If you answered yes for part d, did the patient accept?
   o I don’t know
   o Yes
   o No  Please describe the reason they gave for declining (if they did not give a reason please leave blank):

7. A patient comes to see you whose family history is suspicious for a hereditary cancer syndrome. However, the patient does not want testing for him or herself. After discussion of the possible implications for his/her family, he/she is not concerned about the implications for them.

   a. Would you offer the patient and his/her family information on support groups?
      o Definitely
      o Probably
      o Undecided
      o Possibly
      o Definitely not

   b. Would you discuss with the patient the option of DNA banking for his/her DNA?
      o Definitely
      o Probably
c. What are your reasons for discussing or not discussing the option of DNA banking?

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

d. Have you been in this situation or a similar one and discussed the option of DNA banking?
   o Yes    Please describe the most recent:
   ______________________________________________________________________
   ______________________________________________________________________
   ______________________________________________________________________
   o No

e. If you answered yes for part d, did the patient accept?
   o I don’t know
   o Yes
   o No    Please describe the reason they gave for declining (if they did not give a reason please leave blank):
   ______________________________________________________________________
   ______________________________________________________________________
   ______________________________________________________________________

8. A 35-year-old female comes to see you who was diagnosed with breast cancer and is in remission now. Her family history is negative for other affected individuals. You ran BRCAPRO for her, which gave a risk of 2.2% for having a BRCA1/2 mutation. She decides to do testing and her results are negative for a BRCA 1/2 mutation.

   a. Would you offer the patient and her family information on support groups?
b. Would you discuss with the patient the option of DNA banking for her DNA?
   o Definitely
   o Probably
   o Undecided
   o Possibly
   o Definitely not

c. What are your reasons for discussing or not discussing the option of DNA banking?

   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________


d. Have you been in this situation or a similar one and discussed the option of DNA banking?
   o Yes    Please describe the most recent:

   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
   o No

e. If you answered yes for part d, did the patient accept?
   o I don’t know
   o Yes
   o No    Please describe the reason they gave for declining (if they did not give a reason please leave blank):

   ________________________________________________________________
   ________________________________________________________________
   ________________________________________________________________
9. A 35-year-old female comes to see you who was diagnosed with breast cancer but is in remission now. Her family history is negative for other family members with cancer. You ran BRCAPRO for her, which gave a risk of 2.2% for having a BRCA 1/2 mutation. She decides that she does not want testing.

a. Would you offer the patient and her family information on support groups?
   - Definitely
   - Probably
   - Undecided
   - Possibly
   - Definitely not

b. Would you discuss with the patient the option of DNA banking for her DNA?
   - Definitely
   - Probably
   - Undecided
   - Possibly
   - Definitely not

c. What are your reasons for discussing or not discussing the option of DNA banking?
   ___________________________________________________________
   ___________________________________________________________
   ___________________________________________________________

d. Have you been in this situation or a similar one and discussed the option of DNA banking?
   - Yes Please describe the most recent:
   ___________________________________________________________
   ___________________________________________________________
   ___________________________________________________________
   - No

e. If you answered yes for part d, did the patient accept?
   - I don’t know
10. A 65-year-old female comes to see you who was diagnosed with breast cancer at age 53. Her sister was diagnosed with breast cancer at age 50 and a paternal aunt was diagnosed with breast cancer at age 65. You ran BRCAPRO for her, which gave a risk of 2.1% for having a BRCA 1/2 mutation. She decides to do testing and her results are negative for a BRCA 1/2 mutation.

a. Would you offer the patient and her family information on support groups?
   o Definitely
   o Probably
   o Undecided
   o Possibly
   o Definitely not

b. Would you discuss with the patient the option of DNA banking for her DNA?
   o Definitely
   o Probably
   o Undecided
   o Possibly
   o Definitely not

c. What are your reasons for discussing or not discussing the option of DNA banking?

   __________________________________________________________
   __________________________________________________________

   __________________________________________________________

   __________________________________________________________

   __________________________________________________________

d. Have you been in this situation or a similar one and discussed the option of DNA banking?
   o Yes   Please describe the most recent:
11. A 65-year-old female comes to see you who was diagnosed with breast cancer at age 53. Her sister was diagnosed with breast cancer at age 50 and a paternal aunt was diagnosed with breast cancer at age 65. You ran BRCAPRO for her, which gave a risk of 2.1% for having a BRCA 1/2 mutation. She decides that she does not want testing.

a. Would you offer the patient and her family information on support groups?
   - Definitely
   - Probably
   - Undecided
   - Possibly
   - Definitely not

b. Would you discuss with the patient the option of DNA banking for her DNA?
   - Definitely
   - Probably
   - Undecided
   - Possibly
   - Definitely not

c. What are your reasons for discussing or not discussing the option of DNA banking?
d. Have you been in this situation or a similar one and discussed the option of DNA banking?
   o Yes Please describe the most recent:
   o No

e. If you answered yes for part d, did the patient accept?
   o I don’t know
   o Yes
   o No Please describe the reason they gave for declining (if they did not give a reason please leave blank):

12. A 45-year-old female comes to see you who was diagnosed with breast cancer at age 40. Her mother was diagnosed with ovarian cancer at age 70. She has no other significant family history. You ran BRCAPRO for her, which gave a risk of 13.3% for having a BRCA 1/2 mutation. She decides to do testing and her results are negative for a BRCA 1/2 mutation.

   a. Would you offer the patient and her family information on support groups?
      o Definitely
      o Probably
      o Undecided
      o Possibly
      o Definitely not
b. Would you discuss with the patient the option of DNA banking for her DNA?
   - Definitely
   - Probably
   - Undecided
   - Possibly
   - Definitely not

c. What are your reasons for discussing or not discussing the option of DNA banking?

   ____________________________________________________________
   ____________________________________________________________
   ____________________________________________________________

   d. Have you been in this situation or a similar one and discussed the option of DNA banking?
   - Yes      Please describe the most recent:
   ____________________________________________________________
   ____________________________________________________________
   ____________________________________________________________
   - No

   e. If you answered yes for part d, did the patient accept?
   - I don’t know
   - Yes
   - No      Please describe the reason they gave for declining (if they did not give a reason please leave blank):
   ____________________________________________________________
   ____________________________________________________________
   ____________________________________________________________

13. A 45-year-old female patient comes to see you who was diagnosed with breast cancer at age 40. Her mother was diagnosed with ovarian cancer at age 70. She has no other significant family history. You ran BRCAPRO for her, which gave a risk of 13.3% for having a BRCA 1/2 mutation. She decides that she does not want testing.
a. Would you offer the patient and her family information on support groups?
   - Definitely
   - Probably
   - Undecided
   - Possibly
   - Definitely not

b. Would you discuss with the patient the option of DNA banking for her DNA?
   - Definitely
   - Probably
   - Undecided
   - Possibly
   - Definitely not

c. What are your reasons for discussing or not discussing the option of DNA banking?

   _______________________________________________________

   _______________________________________________________

d. Have you been in this situation or a similar one and discussed the option of DNA banking?
   - Yes    Please describe the most recent:

   _______________________________________________________

   _______________________________________________________

   - No

e. If you answered yes for part d, did the patient accept?
   - I don’t know
   - Yes
   - No    Please describe the reason they gave for declining (if they did not give a reason please leave blank):

   _______________________________________________________

   _______________________________________________________
Demographics:

1. What is your gender? (Please select one)
   - Female
   - Male
   - Unspecified

2. What is your current age?
   - 21-30
   - 31-40
   - 41-50
   - 51-60
   - 61-70
   - 71-80

3. Do you have children?
   - Yes    If Yes, how many? _____
   - No
   - Currently pregnant

4. How long have you been working in clinical practice? _________

5. How long has it been since you graduated from graduate school? _________

6. What region of the United States do you currently work in?
   - Region I (CT, ME, MA, NH, RI, VT)
   - Region II (D.C., DE, MD, NJ, NY, PA, VA, WV)
   - Region III (AL, FL, GA, KY, LA, MS, NC, SC, TN, PR)
   - Region IV (AR, IL, IN, IA, KS, MI, MN, MO, NE, ND, OH, OK, SD, WI)
   - Region V (AZ, CO, MT, NM, TX, UT, WY)
   - Region VI (AK, CA, HA, ID, NV, OR)

7. What is your workplace setting?
   - Public Hospital
   - Private Hospital
   - University Medical Center
   - Private Practice
Non-Medical Setting
Other (please specify) _______

8. What is (are) your clinical specialty area(s)? Please indicate the percent of time spent in an average week in each of the areas that you choose.
   o Adult _______
   o Cancer Genetics _______
   o Pediatrics _______
   o Prenatal _______
   o Specialty Disease _______
   o Other (please specify) _______

9. What is the make-up of your patient population by race? Please list approximate percentages.
   Caucasian _______
   African America/African _______
   Hispanic _______
   East Asia/Southeast Asian _______
   (ex. China, Philippines, Korea, etc.)
   South Asian _______
   (ex. India, Pakistan, Sri Lanka, etc.)
   Middle Eastern _______
   Other _____

Training and Protocol Questions:

10. In what region did you attend graduate school?
    o Region I (CT, ME, MA, NH, RI, VT)
    o Region II (D.C., DE, MD, NJ, NY, PA, VA, WV)
    o Region III (AL, FL, GA, KY, LA, MS, NC, SC, TN, PR)
    o Region IV (AR, IL, IA, KS, MI, MN, MO, NE, ND, OH, OK, SD, WI)
    o Region V (AZ, CO, MT, NM, TX, UT, WY)
    o Region VI (AK, CA, HA, ID, NV, OR)

11. Did you receive any training in graduate school regarding when to discuss the option of DNA banking?
    o Yes      If yes, where did you go to school? _______
    o No
12. Do you have a protocol of when to discuss the option of DNA banking at your current job?
   o Yes
   o No

13. Have you worked anywhere where there was a protocol on when to discuss the option of DNA banking?
   o Yes   If yes, where? _______
   o No

14. Typically, when do you discuss the option of DNA banking with patients?