

Evaluation Report:

**Student Bioethics Forums and
Public Bioethics Forums**

Science Museum of Minnesota

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PART 1: STUDENT BIOETHICS FORUMS

I. Executive summary

Five Student Bioethics Forums were held between November 1997 and February 1998 at the Science Museum of Minnesota. For each forum two teachers who attended the Bioethics Leadership Institute in the spring of 1997 each brought twenty 10-12th-grade biology students to the museum for a day of activities related to biomedical technology and bioethics. The goals of the forums were to:

1. Increase students' awareness and understanding of bioethical issues.
2. Pool the forum participants' collective ideas and arguments to broaden students' views of the complexity and relevance of bioethical issues.
3. Develop a group of experienced student leaders to continue bioethical discussions in schools.

Activities during the forums included a theater performance about genetic testing for Huntington's disease, guest speakers, a simulation of HIV transmission and testing, and group discussions.

This report is based on written evaluations, student journals, pre- and post-forum student assignments, and informal conversations with students and teachers. It concludes that students were exposed to a broad range of bioethical issues; that one effect of this exposure was an increased appreciation of the complexity of bioethical issues and the diversity of opinions concerning these issues; and that at least some students have used their experiences at the forums to contribute to classroom activities back at their schools. The forums therefore achieved the goals stated above.

Recommendations for future forums include increasing teacher involvement in the forums, better supervision of the student discussion groups during the forums, and electronically linking classrooms at different schools before and after the forums to extend the impact of the learning communities that are created during the forums.

II. Introduction

Public Programs in Health Care Ethics is a two-year project at the Science Museum of Minnesota (SMM) focusing on recent developments in genetic and biomedical technologies and the impact of those technologies on personal health care and social policy decisions.¹ Through this project the SMM seeks to engage museum visitors and the wider community in critical thinking about bioethics to help turn opinions regarding biomedical issues into reasoned judgements. A high school bioethics curriculum enhancement project is a component of the SMM's Public Programs in Health Care Ethics. The first component of the high school curriculum enhancement project was a workshop for biology teachers, the Bioethics Leadership Institute, which was held in June 1997.² A series of Student Bioethics Forums were the second major component of the high school bioethics curriculum project.

Five Student Bioethics Forums were held between November 1997 and February 1998 at the SMM (Table 1). For each forum two teachers who attended the Bioethics Leadership Institute each brought twenty 10-12th-grade biology students to the museum for a day of activities related to biomedical technology and bioethics. Lee Schmitt, Manager of Teacher Programs at the SMM, led most of the activities, but the museum's theater troupe, guest speakers, and the teachers also participated in the forums.

Table 1. The schools attending the Student Bioethics Forums.

Schools	Date
Coon Rapids High School St. Paul Central High School	November 5, 1997
The Blake School Wayzata High School	December 10, 1997
Randolph High School Chaska High School	January 14, 1998
Shakopee Senior High School	January 28, 1998
Maple Grove High School Humboldt Senior High School	February 11, 1998

¹Public Programs in Health Care Ethics is funded by a grant from the Allina Foundation to the Science Museum of Minnesota.

²I have described and evaluated the Bioethics Leadership Institute in a separate report to the Science Museum of Minnesota.

Goals of the forums

The goals of the Student Forums, which Schmitt reviewed with each group of students, were as follows:

1. Increase awareness and understanding of bioethical issues in our community.
2. Pool our collective ideas and arguments to broaden our individual views of the complexity and relevance of bioethical issues.
3. Develop a group of experienced student leaders to continue bioethical discussions back at your schools.

Schmitt also shared a quote with the students at the beginning of the forums that suggests the value he placed on open-minded inquiry:

Education's purpose is to replace an empty mind with an open one.
-Malcolm S. Forbes

Evaluation methods

In this report I describe the forums; analyze students' contributions, experiences, and reactions; assess the forums' quality relative to the goals stated above; and make recommendations for the future. I observed and participated in the forums to better understand the experiences and views of the students and other forum participants. At each forum I took field notes, collected the presentation materials used by Schmitt and the guest speakers, and spoke with students to get their reactions. In addition, all students were asked to respond to several journal questions. While assuring students of their anonymity, I asked them to make their journals available to me for this evaluation and most agreed to do so.³ At the conclusion of three of the forums (November 5, January 14, and February 11) students completed a written evaluation that focused on their interest in the forum, what they learned, and the most and least enjoyable aspects of their experience. A copy of the evaluation instrument is in the appendix. At two of the forums an additional journal question that asked students to reflect on their experiences was substituted for the evaluations.

³Prior to conducting this evaluation the procedures employed were approved by the Institutional Review Board: Human Subjects Committee at the University of Minnesota.

III. Description and analysis of the forums

Table 2 outlines the schedule of events during the forums. They began at 9:00 a.m. with a performance of *Genetic Prophecy* by the SMM's acting troupe in the Science Theater. After the performance the students moved to the SMM's Penthouse, a space with room for large-group discussions and smaller break-out groups. When the students arrived at the Penthouse, they were asked to record in their journals what they hoped to learn that day. Following Schmitt's review of the plan for the day and a social icebreaker, students discussed the issues raised by the play. After a short break came a presentation by a guest speaker and group discussions about the presentation. In the afternoon students participated in a simulation of the transmission of human immunodeficiency virus (HIV), followed by a discussion of the personal and social implications of HIV testing. A final group discussion of the issues that arose during the day concluded the forum, after which the students responded to a final journal question or filled out the evaluation form.

Table 2. Schedule of activities in the Student Bioethics Forums.

Time	Activity	Location
9:00	Theater performance of <i>Genetic Prophecy</i>	Science Theater
9:30	<ul style="list-style-type: none"> - Journal writing - Goals for the day - Icebreaker - Small group discussion of the play - Group reports 	Penthouse
10:15	Break (milk and cookies!)	Penthouse
10:30	<ul style="list-style-type: none"> - Guest speaker - Small group discussion - Group reports 	Penthouse
11:45	Lunch	Penthouse
12:15	<ul style="list-style-type: none"> - Simulation of HIV transmission & testing - Discussion and journal writing 	Penthouse
1:00	<ul style="list-style-type: none"> - Closure: whole group discussion - Evaluations or journal writing 	Penthouse
1:15	Students depart	

Here I draw examples from the five forums to review each of the activities and students' reactions to them.

Bioethics on stage: *Genetic Prophecy*

The play *Genetic Prophecy* was commissioned by the SMM as a component of the Public Programs in Health Care Ethics project and was performed by the its theater troupe. The plays consists of two vignettes: i) a married couple in their 30s in which the wife has a family history of Huntington's disease, and ii) a brother and sister whose father died of Huntington's disease. In the first vignette we listen in to the private thoughts of the husband and the wife as they individually consider the pros and cons of determining the wife's status with a genetic test. The wife considers the burden she will be to her husband if she develops Huntington's disease and how a genetic test may allow them to better plan for the future. She wants to have children, but not if there is a risk of passing Huntington's disease on to another generation. The husband fears a positive test result and considers how his life will change if his wife develops the disease. He ponders whether having children might be a way to keep a piece of his wife in his life even after she dies. When the test result comes back positive (presence of the Huntington's disease marker), we see the couple develop a more intense appreciation for each other and for the moment in which they are living. In the second vignette the siblings, Jan and Nate, are also contemplating having the genetic test for the Huntington's disease marker . Jan, it seems, has coped well with the uncertainty of her genetic inheritance; her life is in relative order, she is raising two children, and she is planning for the future. Nate, on the other hand, reacts to the uncertainty of his future by living with a short term outlook. He has been unsuccessful in college, can not hold a job, and is in debt. He lives for the moment and sees little point in taking a test that will deliver either a death sentence or the equally disturbing news that the central assumption in his life—that he has no future to plan for—is incorrect. The play ends without telling us whether Jan and Nate decide to be tested.

Genetic Prophecy accurately portrays the medical facts of Huntington's disease and embeds those facts in a rich context that reveals some of the personal implications of genetic conditions and genetic testing. Students were attentive throughout the twenty minute performance and the ten minute question-and-answer session with the actors. The actors in SMM production do background research in order to respond to questions from the audience. The students' questions were typically about technical aspects of Huntington's disease and genetic testing, and with the exception of a few minor mistakes, the actors' responses were accurate.

The forum moved to the SMM's Penthouse after the play. After a journal question, an icebreaker, and a review of the day's goals by Schmitt, discussion turned to the issues raised in the play. The students formed five groups (named after the five bases in nucleic acids: adenine, guanine, cytosine, thymine, and uracil) of eight (four students from each school) and spread out across the room to discuss the second vignette in the play. Schmitt asked them to think about Jan's and Nate's

lives, to develop a list of the pros and cons of being tested, and finally to vote on whether Jan and Nate should have the genetic test. The students often had immediate personal reactions to genetic testing, a knee-jerk response that Schmitt anticipated. He stressed that they needed to move beyond their personal reactions to consider the unique circumstances of Jan's and Nate's lives.

While observing the small groups I noted that while it was initially difficult for many students to overcome their immediate reactions to genetic testing, the discussions brought out more perspectives and caused students to rethink their opinions. Most of the students thought Jan should have the test; they believed it would remove uncertainty and, in the event of a positive result, allow Jan to plan for her future. Others doubted that the test, no matter what the result, would change the way Jan lives. "The test may say you are going to die," said one student in the guanine group, "but there are lots of things you can die from." A positive result would be "just one more thing to worry about in your life," said another student, and may lead to loss of insurance coverage. Students were even more divided concerning Nate. Most also felt Nate should have the test, but many doubted his ability to deal effectively with the result. Some believed that a positive result would cause Nate to take even less care in his life or consider suicide. Even a negative result (absence of the Huntington's marker) might drive him to despair over his years of aimless living. Most students, however, believed that learning more about his fate was worth the risk for Nate. A negative result might "open his eyes to life", said one student, and motivate him to make something of his future.

After approximately twenty minutes in small groups the students reformed the large group and reported on their discussions. As groups described their decisions, Schmitt noted that on the basis of the same set of facts different groups sometimes arrived at different conclusions. It is easy to tell students that bioethical decisions are complex and require careful attention to details, but a realistic case study like this is a better way to raise these issues. The play effectively set complex ideas in a realistic context and it was an energizing way to begin each forum. In lunch conversations with students had good things to say about the play. "Now I can see what good all that Mendelian genetics we've been studying is," one student told me. The performance clearly captured their attention and brought a level of intensity to learning that is difficult to achieve in classrooms. The teacher from Wayzata said her students were talking about the play on the bus ride back to school. The play was a marvelous fusion of art and science and I believe it reached some students who otherwise have difficulty seeing the relevance of science to their lives.

Guest speakers: Bioethics in the real world

Following a break for milk and cookies (that received consistently high reviews), a guest speaker addressed the students. As shown in Table 3 different

guests attended each forum and spoke on different topics. Mary Ahrens, a genetic counselor at Fairview-University Hospital in Minneapolis, talked about what genetic counselors do. She described the training required to enter the field, and how science, medicine, and counseling come together in her interactions with clients.

Dan Bergman, of the Minnesota Bureau of Criminal Apprehension (MBCA), described the use of DNA evidence in criminal prosecutions. Bergman has experience in investigating crime scenes, analyzing protein and DNA evidence, and testifying in court. He played a videotape the MBCA uses in court to describe DNA analysis procedures and brought along posters displaying DNA fingerprint evidence used in court.

Table 3. Guest speakers at the student forums.

Guest speaker	Topic	Date
Mary Ahrens, genetic counselor, Fairview-University Hospital	What do genetic counselors do?	November 5, 1997
Dan Bergman, lab technician, Minnesota Bureau of Criminal Apprehension	Forensic applications of molecular biological techniques.	December 10, 1997
Sally Spalding	A personal perspective on Huntington's disease.	January 14, 1998
Carl Elliot, Center for Bioethics, University of Minnesota	What's wrong with enhancement technologies?	January 28, 1998
Bonnie LeRoy, Minnesota Association for Human Genetics	Personal and social implications of genetic testing.	February 11, 1998

Sally Spalding told a very powerful personal story of being tested for the Huntington's disease marker and receiving a positive result. She recounted her father's illness with Huntington's disease, her decision to be tested for the marker in 1988, the effects of learning that she has a 92% chance of developing Huntington's disease, how her children have reacted to the news, and her plans for the future.

Carl Elliot, a philosopher from the Center for Bioethics at the University of Minnesota, challenged the students to think about the ethics of enhancement

technologies. Enhancement technologies are drugs and procedures that are used to enhance normal characteristics, rather than to cure or correct diseases or abnormal conditions. For example, human growth hormone can be used to enhance the height of normal-sized children, and Prozac can be used to improve the mental outlook of individuals who are not clinically depressed. Elliot played devil's advocate and encouraged students to think more carefully about their feelings toward enhancement technologies. In so doing the students generated many of the same justifications and criticisms of enhancement technologies that are offered by professional bioethicists.

Finally, Bonnie LeRoy, of the Minnesota Association for Human Genetics, described what genetic counselors do and, using Huntington's disease as an example, discussed the issues that counselors encourage clients to consider before having a genetic test. LeRoy examined in more depth the issues that students earlier identified in their discussions of the characters in the play, Jan and Nate. She also addressed the potential impact of genetic testing on access to health insurance and the status of state and Federal laws concerning genetic tests and health insurance.

Using guest speakers poses a risk that they will not adapt their presentations to the background knowledge of the students or that they will *talk to* students in lecture style rather than *speaking with* them. There were instances of these problems in the forums, but overall the guest speakers were a remarkable success. Among the most outstanding moments of the forums occurred in interactions between guest speakers and the students. For instance, Carl Elliot delivered a talk that could be presented to advanced undergraduate students; he challenged the students with serious philosophical and ethical arguments. Students rose to this challenge and found Elliot willing to take their ideas seriously, though not uncritically. Many of them were bothered by the prospect of individuals seeking pills or treatments for aspects of their bodies or personalities that, though medically normal, they perceived as deficient or in need of change. "You aren't facing the problem if you take a pill," said a student, "you should face your problems on your own." Elliot pointed to the case of Prozac and asked what was wrong with a healthy person taking a pill his/her entire life if that pill makes them feel even better than normal and doesn't do any harm. A student countered, "The problem with that is that we teach kids there is a pill for everything. It's just an excuse to pop pills, you have to learn to deal with things on your own," she said. "If you are a Christian, you can't go for this," said another student. "If we make everything perfect, what's He [God] going to grade us on?" Through this dialogue with Elliot the students collectively identified three issues that also concern ethicists: i) cultural complicity: the pressure to conform to shifting norms in society, ii) the shifting and relativistic definitions of "natural" and "normal", and iii) the problem of capitalism: are consumer demand and the potential for profit sufficient justifications for developing enhancement technologies? This was a valuable exchange that

demonstrated how serious content can be engaging and relevant to high school students.

Simulation of HIV transmission and testing

Following lunch the students participated in a simulation of the transmission of human immunodeficiency virus (HIV). The teachers, with assistance from Schmitt, prepared materials and led students through this activity. Students were told only that they were going to participate in an activity that involved the simulated exchange of body fluids with other individuals. This, needless to say, quickly got their attention. A cart with forty paper cups containing a clear liquid was wheeled into the room and the students each picked one up. The students were told to mingle freely with their colleagues and to share the contents of their cup with 2-3 other people. To do this the fluid in one cup was poured into a second cup and then half of the fluid was returned to it. When the sharing of fluids was completed the students received more information. One of the forty cups contained a dilute solution of sodium hydroxide (NaOH), which simulated the presence of HIV. The extent that the simulated virus was spread through the population was measured by putting a drop of phenolphthalein in each cup. This chemical indicator turns pink in the presence of sodium hydroxide, even in very dilute concentrations. Students lined up for their HIV tests and discovered to their surprise that approximately half of them were infected. In four of the five forums from 50%-75% of the students tested positive, with the highest incidence of infection occurring in students from the same school as the original carrier. It seems that students were much more likely to share fluids with others from their school than with students from the other school. All the students attending the forum on January 28, 1998 were from Shakopee, and in this instance the infection rate was 100%; there were fewer social barriers to sharing fluids and the simulated virus spread much more rapidly.

Students were consistently surprised by the extent of infection in the population and became very aware of how social factors can influence the spread of an infection. By far the most profound reaction was their desire to know the identity of the original carrier of the simulated virus. This was no mere curiosity, many students argued strongly that it was "just stupid" not to identify the person, and that the activity didn't have any point if the identity of that individual was withheld. Schmitt and the teachers refused to identify the student who had picked up the infected cup and were accused, with some humor but also in true frustration, of being "unfair" by withholding the information. Taking advantage of a teachable moment, Schmitt asked students to justify their need for the information. What at this point would they do with the knowledge? A few students suggested that the demand for information was really a search for a scapegoat on which to lay the blame for the behavior of an entire group of people. Others protested that they "just want to know."

The students' response to the HIV activity can be seen as a clash between the public's curiosity (and perhaps its desire to assign blame) and a commitment to maintain the confidentiality of biomedical test results. In more abstract discussions of genetic testing, for example, students generally believed that test results should remain confidential and under the control of the individual who is tested. But in a more concrete context there was overwhelming social pressure to identify the individual who was the first carrier of a virus in a population. The strength of the students' reaction was not fully anticipated, and if more time had been available this activity could have been used to challenge students' often easy assumptions that test results will be held in confidence even in the face of social and economic pressures to divulge the information. More examination of the students' reactions would have tied the HIV activity more strongly to the bioethics themes in the rest of the forum. As it was the students received a valuable lesson in the influence of social factors on the rate of spread of an infectious agent, and experienced first hand the social pressure that can develop to make personal health information public simply because the information exists, not because there are compelling reasons for doing so.

III. Student responses and the success of the forums

This section i) describes the results of student evaluations of the forums, ii) summarizes student responses to journal questions and pre- and post-forum questions assigned by their teachers, and iii) comments on the degree to which the goals of the forums were achieved.

Student evaluations: 11/5/97, 1/14/98, & 2/11/98

On November 5, January 14, and February 11 students completed written evaluations of the forums. A copy of the evaluation instrument is in the appendix. Table 4 contains the results of two items in which students rated how much they learned and their level of interest in the forums. More than 95% of the students rated the forums positively for both the amount learned and their level of interest.

Table 4. Students' ratings of how much they learned and their interest in the forums. (n=106)

How much did you learn about bioethics during this field trip?

(Rating scale: 1 = many things; 2 = a few things; 3 = not much; 4 = nothing)

<u>rating</u>	1	2	3	4
<u>% of respondents</u>	53.8	42.4	3.8	0

How interesting was this field trip?

(Rating scale: 1 = very interesting; 2 = sort of interesting; 3 = sort of boring; 4 = very boring)

<u>rating</u>	1	2	3	4
<u>% of respondents</u>	41.5	55.7	2.8	0

Table 5 contains examples of students' responses to three questions about what the students learned and how their thinking changed as a result of the forum.

Table 5. Examples of students' responses to free-response questions on the evaluation form. (Dates indicate when the question was used.)

November 4, 1997:

If a friend who isn't in your biology class asks what you learned during this trip to the Science Museum, what will you say?

- I learned about bioethics and decision making. And that there are lots of repercussions.
- I learned that biology affects many peoples' lives. That with new technology comes many hard ethical choices.
- I learned that biology really is useful, not just a required class.
- We answered a lot of questions that made me think about what I would do and how I would deal with that type of situation.
- It made you think about how your life stands & helped you to figure out what choices might be best for you if you had the possibility of developing a disorder.

January 14, 1998:

What is the most important thing you learned about bioethics during your trip to the Science Museum?

- How strongly peoples' opinions differ.
- How these kinds of diseases affect peoples' lives.

(Table 5, con't.)

- I learned of more risks and benefits of finding out genetic information about yourself.
- Different people have different views on the subject of knowing if you have Huntington's or not. I personally don't know why anyone wouldn't want to be tested, but others have different views than me.
- I learned that no matter how much genetic testing can help, it can still hurt people, too. There are so many things that need to be considered when talking about bioethical issues. Today was very interesting.

February 11, 1998:

Describe a specific example of how this field trip changed the way you think about bioethics.

- I learned more about how to make choices concerning my genetic stuff.
- I now know of how many people think, not just my side, but a lot of sides to one simple question.
- It gave me broader views to the topic of bioethics. It made me think more of the problems of everyday life.
- I feel the issues have changed in [my] mind. I used to see the choices as "two-valued", right or wrong, but in situation[s] with complex and diverse "sub-issues" the choices become a compromise.
- While we were talking about HIV testing I started thinking about all the innocent people that could possibly be affected. I had never really thought about that. I had only thought about the person's with HIV rights. I guess I learned how to look at the bigger picture better.

Table 6 summarizes students' views of the most and least interesting aspects of the forums, and their suggestions for improving the forums. The HIV simulation was rated the most interesting part of the forums, followed by the guest speakers, small group discussions, and the play. The guest speakers and small group discussions were also rated among the least interesting aspects of the forums, followed by the journals. The apparent division of opinion among the students concerning the guest speakers is due almost entirely to variation in responses *among* the forums rather than *within* a forum. In other words, some guest speakers were very well received (Bergman, Elliot, and Spalding) and others (Ahrens and LeRoy) were criticized by some students for speaking too long, and being difficult to understand or uninteresting. In my opinion all of the speakers did a commendable job and presented topics that were appropriate for high school students. But the students' reactions should remind us of the importance of actively engaging them in presentations and using real-life examples and cases rather than abstract generalizations. The most common suggestion to improve the forums is to include more hands-on activities, which reflects the popularity of the HIV simulation.

Table 6. Summary of students' views of the most and least interesting aspects of the forums, and suggestions for improving the forums. (n=106)

Item	Most frequent responses ($\geq 10\%$) (% of students)
The most interesting part of the day.	HIV transmission & test simulation ... 46.2 Guest speaker 26.4 Small group discussions 17.0 Theater performance 12.3
The least interesting part of the day.	Guest speaker 30.2 Small group discussions 13.2 Journals 10.4
Changes that would make the field trip a better way to learn about bioethics.	More hands-on activities; less sitting .. 20.7 Identify the HIV carrier* 11.3 Don't change anything 12.3

*These students objected that the identity of the original carrier of HIV in the simulation was not revealed.

Student journals: 12/10/97 & 1/28/98

At the conclusion of December 10 forum Schmitt showed this question to students and asked them to respond in their journals:

I have changed my mind today! Give at least one example: "I used to think...Now I think..."

The following responses, each from a different student, demonstrate the range of issues the students encountered and the variety of effects the forum had on them.

I used to think that it was such an easy decision that, yes, I want the results [of a genetic test]. It's not that easy. There are so many other decisions besides Do I want to know my results? There are ones such as Who do I want to know? What laws or restrictions should be made?

I've changed my mind about how available the results of genetic tests should be. I used to think that the results should be open to the public, but now I think it is a very personal matter that should be kept private, unless the individual opts to release the information.

I used to think that being genetically screened was a completely personal decision and that the person involved is the only one who should make it. Now I

think that many people can be affected by that knowledge &, in some cases, they should know.

I used to think everybody in my class pretty much felt the same way on genetic testing and AIDS [sic, HIV] testing as I did, but now I realize that there are a lot of people with different opinions on how both tests should be handled.

I used to think that courts did not like DNA evidence. Now I found out that the courts are actually quite open to it.

At the conclusion of the January 28 forum students were asked this question:

How has your experience today changed the way you will look at genetic issues?

Students described their increased appreciation of the complexity and multiple perspectives associated with the issues they discussed:

Today has really broadened my outlook on human morals and values and responsibility. I have never really looked at my own values...and some of the many decisions I may have to face.

This has really opened my eyes to new genetic issues and shown me both sides of these issues...I enjoyed being presented with the new issues & controversial questions to discuss. It definitely changed my thinking.

Nothing really changes my perspective. I heard a lot more arguments from certain topics, but nothing really changed my view on issues. I think that people really have no clue about some things.

Genetic issues take a lot more thinking and processing of info to make a decision than I thought before. There are many new angles to an issue than I thought before. It affects many more people than I thought.

I realize there is more to this issue than basic wrong or right. It's also been informative hearing who thinks how. The issues have so many sides that each issue is a personal choice and is very complex and interesting. I

love this experience!!

I have found out these issues are much more controversial than I thought. I used to think Prozac, Ritalin etc. were all bad (like most of the kids here thought), but when Lee [Schmitt] and Dr. Elliot, and especially Steve from the U of M⁴ talked & got involved in my discussions, they changed my views. Thank you, this was very enjoyable.

Student responses to pre- and post-forum questions

Several of the teachers had their students respond to a question before and after the forum to encourage students to reflect on the impact of the forum on their beliefs. For example, students from Coon Rapids were asked to describe how their lives might be affected by biotechnology. Before the forum many of the students mentioned cloning, the production of organs for transplants, designer children through gene manipulation, and genetic testing. After the forum the students, like these two, wrote mostly about genetic testing:

With this new technology we will have...to decide if we want to be tested for a genetic disease. If I had the decision to be tested for a genetic disease I would want to know if I had the disease. I wouldn't have to live life wondering, I could be able to get on with my life, and plan for the future...I think it is better to know and be tested. It takes a lot of thinking. There are a lot of what-ifs that come up and makes you ask yourself what you would do and why or why not.

I think that my life will be greatly effected by this new technology. I don't think that I would ever have genetic testing done, unless it was serious and there was a cure for what I was being tested for.

At The Blake School students were asked i) whether there are situations in which an individual is ethically bound to be genetically tested and to share those results with another party, and ii) whether society should legally compel individuals under certain circumstances to be genetically tested and to disclose the

⁴This student took part in an informal lunchtime discussion that I initiated about the students' reactions to enhancement technologies.

results to certain parties. Before and after the forum, many students, like this one, recognized an ethical obligation to inform spouses and family members of the results of genetic tests:

Suppose that my father was genetically tested. It was determined that his genes contained a certain disease. There is a possibility that the disease was passed down to me, and I, together with my wife am about to make a decision to have a child. I believe that my father should inform me about the results of his test, so that my wife and I could perhaps be able to plan the future of our family better.

Regarding laws mandating genetic testing, many students supported the mandatory testing of criminal suspects, if genetic information would help solve the case. Before the forum a student wrote:

An example of a situation in which I feel that genetic testing and subsequent disclosure of the results should be mandatory would be if the person in question is a murder suspect. In a case such as that, the mandating of genetic testing and all of that would simply be used in aiding the investigation, and solving crimes is usually considered to be beneficial to society at large.

Some students were persuaded of this position after the forum (Dan Bergman, an enthusiastic proponent of the use of DNA evidence in criminal prosecutions was the guest speaker).

After attending the Bioethical seminar and continuing classroom discussions, I have changed my view regarding law requirements tied to genetic testing. When I thought through this issue earlier, I did not include the use of genetic fingerprints in law enforcement. I said there should be no laws legally binding anyone to provide their genetic information. I now believe that genetic screening of a sample could complete a case. It would greatly advance the justice in our country.

Other students stood by their views that there should be no laws compelling genetic testing, even for law enforcement:

My feeling towards whether society should make laws requiring genetic testing has not changed. It is still no.

Privacy is the key. As soon as you let something/someone like law enforcement have access to that kind of information, others will believe they have the right to it, and so on.

Were the goals of the forums achieved?

How successful were the forums in achieving the goals that Schmitt reviewed with the students?

1. Increase awareness and understanding of bioethical issues in our community.

The forums met this goal by providing students with opportunities to apply their new and prior knowledge of bioethics and biomedical issues in a variety of stimulating contexts. The theater performance set technical aspects of genetic disease and testing in an intensely personal context; the guest speakers brought new information and experiences to students and challenged their preconceptions; the HIV simulation demonstrated the social consequences of personal behaviors; and the group discussions gave students the chance to explore their opinions with their peers. The forums certainly raised more questions than they answered, but that is the nature of increased awareness and understanding in bioethics.

2. Pool our collective ideas and arguments to broaden our individual views of the complexity and relevance of bioethical issues.

The student journals suggest that a major outcome of the forums was a heightened appreciation of the complexity of bioethical issues and the diversity of views, not only in society at-large, but among their peers. For the students who were listening, thinking, and open to new perspectives (and I believe most of them were), the forums were certainly a broadening experience, full of exciting new possibilities and worrisome potential consequences.

3. Develop a group of experienced student leaders to continue bioethical discussions back at your schools.

This goal is in the hands of the students and their teachers, but the forums provided them with models of how critical and respectful discussions of bioethics can be carried on. There is evidence that the knowledge and creative energy generated by the forums has impacted classrooms back in the students' schools. For instance, after their

forum students from St. Paul Central accepted special responsibility for facilitating a discussion of the HIV simulation with other students who did not attend the forum. At Maple Grove High School students from the forums assumed the roles of persons affected by Huntington's disease and answered questions from their classmates. These are hopeful signs that the students carried new insights and confidence away from the forums, and that their teachers were committed to linking classroom instruction to the students' experiences at the forums.

IV. Comments and Recommendations

The forums were a success and could be repeated with little modification. In my view, however, the following issues deserve consideration.

1. *Teacher involvement.* There was insufficient teacher involvement in the planning and implementation of the forums. As originally conceived, the teachers were to take the lead in planning and implementing the forums. But their already heavy professional obligations and the difficulty of bringing ten teachers together for planning meetings meant that most of the planning and implementation of the forums was handled by Lee Schmitt and his staff. The teachers did not fulfill their leadership roles in this component of the Bioethics Curriculum Enhancement Project. This was more disappointing to Schmitt than it was to the teachers, who were pleased with the quality of the forums and comfortable with their peripheral roles.

The only component of the forum in which teachers were actively involved was the HIV simulation. The teachers brought and prepared the materials and directed students through the activity, though they typically asked Schmitt to take the lead in the follow-up discussion. Most of the time the teachers stood in the back of the room and observed. There are pros and cons to this low level of teacher engagement. On the positive side, some teachers said they enjoyed observing their students at work, a perspective they don't often have in their own classrooms. A number of them also believed that the students contributed more to the group discussions because regular teachers were not present. Getting students out of classrooms and into a new setting may well have encouraged a more open exchange of ideas than is possible in many classrooms, in which social pressures and expectations of various kinds can hamper group discussions. Somewhat paradoxically, the students may have opened up more to strangers than they would to their own teachers. On the other hand, the teachers in this program are leaders in their profession and committed to bioethics education. The students have no opportunity to benefit from this expertise if their teachers do not participate in the forum.

2. *Supervising the small group discussions.* The small groups were almost entirely unsupervised. A role the teachers might play in the future is monitoring the small group discussions to keep them on task and to insure that all the students are being heard. I circulated among the groups and was impressed by how well they functioned, but groups were occasionally off task or dominated by a one or two individuals. These problems will be reduced if teachers move among the groups to briefly check on their progress and focus the discussion. The teachers should not attempt to run the discussions; the students should retain "ownership" of the small groups. This will minimize the possibility of inhibiting the discussions, but provide some check on the quality of the group interactions.

3. *Linking classrooms before and after the forums.* Students arrived at the forums without any standard set of preparatory experiences, nor was there any provision for a common set of follow-up activities. The quality of the forums did not seriously suffer because of this lack of coordination among the participating teachers, but more could be made of the cross-classroom learning community created by the forum. One of the teachers suggested that putting students in e-mail contact with one another before and after the forum might be a way to nurture the contacts made at the forums. Members of the base groups could meet each other via e-mail and describe the bioethics issues they are exploring in their classes, or discuss a question in preparation for the forum. A goal of this extended contact among the students is to span the barriers that isolate students and teachers in their classrooms and to infuse the spirit of exploration and open discussion that characterized the forums into everyday classroom activities.

PART 2: PUBLIC BIOETHICS FORUMS

I. Executive summary

The goal of the Public Bioethics Forums is to engage adult audiences in discussions of genetic and biomedical technologies and the impact of these technologies on personal health care and social policy decisions. This report describes and evaluates two public forums on the personal and social implications of breast cancer genetics, held at the Science Museum of Minnesota on March 19 and 26, 1998. The forums were two hours in length and featured presentations from a panel followed by audience questions and discussion. Issues discussed in the forums included the genetics of breast cancer, the risks and benefits of genetic testing, understanding test results and their impact on lifestyles, confidentiality and access to test results, and paying for genetic tests.

Excellent panels of speakers were assembled for the forums and their presentations were of consistently high quality. In both forums interesting discussions followed the presentations, although the large auditorium used for the first forum was not a good setting for a group discussion. The second forum was in a smaller theater and the audience discussion period was more successful. Approximately twenty people attended each forum. This attendance was disappointingly low and apparently due to limited publicity about the forums. In the future more lead time for publicity and better coordination with other components of the Public Programs in Health Care Ethics project should improve the attendance. Audience surveys are available only for the second forum. The panel and audience discussion were rated positively and most of the respondents said the forum affected the way they think about genetic testing for breast cancer. The surveys also suggest that there is interest in more forums of this type.

This report recommends that i) future forums be better publicized and coordinated with others components of the bioethics project, and ii) the transition during the forums from panel presentations to open discussion be carefully facilitated to encourage audience participation.

II. Introduction

The goal of the Public Bioethics Forums is to engage adult audiences in discussions of genetic and biomedical technologies and the impact of these technologies on personal health care and social policy decisions. This report describes and evaluates two public forums on the personal and social implications of breast cancer genetics, held at the SMM on March 19 and 26, 1998.

Evaluation methodology

In consultation with Bill Allen, manager of Adult Education and Travel Programs at the SMM and organizer of the forums, I developed a written survey to obtain feedback from the audience. The survey was included in the printed program that audience members received (copies of the program and the survey are in the appendix). I also attended the forums to collect field notes on the presentations and discussions.

III. Description and analysis of the forums

The first forum concerned the personal side of breast cancer genetic screening: Who should be screened for a breast cancer gene? Would you want to know the results of a genetic test for breast cancer? and How might that information affect your life? The second forum explored social implications of genetic screening for breast cancer: Who should pay for the screening? Who should have access to the results? and Is there such a thing as genetic privacy? Both forums were two hours in length and featured presentations from a panel followed by audience questions and discussion.

Forum 1: personal perspectives

Approximately 20 people attended the first forum, which was held in a large auditorium at the SMM. Panel members for the first forum included:

- Mary Ahrens, genetic counselor, Fairview-University Hospital
- Dr. Thomas Armatruda, co-director, Fairview-University Familial Cancer Center
- Karen Gervais, director, Minnesota Center for Health Care Ethics
- Kim Hines (moderator), associate artist, Illusion Theater
- Barbara Weiner, executive director, Women's Cancer Resource Center

Thomas Armatruda began the panel presentations by reviewing the basic biology of cancer and evidence for the genetic basis of some breast cancers. Mary Ahrens next described how genetic counselors help their clients evaluate the risks and benefits of genetic screening and interpret the meaning and implications of genetic test results.

To simulate this experience, Ahrens gave each audience member a 'gene' envelope that contained two genes: either two 'normal' genes or one 'normal' gene and a 'cancer' gene. These sealed envelopes were not opened until later in the forum. Barbara Weiner represented the personal face of coping with the risks and effects of breast cancer. She reviewed her family's history with breast cancer, her decision to have a prophylactic mastectomy, and her efforts to provide support and information to women through the Women's Cancer Resource Center. Finally, Karen Gervais reviewed some ethical dilemmas of genetic screening for breast cancer by returning to the 'gene' envelopes Ahrens had distributed. Opening the forum for audience questions and comments, Gervais asked the audience to describe the issues on their minds as they considered the fate that their 'gene' envelopes held. Several interesting themes emerged in the discussions among the panelists and audience members:

More information does not necessarily mean more control. This is an example of one of the dilemmas associated with genetic testing to which Gervais referred. It is illustrated by the reaction of one audience member to what she found in her 'gene' envelope. Before opening the envelope she said she viewed genetic testing as a way to get more control over her life; acquiring information, in her view, is the first step in problem solving. When she opened her 'gene' envelope and found no cancer gene, however, she said her reaction was not relief, but disbelief. She explained that in her real life she is convinced that she has a cancer gene and would doubt the validity of a test that indicated otherwise. In this case, Gervais suggested, the information delivered by a genetic test was met with disbelief, not a sense of empowerment. Similarly, a positive test result leaves the uncertainty of when and how cancer may appear. And as Ahrens stressed, a negative genetic test for breast cancer is not a guarantee that no cancer will develop.

What will a genetic test do for you? Ahrens encourages her clients to carefully consider this question before having a test. Are you willing to change your lifestyle based on the results of a test? Will a test tell you something that your family history doesn't? Will a positive test cause more distress than not knowing your genetic status? Several different responses to these questions were offered during the forum. Some people objected to having a technology label them as healthy, at risk, or destined for illness. Weiner warned of the emerging commercial exploitation of genetic testing based on public misunderstandings of the risks and benefits of testing. Hines wondered whether knowing that she has a disposition for a condition would cause her to "worry myself into the disease." Still others saw testing as a means of greater self-determination in the face of a genetic endowment over which they have no control.

Genes are shared so should the results of tests also be shared? Our genes are not our own—to various degrees we share them with parents, siblings, children and other relatives. The results of genetic tests are therefore simultaneously personal

and to some degree communal. What effect should this have on our decisions concerning genetic testing? Do we have a moral obligation to get the permission of others before we have ourselves tested? Do we have an obligation to inform others of our test results? What if you are tested but your close relatives don't want to know the results?

Forum 2—societal perspectives

Eighteen people attended the second forum, which was moved from the auditorium used for the first forum to the smaller Science Theater. The panelists for the second forum included:

- Mary Ahrens, genetic counselor, Fairview-University Hospital
- Bill Allen (moderator), manager, Adult Education and Travel Programs, Science Museum of Minnesota⁵
- Karen Gervais, director, Minnesota Center for Health Care Ethics
- Gene Merriam, former Minnesota state legislator
- Dr. Richard K. Simmons, medical director of utilization review, Allina Health System
- L. Joe Thompson, director, Total Compensation Resource Center, 3M Company
- Barbara Weiner, executive director, Women's Cancer Resource Center

Ahrens and Weiner made presentations similar to those they made at the first forum. Gene Merriam, a former state legislator, described Minnesota's Genetic Discrimination Act, which prohibits discrimination in insurance underwriting based on the results of a genetic test. Dr. Richard Simmons of Allina Health Systems, predicted that genetic manipulation will replace drug therapy as a dominant means of treatment in the next 50 years. But in his view genetic tests are limited in what they tell us and must be carefully interpreted. For instance, genetic tests are not diagnostic—they do not detect the presence of disease, they only inform us of relative risk. Simmons argued that it is therefore very important that counseling be a component of genetic testing. Like Weiner, he warned of the possible abuses of commercially available testing that does not include personal counseling about the implications of the results. L. Joe Thompson, who supervises the insurance benefits program at 3M Company said that the topic of genetic screening has not "hit the radar screen of any benefits manager in any major company" that he knows of. He said that 3M has no interest in the genetic characteristics of its employees and will not base any employment or benefits decisions on the results of genetic tests. Gervais discussed genetic testing in the context of community rating versus individual medical underwriting as means of

⁵Kim Hines was originally scheduled to be the moderator, but she could not attend.

determining health insurance coverage. Using a community rating, premiums and benefits are calculated based on the average incidence of health problems in the population covered. Individuals with greater genetic risks benefit by having their coverage based on the population-wide incidence of genetic conditions. Using individual underwriting coverage is based on an individual's characteristics, so individuals with increased genetic risks might pay more or receive reduced benefits. Gervais pointed out that while using the results of genetic tests in underwriting decisions is illegal in Minnesota, there is no Federal law prohibiting this practice.

The audience discussion that followed ranged widely from issues concerning genetic testing to specific questions concerning the biology of breast cancer. Here is a selection of major topics that arose:

Absolute confidentiality versus the need for counseling. To prevent employment or insurance discrimination, one audience member argued that the results of genetic tests should be reported *only* to the person tested. Ahrens and Simmons countered that counseling is vital to insure that the implications of the test results are properly understood. A second audience member argued that individuals who take genetic tests ought to be entitled to choose either complete anonymity or to seek counseling concerning the results. This autonomy, she said, was a matter of respecting the dignity of individuals.

Who pays for genetic tests? A related issue that ran throughout the forum was who should pay for genetic tests and how that affects access to the results. Gene Merriam pointed out that if insurance companies pay for the tests, they have a reasonable expectation of having access to the results. If confidentiality is highly valued, it also comes at a high price. Individuals can pay for their own genetic tests, but the tests are expensive and so access to confidential testing might be limited to the wealthy.

Traditional screening for breast cancer versus genetic tests. A breast cancer survivor in the audience was concerned that a genetic test for breast cancer not be viewed as a replacement for traditional screening procedures. Breast cancer, she argued, has multiple origins and all individuals have some degree of risk. A negative test result does not mean that breast cancer will not develop nor that regular breast examinations are unnecessary.

What's the purpose of a genetic test for breast cancer? The discussion of traditional screening versus genetic tests returned to a central issue in both forums: What is the purpose of genetic testing and what do the results do for us? Near the end of the discussion period Bill Allen asked whether the

forum had changed anyone’s mind about having a genetic test for breast cancer. A women in her twenties who had not spoken before said that her 32 year-old sister had just been diagnosed with breast cancer. She explained that she was already following aggressive screening and prevention measures and could not see how a positive or negative test results would change her behavior. Barbara Weiner, on the other hand, facing a family history of breast cancer elected to have a prophylactic mastectomy. As Karen Gervais suggested, information from family histories or genetic tests may change the details of the dilemma one faces, but it does not resolve the dilemmas.

IV. Audience surveys

Audience surveys were distributed at both forums (the survey is included in the appendix). The surveys for the first forum were misplaced by the SMM, so only surveys from the second forum are analyzed here.

Surveys were returned by 10 audience members (nine females, 1 male) whose demographic characteristics are in Table 1.

Table 1. Demographic characteristics of survey respondents.

Age (years)	No. and gender of respondents	Occupation
31-40	1 (female)	administrative assistant
41-50	5 (female)	clerical; finance; health care; nurse; phone company
51-60	1 (male)	retired
61 or more	3 (female)	nurse; recreational therapist; retired

Table 2 contains the respondents’ ratings of three aspects of the forums and any additional written comments they made. The panelists’ presentations and the audience discussion period were both positively rated. Six of the ten respondents also agreed that how they think about genetic screening for breast cancer was changed by their experience at the forum.

Table 2. Audience ratings of three aspects of the forum. Rating scale: SD = strongly disagree, D = disagree, A = agree, SA = strongly agree, nr = no response. (n = 10)

Statement	Rating scale					Respondents' comments (response on rating scales in parentheses)
	SD	D	A	SA	nr	
The quality of the panelists' presentations was high.	0	0	4	5	1	<ul style="list-style-type: none"> •Brought out points I never realized. (SA) •Good range of backgrounds on panel. (A)
The audience questions and discussion during the second hour were valuable components of the forum.	0	1	3	4	2	The one woman just wanted to voice her opinion on everything; inhibited others from speaking for a sure 1/2 hour-later got better. (D & A, scored as D)
How I think about issues related to genetic screening for breast cancer will change as a result of what I heard tonight.	1	2	6	0	1	It will probably influence a future decision. (D)

Seven of the ten respondents learned of the forum from newspapers and two from a friend or by word of mouth. One individual urged that the forums be better advertised. The reasons given for attending the forum ranged from general interest to personal experience with breast cancer:

•Why did you attend this forum?

- Have a sister who died of breast cancer @ age 44.
- My younger sister has breast cancer.
- I have strong family history—mother and grandmother died from breast cancer at age 53.
- Cysts in past two years only.
- Interest.
- Need more high quality information.
- To learn and be more informed.
- No response (3)

The following topics were suggested for future bioethics forums:

- End of life care
- Allocation of resources

Stomach or colon cancer.

There are lots of issues just dealing with medicine and who has access.

How reliable are clinical trials? For example, strong evidence exists that results were misrepresented in at least two important breast cancer trials (eg., Fischer).

What are biases of cancer establishments? How much do sources of funding influence the results and their implementation?

Finally, seven of the ten indicated that they would pay \$5.00 to attend a similar forum, one said "probably", and two did not respond.

V. Comments and recommendations

1. *Panelists.* The panels assembled for the forums were of very high quality. All of the panelists made interesting, accessible presentations, and they represented a well balanced range of perspectives.

2. *Format of the forums.* Combining presentations by "experts" with free flowing group discussions is difficult, and these forums demonstrated some of the shortcomings of this format. The first forum was held in a large auditorium which made group discussion, particularly dialogue among audience members, difficult. The panelists were far away from the audience and the audience members were also far from one another. The transition from presentations to group discussion was rather abrupt and the discussion got off to a slow start. The second forum was in a smaller room with theater-style seating that was better for a group discussion. The audience engaged the panelists and to a limited extent each other, and most in the audience contributed to the discussion. For future forums the transition from presentations to discussion should be carefully planned to help audience members move from a passive to an active role in the forum. For instance, to move from presentations to discussion audience members might be asked to consider a yes/no question and then be invited to indicate their decision with a show of hands. Individuals can then be asked to explain their choices and a general discussion can build on the issues that emerge in these explanations.

3. *Attendance.* The number in attendance at the forums was disappointingly small, especially considering the excellent panels that were assembled. Announcements for the forums were placed in several local newspapers, but this seems not to be an effective way to get the word out. The most obvious group to attract to the forums are SMM members, but there was not sufficient lead time to advertise the forums in SMM mailings. Another potential audience that was not tapped were the teachers and students who participated in the student bioethics forums. Longer lead time and better coordination among components of the bioethics project are likely to tap

enthusiastic audiences and significantly boost the attendance at future forums.

V. Appendix

- Students Bioethics Forums

Evaluation instrument

- Public Bioethics Forums

Program

Audience survey

**Student Bioethics Forum
Science Museum of Minnesota**

DIRECTIONS: Please tell us what you think about the field trip to the Science Museum. Do not write your name on this paper. Thank you.

1. How much did you learn about bioethics during this field trip? Choose one:
 - a. Many things
 - b. A few things
 - c. Not much
 - d. Nothing

2. How interesting was this field trip? Choose one:
 - a. Very interesting
 - b. Sort of interesting
 - c. Sort of boring
 - d. Very boring

3. Describe a specific example of how this field trip has changed the way you think about bioethics.

(Turn the page over)

4. What was the most interesting part of your day at the Science Museum?

5. What was the least interesting part of your day at the Science Museum?

6. How would you change this field trip to make it a better way to learn about bioethics?

BREAST CANCER FORUM

Exploring the
Personal and Societal
Implications of Breast
Cancer Genetics

March 19 and 26
at the Science Museum of Minnesota



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Thursday, March 19, 1998

THE PERSONAL SIDE OF BREAST CANCER GENETIC SCREENING

Should you be screened for a breast cancer gene? Would you want to know the results of a genetic test for breast cancer? How might that information affect your life? Explore these topics with the following panelists:

Mary Ahrens is a genetic counselor at the Familial Cancer Clinic at Fairview-University Medical Center in Minneapolis, a program that assists individuals at high risk for cancer through early detection, screening, prevention, and research.

Dr. Thomas Amatruda is a physician who has specialty training in medical oncology, the care of people with cancer, and in molecular biology. Dr. Amatruda is an assistant professor of Medicine at the University of Minnesota, and is a co-director of the Fairview-University Familial Cancer Clinic.

Karen Gervais is director of the Minnesota Center for Health Care Ethics, an academic, clinical, and policy consortium. She has written and lectured extensively on ethical issues associated with health care and is editing a casebook on ethical issues in managed care.

Kim Hines, moderator, is an associate artist at Illusion Theater in Minneapolis. An actor, director, and playwright, Hines has a keen interest in health issues, and has been the recipient of numerous grants and awards, including the prestigious 1997 Bush Artist Fellowship Award for playwriting.

Barbara Wiener is the executive director of the Women's Cancer Resource Center in Minneapolis, an organization offering information, support, and advocacy to women living with cancer and their loved ones.

Thursday, March 26, 1998

SOCIETY'S RESPONSIBILITY FOR BREAST CANCER

Who should pay for genetic testing and who should have access to genetic information? Is there such a thing as "genetic privacy"? Discuss these topics with the following panel members:

Mary Ahrens is a genetic counselor at the Familial Cancer Clinic at Fairview-University Medical Center in Minneapolis, a program that assists individuals at high risk for cancer through early detection, screening, prevention, and research.

Karen Gervais is director of the Minnesota Center for Health Care Ethics, an academic, clinical, and policy consortium. She has written and lectured extensively on ethical issues associated with health care and is editing a casebook on ethical issues in managed care.

Kim Hines, moderator, is an associate artist at Illusion Theater in Minneapolis. An actor, director, and playwright, Hines has a keen interest in health issues, and has been the recipient of numerous grants and awards, including the prestigious 1997 Bush Artist Fellowship Award for playwriting.

Gene Merriam served in the Minnesota State Senate, representing the northern suburban area for 22 years, and in 1995 authored the state's Genetic Discrimination Act. He is now the chief financial officer for ECM Publishers Inc. in Coon Rapids.

Dr. Richard K. Simmons, a family practice physician, has served as a medical director for Physicians Health Plan and Medica, and is currently the medical director of utilization review at Allina Health System.

L. Joe Thompson is director of the Total Compensation Resource Center at 3M Company and is ultimately responsible for the health care benefits of all 3M employees.

Barbara Wiener is the executive director of the Women's Cancer Resource Center in Minneapolis, an organization offering information, support, and advocacy to women living with cancer and their loved ones.

AUDIENCE SURVEY

Please tell us what you think about tonight's panel presentation and discussion. Your responses are completely anonymous. If you wish to make more extended written comments, you may use the computers located immediately outside the auditorium, or you may access the museum's web site at any time to share your comments (<http://www.exdesign.smm.org>). Thank you for your feedback.

1. The following information will help us understand who attended tonight's forum.

Your gender (circle one): female male
Your age (circle one): less than 20 20-30 31-40 41-50 61 or more
What is/was your primary occupation or profession? _____
What is the postal zip code of your home address? _____

2. Please agree or disagree with the following statements by circling the appropriate response. If you wish, clarify or expand upon your response in the space provided.

The quality of the panelists' presentations was high (circle one).

Strongly disagree Disagree Agree Strongly agree

Comments: _____

The audience questions and discussion during the second hour were valuable components of the forum (circle one).

Strongly disagree Disagree Agree Strongly agree

Comments: _____

How I think about issues related to genetic screening for breast cancer will change as a result of what I heard tonight (circle one).

Strongly disagree Disagree Agree Strongly agree

Comments: _____

3. Please respond to the following questions.

How did you learn about this forum? _____

Why did you attend this forum? _____

What topics should be addressed in future public forums dealing with the ethics of health care and biomedical technologies?

Tonight's forum was free of charge. Would you attend a similar forum with a \$5 attendance fee (circle one)? Yes No