



Published in final edited form as:

J Genet Couns. 2013 August ; 22(4): 508–516. doi:10.1007/s10897-013-9577-3.

Promoting Public Awareness and Engagement in Genome Sciences

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Abstract

Public understanding of genetic concepts and associated ethical and policy issues can enable informed deliberation and decision-making. Effective strategies for increasing public understanding involve providing forums incorporating the unique perspectives and attitudes of the public, while allowing opportunities to learn first-hand from scientists about genome research and related applications. Through a partnership between the Duke Institute for Genome Sciences & Policy (IGSP) and the Museum of Life and Science in Durham, NC, we developed and piloted a program aimed to bridge the concepts of formal (public school) and informal (community-based science museum) science learning with the experiential context of family and participatory learning. Called *Genome Diner*, we piloted the program with 40 genetic/genomic researchers, 76 middle school students and their parents ($n=83$) from Durham, NC. Program impact was assessed via pre/post surveys for each participant group. Following participation, parents were significantly more likely to correctly interpret the implications of a genome research finding, and both students and parents indicated higher interest in research as well as higher confidence in accessing and understanding genome research. Genetic literacy of parents and students was not affected by participation in the program, likely due to the relatively high knowledge scores pre-Diner: 88.3% and 78.5%, respectively. The interactive format of *Genome Diner* provided an opportunity for students and parents to explore and discuss interests and issues about genomic research alongside genome scientists, positively influencing attitudes toward genetic research and researchers themselves. These interactions are critical for maintaining public interest and knowledge about genomic research and applications.

Keywords

Education; Community; Engagement; Attitudes; Knowledge; Genomics; Research

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Conflict of Interest Statement: The authors have no conflicts of interest to declare.

The *Genome Diner* activity is available at <http://www.genome.duke.edu/genomediner/>; a limited number of classroom kits are available upon request.

Introduction

The ability to translate science into personally meaningful information may depend on the public's understanding of science (Bates, 2005; Bates, Lynch, Bevan, & Condit, 2005). With the rapid pace of discovery and technology development in genome sciences, even the most science-oriented publics may struggle to develop a foundational knowledge base to fully recognize the potential benefits and risks arising from the genome revolution. Many studies have revealed a complex relationship between scientific knowledge and attitudes (Gaskell, 2003; Gottweis, 2002; Hampel, Pfенning, & Peters, 2000; Pardo, Midden, & Miller, 2002; Pfister, Bohm, & Jungermann, 2000; Sturgis, Cooper, & Fife-Schaw, 2005; Wellcome Trust, 1998). For example, a study of 1,216 Finnish individuals revealed that increased knowledge was frequently associated with both greater enthusiasm and skepticism towards genetic testing, whereas lack of knowledge often led to inability to form opinions on the topic (Jallinoja & Aro, 2000). In contrast, a review of European and American public surveys regarding biotechnology in general found no evidence to support a correlation between knowledge and attitudes towards it (Gottweis, 2002).

Public knowledge about genome research, applications, and ethical implications may enable a meaningful discourse and informed decision-making about research participation, clinical testing, and societal issues. As many population-based studies require hundreds to thousands of participants in order to be adequately powered to conduct multiple analyses, informed publics may aid recruitment efforts. Broad public participation in such studies, particularly of minority populations, requires both a valuing of the potential benefits of that research (Gadegbeku et al., 2008; Halbert, Gandy, Collier, & Shaker, 2006; McDonald et al., 2012; White, Koehly, Omogbehin, & McBride, 2010) and a trust of the researchers themselves (Braunstein, Sherber, Schulman, Ding, & Powe, 2008; Corbie-Smith, Thomas, Williams, & Moody-Ayers, 1999; McDonald, et al., 2012). Greater engagement with researchers may have multiple benefits, not only promoting public understanding of some of the applications of genetics and genetics research, but providing an opportunity for researchers to address prospective participants' concerns and facilitating a dialog between researchers and participants that likely does not exist. Ultimately, fostering greater interaction between researchers and the public may improve trust and transparency, factors considered essential to improving research participation in clinical trials (Bussey-Jones et al., 2010).

To develop a deeper understanding of public attitudes, promote awareness of genetics and genomics research and applications, and assess the effect of direct interaction between researchers and middle school students and their parents, we developed and piloted a program called *Genome Diner*. Designed through a partnership between the Duke Institute for Genome Sciences & Policy (IGSP) and the Museum of Life and Science (MLS) in Durham, NC, the program employs a unique strategy aimed at bridging the concepts of formal (public school) and informal (community-based science museum) science learning, with the experiential context of family and participatory learning. We also aimed to promote researchers' understanding of public knowledge and attitudes toward genetics research and researchers. Here we present the results of the two-year Genome Diner pilot program and its impact on parent and student knowledge and attitudes about genetics in general, and genetics research and researchers in particular.

Methods

Program Development

As described previously (O'Daniel et al., 2012), the Genome Diner program was modeled after public engagement efforts in the UK shown to be effective in stimulating public learning and discussion of biotechnology (Duensing, 2007; New Economics Foundation,

2003). In summary, we developed an informal discussion game based on a diner theme through a collaborative partnership between the IGSP and the MLS in Durham, NC (<http://www.genome.duke.edu/genomediner/>). Participants in the program chose one of two areas of genome research to discuss: 1) population-targeted genomic research and 2) genomic health/trait association research. For each topic, the program included discussion questions on key scientific concepts and ethical issues.

Participants

Middle school students (7th- and 8th-grade, ages 12–13 years), their parent/guardian(s), and genetic/genomic researchers were recruited for the pilot study. We specifically targeted this age group because basic genetic concepts are included in the 7th-grade curriculum. Middle schools (grades 6th–8th) in the Durham County school district have an average population of 634 students, with an average class size of 20–21 students. The two schools targeted had 7th and 8th grade populations of 421 and 528 respectively. The program was widely advertised to most 7th and 8th grade students and their parents via a science classroom visit from a member of our research team as well as flyers, school announcements, parent-teacher emails and postings on the school webpage. Students from other grades were permitted to attend but were not specifically targeted. Dinner and free museum passes were provided to all participants. The study was approved by the Duke University Medical Center Institutional Review Board.

Genome Diner Sessions

Eight sessions were held during Spring 2009 and 2010 at the two partner middle schools. Informed consent was obtained from parents and assent obtained from students. Parent/student dyads or triads were arbitrarily assigned to tables with a facilitator from the MLS and a researcher. The maximum number of participants per table was ten and the minimum was six, with at least two parent/student groups represented at each table along with a researcher and a facilitator. Each table was permitted to choose one of the two areas of genome research for discussion, but participants were encouraged to switch topics if desired or to discuss both if time permitted. To encourage student/parent engagement, the format was purposely designed to be interactive rather than didactic. The facilitator's role was to guide participants through the program materials, interjecting questions and proposing ideas to consider in order to stimulate group discussion. The amount of discussion was not a measured factor. Allotted time for discussion was between 60 to 75 minutes.

Survey Instruments

To assess the impact of program participation, we developed separate parent/guardian and student surveys to be administered before and after the Genome Diner program, comprised of the following sections:

Demographics—Basic demographic and background information (pre-Diner only).

Knowledge of Genetics—Eight true/false questions about genetics were adapted from previous studies assessing public knowledge of genetics (Calsbeek, Morren, Bensing, & Rijken, 2007; Jallinoja & Aro, 2000). Questions focused on scientific definitions, inheritance and practical application of genetics: 1) You can see a gene just by looking at it with your eyes; 2) A gene is a piece of DNA; 3) Healthy parents can have a child with an inherited disease; 4) If you have a genetic risk for a certain disease, there is no way to avoid getting that disease; 5) Different body parts have different genes; 6) A gene is a disease; 7) Most diseases are completely caused by things in the environment; and 8) A person's DNA can be used to specifically identify them (pre- and post-Diner).

Research Literacy—Three multiple choice items and one open-ended item assessed participants' comprehension of a short narrative regarding genetic research findings. Items examined respondents' abilities to discern the take-home message and practical implications of the research.

Attitudes about Genetics Research—To assess public attitudes towards genetics research and researchers, parents and students were asked to rate their agreement with 19 statements using a visual analog scale (VAS) with anchors for strongly disagree (0) and strongly agree (10) (see Table 2 for list of statements). Ten of the questions were adapted from published studies (noted in Table 2). An additional nine questions were developed by the research team based on a literature review and discussion with researchers and were not validated. Respondents were asked to make a mark on a line between these anchors to indicate their level of agreement. Examination of factor analysis results for attitude items revealed a three factor solution, indicated both by eigen values and the scree plot. After oblique rotation, items with factor loadings of above .35 were retained on each subscale. The majority of the attitude items loaded cleanly onto one of the three subscales; two items did not have a strong loading on any of the factors and were deleted. Answers within each subscale were averaged, after reverse coding where necessary. A content analysis of the subscale items suggested that factors represented the following attitude constructs:

1. **Understanding and Positive Feelings:** this subscale contains six items that assess public interest in and support of genetics research, including their beliefs that genetics research can benefit society. These items have acceptable internal consistency, as indicated by a calculated Cronbach's alpha of 0.70.
2. **Trust:** this subscale contains seven items that assess public trust of researchers and willingness to participate in genetics research (Cronbach's $\alpha = 0.60$).
3. **Worry:** this subscale contains four items that assess public worry about genetics research and the possible implications of genetics findings (Cronbach's $\alpha = 0.65$).

Internal consistency is below the acceptable standard for both the Trust and Worry subscales, which calls into question the robustness of measurement for the underlying constructs. However, we believe that these constructs still have value in providing a broad view of attitude change over time. Given the low alpha values, attitude change was also analyzed at the item level.

We developed a number of additional items to include in the pre/post-Diner surveys to gather data on variables hypothesized to influence responses to genetics knowledge and attitude questions. These questions were also assessed for accuracy and comprehension in our pilot session. The program satisfaction questions were based on questions used by the MLS to evaluate their community programs.

Exposure to Genetics—Eight open-ended, multiple choice, and VAS items assessed interest in and exposure to genetics topics in the media and the community.

Confidence—Two VAS items assessed respondents' confidence in their ability to find and understand information on genetics research.

Program Satisfaction—Program satisfaction was assessed using six VAS items and two open-ended items (post-Diner). These were developed based on similar program assessments used by the MLS.

Survey Analysis

Participants completing both the pre- and post-Diner surveys were included in analyses. Descriptive statistical analysis was conducted to examine participant demographics and baseline knowledge and attitudes. Change over time, from baseline to post-Diner, was assessed using paired t-tests for continuous VAS items (e.g., attitudes) and for subscales. Chi square tests assessed change on dichotomous items. To examine predictors of participant responses and assess differences between parent and student responses on knowledge and attitudes pre and post-Diner, general linear models with Tukey post-hoc comparisons among groups were run. Differences in survey responses between tables or Diner sessions were not examined. Two-tailed tests are reported for all analyses, using a Type I error level of 0.05.

Results

Participant Characteristics

A total of 76 students, 83 parents/guardians and 40 genome science researchers participated in one of eight Genome Diner sessions, representing less than 10% of the targeted middle school populations. All participants completed both a pre- and post-assessment, administered immediately before and after Genome Diner sessions. The majority (71%) of students were 7th graders. The parent/guardian population was comprised of 53% African-American and 43% White; 80.8% had a Bachelor's or graduate degree (Table 1). Sixty-two percent reported an annual household income of more than \$80,000. As compared with the school population, the racial composition of this sample over represents White students and under represents Latino students, but represents an accurate proportion of African-American students. The income level of the sample is much higher than that of the student body as a whole: 52% of the students at participating schools are provided with subsidized lunch based on low family income (under roughly \$40,000/year for a family of four). Parents' reported education level in the pre-Diner survey demonstrated a higher than typical education level compared to county statistics (an estimated 44% of Durham County adults have a Bachelor's or graduate degree; City of Durham and Durham County, 2011). Data on aggregate parents' education were not available at the school level, but study participants were likely more educated than the average parent from this school district.

Knowledge of Genetics

Genetic knowledge was assessed pre-Diner and post-Diner for students and parents/guardians. Pre-Diner, parents averaged 88.3% correct and students averaged 78.5% correct. No statistically significant change in knowledge was noted after participation in the Genome Diner program, with parents averaging 86.9% correct and students 77.8% correct. For parents, a general linear model with parent sex, race, education, age, and income included as predictors demonstrated that only race [$F(1,71) = 5.5, p = .02$] was significantly associated with overall knowledge score; African American parents averaged 84% correct versus 93% for respondents of other races. No factors were found to be associated with student knowledge scores. Furthermore, student knowledge scores were not predicted by parents' education.

Research Literacy

When asked how much they had heard or read specifically about genetics research prior to participating in Genome Diner, both parents and students had comparably high VAS scores (parent $M = 4.3$, student $M = 5.5$, where 0 = not at all and 10 = a lot). In the pre-Diner survey, parents and students were asked to read the following hypothetical news report about a genomic discovery and answer a set of questions based on the report. A slightly

different version of the news report was used in the post-Diner survey to limit recall of answers due to the rapid test/re-test and encourage careful consideration of the responses given their new knowledge.

“There is a story on the morning news about researchers from Duke who have identified a gene for heart disease. The study looked at the genes of 500 patients at the Durham Veterans Affairs Hospital. The reporter says that one version of the identified gene (“version Y”) led to a 50% increase in heart disease risk. In a short interview, the researchers say they believe this could be a major breakthrough for doctors and their patients.”

We asked participants what it meant to have “version Y” of the gene for heart disease with the following choices:

- a) You may have heart disease right now, but not know it;
- b) You will almost certainly get heart disease in the future;
- c) You may be more likely to get heart disease compared to others;
- d) You are more likely to get heart disease versus another health condition;
- e) There is not enough information to tell.

Pre-Diner, 72.0% of parents answered correctly that having version Y of the gene meant that they may be more likely to get heart disease compared to others. Post-Diner, significantly more parents (90.7%) answered the question correctly [$\chi^2(1, n=75) = 19.9, p < .0001$]. Students showed no significant change on this knowledge item pre- to post-test: 74% answered the question correctly at pretest versus 77% at posttest [$\chi^2(1, n=69) = 3.4, p = .07$].

We also asked participants about their general interest in this story if they had heard it on the news. To assess interest and possible underlying reasons, participants were asked to indicate whether they would “listen” or “ignore” the story if they heard it on the news, providing three potential reasons for each (for a total of six answer choices: I know/I do not know someone with heart disease, I believe/I don't believe in the importance of genes in heart disease, I am/I am not interested in research). Responses were dichotomized into listen/not listen for analysis. Overall, pre-Diner, 93.2% of parents and 69.1% of students indicated they would listen to the report. Post-Diner, the number significantly increased in both groups — 95.9% (Fisher's Exact Test, $p = .01$) of parents and 85.3% [$\chi^2(1, n=68) = 13.3, p = .0003$] of students indicated they would listen to the report. Pre-Diner, the most prevalent reason indicated by parents and students who would listen to the report was that they believed “genetics plays a big role in heart disease,” whereas their most prevalent reason for ignoring the story was “disinterest in research.”

Attitudes about Genetics Research

Parents and students indicated a high level of interest in genetic research prior to the Diner session, which significantly increased post-Diner (see Table 2). In addition, parent and student interest in participating in genetic research increased significantly. Students felt more confident about the safety of participating in genetics research post-Diner, with scores increasing from $M = 5.6$ to 6.2 (no significant change for parents, $M = 6.6$ to 6.9).

Participation in Genome Diner did not significantly influence the high opinions of either group about whether they considered genetic testing for early detection of disease to be a “good idea” (parents $M = 8.4$ to 8.2 ; M students 8.2 to 8.0). When asked whether they believed that genetic research could lead to better health care, scores were also high but

neither parents nor students had a significant difference in opinion post-Diner ($M_{\text{parents}} = 8.5$ to 8.4 ; $M_{\text{students}} = 7.9$ to 7.8).

Although students showed an increase on the Understanding and Positive Feelings subscale post-Diner, they also indicated significantly more worry about how findings from genetic research could change their lives ($M = 4.9$ to 5.8 ; see Table 2). Students showed an increase in their disagreement with the statement “genetics research does not affect me” post-Diner ($M = 3.8$ to 3.1), indicating that they became more aware of the implications of genetics research in their own lives. Consistent with this awareness, students were more worried that genetic research could lead to eugenics post-Diner ($M = 4.8$ to 5.7).

Parents agreed strongly with the items on the Understanding and Positive Feelings subscale ($M = 8.2$), moderately with items on the Trust subscale ($M = 6.4$), and were divided on the Worry items ($M = 5.1$), but overall none of these subscale scores changed following Diner participation. Parents reported a strong awareness that genetics research affects their lives both pre- and post-Diner ($M = 7.7$ pre-Diner and post-Diner), as exemplified by their greater awareness (as compared to students) that genetics research could lead to eugenics ($M = 6.4$ pre-Diner and 6.1 post-Diner).

Participant demographics predicted some of the baseline attitudes and changes in attitudes post-Diner. Given the multiple significance tests conducted, the subgroup analyses are tentative and meant only for hypothesis-generation purposes. Parents who self-identified as African-American had a significantly higher increase in interest post-Diner (average increase = 0.7) compared to parents who did not self-identify as African-American (average increase = 0.1) [$F(1,67) = 5.1, p = .03$]. Students who self-identified as African-American had a lower pre-Diner rating of perceived researcher honesty ($M_{\text{pre-Diner}} = 5.8$) compared to those who did not self-identify as African-American ($M_{\text{pre-Diner}} = 7.0$) [$F(1,73) = 4.4, p = .04$]. This gap narrowed post-Diner ($M_{\text{post-Diner}} = 6.3$ and 6.9 , respectively), but the change was nonsignificant. Similarly, African-American students had lower pre-Diner ratings of the benefits of genetic research for future health care [$M_{\text{pre-Diner}} = 7.4$ vs. 8.5 ; $F(1,72) = 5.0, p = .03$], with little change post-Diner ($M_{\text{post-Diner}} = 7.4$ vs. 8.2).

Post-Diner, parental age was significantly associated with changes in concerns about uncontrolled use of their genetic information by researchers [$F(1,65) = 6.2, p = .02$]. This linear effect suggests that as parental age increased, participation in the Genome Diner was more likely to reduce their trust regarding use of genetic information. In fact, on average, parents under the age of 39 actually became *less* concerned about use of genetic information following Genome Diner participation, whereas parents 40 and older became increasingly more concerned following participation.

Confidence

Participation in Genome Diner significantly influenced parents' and students' level of confidence in being able to find information about genome research (parents $M = 6.9$ to 7.3 ; $M_{\text{students}} 6.1$ to 6.9). Similarly, their confidence in being able to understand information about genome research once they found it significantly increased (parents $M = 5.9$ to 6.8 ; $M_{\text{students}} 6.1$ to 7.3), and is consistent with actual improvements in their research literacy (i.e., ability to accurately interpret a fictitious genomics news story).

Program Satisfaction

Overall, both parents and students were extremely satisfied with the Genome Diner program (parent $M = 9.2$, student $M = 8.9$) and enjoyed the opportunity to talk with genetics researchers (parent $M = 9.0$, student $M = 8.5$). Both groups strongly disagreed with the statement that they did not learn anything new from the experience (parent $M = 1.6$, student

$M = 1.7$) and strongly agreed that Genome Diner was beneficial or useful to them (parent $M = 8.6$, student $M = 8.5$). Both groups agreed that participating in Genome Diner would positively affect how much they noticed or thought about genetics and genetic research (parent $M = 8.3$, student $M = 7.9$).

Discussion

Given the rapid pace of discovery in genetics and genome sciences and development of applications affecting everything from food to health to the environment, the public is increasingly exposed to daily news reports of these advancements. However, beyond the media exposure, we believe it is important that the public have opportunities to engage with researchers to gain a better understanding of genetic concepts, rationale and/or significance of the research and related issues, and to clarify any media misrepresentations or misinterpretation. Likewise, given the unmet recruitment needs for clinical trials (Califf et al., 2012; Ford et al., 2008), it is increasingly important for genetic researchers to become aware of public perceptions and potential concerns about their work so that they may adequately respond to these concerns through their recruitment materials and strategies. Therefore, we developed a community engagement program called *Genome Diner*, bringing together members of the community (parents, students, and museum staff) and genome science researchers. In our pilot study, we demonstrated that attitudes about and interest in genetics/genomics research and researchers improved for student and parent participants. The impact on basic factual knowledge was not significant, likely due to the high genetic knowledge scores at baseline. However, participation in the program resulted in improved ability to accurately interpret a news story on genetic findings, indicating that parents and students were more able to accurately apply their knowledge post-Diner. Likewise, parents and students reported more confidence in their ability to find and interpret genetics research following Genome Diner participation.

The lack of impact of the program on participant attitudes toward genetic research is likely attributed to our study sample's already favorable attitudes. However, both parent and student interest in participating in genetic research increased significantly. Along with greater interest in research, participation in Genome Diner also increased students' worry about how findings of genetics research could affect their lives, perhaps due to greater awareness of potential harms that may come from new knowledge of genetic disease risks or applications of findings to one population. Whereas parents may have had greater awareness of historical harms of genetics or biomedical research in general, these potential harms may have been new to students. Others have also reported that greater knowledge can lead to both positive attitudes and skepticism/concern about genetic testing (Jallinoja & Aro, 2000). Thus, educational activities or materials about genetics and genomics research need to adequately address the potential risks and actions to be taken to prevent or mitigate these risks to address prospective participant concerns.

We detected some sub-group differences with respect to attitudes and interest. For example, African-American students were more likely to indicate lower perceived researcher honesty and potential benefits of genetics research both pre- and post-Diner. We hypothesize that lower perceived researcher honesty may be due to more limited contact with the research community and general mistrust of the medical establishment, whereas lower perceived benefits of genetics research specifically may be attributed to lack of awareness of the implications of genetic research. Given the historical disparity in research and health care benefits for African-American individuals, particularly in this geographic region (Bussey-Jones et al., 2010), this suggests an increased need for transparency and relationship building between researchers and community members. Lower trust of researchers has been associated with lower levels of research participation amongst members of minority groups

(Braunstein, et al., 2008). Likewise, the use of clinical genetic testing has been reported to be lower in some minority groups (Armstrong, Micco, Carney, Stopfer, & Putt, 2005; Lerman et al, 1999). Thus, facilitating greater interactions between the research community and minority communities may be even more critical to promote trust, understanding and participation in research. Public trust in both the science and the source is a primary factor in attitudes towards genetic technologies (Cunningham-Burley, 2006; Gottweis, 2002; House of Lords Select Committee on Science and Technology, 2000). Indeed, African-American parents were more likely to show significantly greater interest in genetics research post-Diner, supporting the value of researcher-community interaction and engagement.

Researchers can influence the public's understanding and attitudes towards research and in this program, genome science research specifically. Both parents and students indicated that they enjoyed the opportunity to talk with genetics researchers and considered their participation in the program to be beneficial or useful. For many students, it was likely their first opportunity to directly engage with scientists and other researchers and learn first-hand about how scientific research is performed and researchers' excitement associated with the process of discovery (Freedman, 1997). Furthermore, engaging students in science programs at universities has been shown to increase student's long-term engagement in science by providing a more accurate representation of science (Markowitz, 2004). As reported in our previous publication on the Genome Diner program (O'Daniel et al., 2012), the positive experience of parents and students was shared by genome researchers as well, who also benefitted from participation in Genome Diner. In particular, researchers' positive changes in perception about the (adult) public's level of understanding of genetics and beliefs about relevance of research illustrate the mutual benefit gained through direct interaction between researchers and the public (O'Daniel et al., 2012).

Study Limitations

Some limitations should be noted in this pilot study. As discussed in our prior publication (O'Daniel et al., 2012), due to the high number of statistical tests performed, some of the findings may be spurious. In addition, low internal consistency on attitude subscales limits interpretability of overarching constructs. Supplemental item-level analyses are useful to clarify specific areas of change over time, but add to the total number of statistical tests (thereby increasing likelihood of spurious results). Findings should be considered exploratory, particularly with regard to subgroup differences.

The small and localized study population and modest response rate (i.e., less than 10% of the targeted middle school population) may limit the generalizability of the data. Although we did not collect data regarding parents' occupations, given the high concentration of biomedical research institutions in the area (most of which would require a college education or higher), it is possible that a sizable proportion worked in areas related to health or biomedical research. As a result, students of parents employed in the health or biomedical research sector may have higher scientific knowledge and developed favorable attitudes toward biomedical research. Furthermore, this high level of scientific knowledge may have limited our ability to assess the impact of the program on baseline knowledge and attitudes (i.e., ceiling effect).

Other factors that could not be controlled in the individual table discussion could also have impacted survey responses, including familiarity with other student/parent participants, comfort sharing opinions with other participants, and background field of study or occupation of parents. The presence of the genetic researchers may have influenced parent and student survey responses to respond favorably, unrelated to the knowledge gained from participating in the program.

Educational Implications and Research Recommendations

While our findings may have limited generalizability, the demonstrated impact of the program on attitudes suggests that it may also be effective in groups of varying educational status. We recognize that not all schools will have access to genome science researchers or the budget to support this type of activity as described here. The American Society of Human Genetics maintains a list of genetics researchers and educators interested in visiting local schools (http://www.ashg.org/education/k12_geon_find.shtml). If researchers are not accessible, undergraduate or graduate students majoring in science from local colleges may fill the role of researchers in this activity, and in turn, provide students of higher learning valuable experience in community engagement. To accommodate busy school schedules, it may be possible to schedule this activity during student lunch breaks or convened without food, though piloting the activity in different settings may be needed to assess the impact of these changes on the effectiveness of the activity.

The engagement format of the Genome Diner program presents a novel approach to foster an interactive discussion between the public and researchers. As a result, participants gained valuable, perspective-changing insight, promoting their attitudes and interest about genome sciences research and applications. Although focused on genomics, the program format may work well with other science or health topics. To assess the effectiveness of this approach on enhancing knowledge, future studies should involve other communities with greater diversity with respect to participant background and parent education status, different case examples in genome sciences and applications, and comparison groups to control for the effects of repeated assessment over a short time period. In addition, maintenance of effects over time should be examined, along with the benefits of “booster sessions” to promote maintenance or strengthening of positive change.

Acknowledgments

This work was supported by the NIH Partners in Research program (NIH R03HG005040).

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Table 1

Characteristics of student/parent participants.

| | Parent/Guardian (n = 83) | Student (n = 76) | School Student Body (n = 1404) |
|-----------------------------------|--------------------------|------------------|--------------------------------|
| Male | 32.5% | 58.4% | 52.0% |
| Race/Ethnicity | | | |
| • White | 43.4% | 44.2% | 22.9% |
| • African-American | 53.0% | 50.7% | 53.1% |
| • Asian | 1.2% | 3.9% | 2.6% |
| • Multi/other | 0% | 1.3% | 3.8% |
| • Hispanic | 2.4% | 5.6% | 17.6% |
| Grade (Student) | | | |
| • 6 th grade | -- | 7.8% | 32.4% |
| • 7 th grade | -- | 71.4% | 35.0% |
| • 8 th grade | -- | 19.5% | 32.6% |
| • 9 th grade | -- | 1.3% | -- |
| Education (Parent) | | | |
| • High school degree | 2.4% | -- | NA |
| • Some college/Associate's degree | 16.8% | -- | NA |
| • College degree | 42.2% | -- | NA |
| • Post-graduate degree | 38.6% | -- | NA |
| Household Income | | | |
| • \$40,000 | 13.0% | -- | ≈52% |
| • \$40,001–\$65,000 | 13.0% | -- | NA |
| • \$65,001–\$80,000 | 11.7% | -- | NA |
| • More than \$80,000 | 62.3% | -- | NA |

Table 2

Parent and Student attitudes Pre- and Post-Diner.

| | Respondent | Pre-Diner Mean | Post-Diner Mean | 2-tailed t statistic |
|--|----------------|----------------|-----------------|-----------------------------|
| Understanding and Positive Feelings Subscale | Student | 7.4 | 7.7 | t(74) = 2.1, p = .04 |
| | Parent | 8.2 | 8.3 | t(81) = 0.3, ns |
| The findings from genetic research will help people to live better lives. ¹ | Student | 7.6 | 8 | t(73) = 1.7, ns |
| | Parent | 8.6 | 8.6 | t(81) = 0.9, ns |
| I think genetic testing for the early detection of diseases is a good idea. ² | Student | 8.2 | 8 | t(69) = 1.2, ns |
| | Parent | 8.4 | 8.2 | t(79) = 0.8, ns |
| Genetic research does not affect me. ^{4*} | Student | 3.8 | 3.1 | t(72) = 2.1, p = .04 |
| | Parent | 2.3 | 2.3 | t(78) = 0.4, ns |
| The US government should fund genetic research. ¹ | Student | 6.6 | 7.2 | t(73) = 1.7, ns |
| | Parent | 7.7 | 7.8 | t(79) = 0.7, ns |
| Genetic research could lead to better health care. ¹ | Student | 7.9 | 7.8 | t(73) = 0.6, ns |
| | Parent | 8.5 | 8.4 | t(77) = 0.5, ns |
| Genetic research is interesting. ⁴ | Student | 7.7 | 8.3 | t(74) = 2.1, p = .04 |
| | Parent | 8.5 | 9 | t(79) = 3.5, p = .0007 |
| Trust Subscale | Student | 5.9 | 5.9 | t(74) = 0.0, ns |
| | Parent | 6.3 | 6.3 | t(81) = 0.5, ns |
| There are some things that scientists should just not study when it comes to genetics. ^{4*} | Student | 3.9 | 5.1 | t(69) = 3.4, p = .001 |
| | Parent | 3.7 | 4.5 | t(80) = 2.0, p = .05 |
| I would consider participating in genetic research. ⁴ | Student | 5.2 | 6.3 | t(72) = 3.1, p = .003 |
| | Parent | 6.6 | 7.3 | t(78) = 2.6, p = .01 |
| Participating in genetic research is safe. ⁴ | Student | 5.6 | 6.2 | t(72) = 2.4, p = .02 |
| | Parent | 6.6 | 6.9 | t(78) = 1.2, ns |
| I have no control over what a researcher could do with my genetic information. ^{4*} | Student | 3.6 | 3.8 | t(72) = 0.5, ns |
| | Parent | 4.4 | 4 | t(77) = 1.1, ns |
| Researchers are completely honest with their study participants. ⁴ | Student | 6.4 | 6.6 | t(74) = 0.7, ns |
| | Parent | 5.9 | 6.2 | t(79) = 1.2, ns |
| Researchers don't like interacting with their study participants. ^{4*} | Student | 3.4 | 3.4 | t(72) = 0.1, ns |
| | Parent | 3.5 | 3.6 | t(77) = 0.6, ns |
| Researchers want to know more than they need to know. ^{3*} | Student | 4.8 | 5.3 | t(72) = 1.9, ns |
| | Parent | 4.1 | 4 | t(79) = 0.4, ns |
| Worry Subscale | Student | 4.1 | 4.7 | t(73) = 2.6, p = .01 |
| | Parent | 4.5 | 4.6 | t(81) = 0.5, ns |
| I worry about how the findings from genetic research could change my life. ² | Student | 4.9 | 5.8 | t(73) = 2.6, p = .01 |
| | Parent | 4 | 4.6 | t(81) = 2.0, p = .05 |
| I worry about the consequences of genetic testing for being able to take out insurance. ² | Student | 4.7 | 4.9 | t(69) = 0.5, ns |
| | Parent | 6.3 | 5.6 | t(80) = 1.7, ns |

| | Respondent | Pre-Diner Mean | Post-Diner Mean | 2-tailed t statistic |
|--|------------|----------------|-----------------|----------------------|
| I worry about how the findings from genetic research could change my children's lives. ² | Student | -- | -- | -- |
| | Parent | 5.2 | 5.3 | t(81) = 0.3, ns |
| The idea of genetic research frightens me. ² | Student | 2.7 | 3.2 | t(73) = 1.9, ns |
| | Parent | 2.5 | 2.7 | t(78) = 0.9, ns |
| Not included in a subscale | | | | |
| Genetic research could lead to eugenics (using genetic information to discriminate against certain people). ¹ | Student | 4.8 | 5.7 | t(70) = 2.0, p = .05 |
| | Parent | 6.4 | 6.1 | t(79) = 1.1, ns |
| A researcher's main goal is to discover things that could improve health and well-being. ⁴ | Student | 7 | 7.2 | t(72) = 1.0, ns |
| | Parent | 7.2 | 7.6 | t(78) = 1.7, ns |

¹ Adapted from Jallinoja P, Aro AR. 2000 Does knowledge make a difference? The association between knowledge about genes and attitudes toward gene tests. *J Health Commun.* Jan-Mar;5(1):29-39.

² Adapted from Morren, Rijken, Baanders, Bensing 2007 Perceived genetic knowledge, attitudes towards genetic testing and the relationship between these among patients with a chronic disease. *Patient Education and Counseling* 65:197-204.

³ Adapted from Henderson GE, Garrett J, Bussey-Jones J, Moloney ME, Blumenthal C, Corbie-Smith G. Great expectations: Views of genetic research participants regarding current and future genetic studies. *Genetics in Medicine.* 2008; 10(3): 193-200.

⁴ Newly developed questions.

* Starred items are presented here with their raw means pre- and post-Diner. Scores for these items were reverse-coded (by subtracting raw score from 10) prior to inclusion in the subscale mean.