

Genetics Education

Innovations in Teaching and Learning Genetics

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Successful Implementation of Genetic Education for Native Americans Workshops at National Conferences

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ABSTRACT

Genetic Education for Native Americans (GENA) was a National Human Genome Research Institute (NHGRI)/Ethical, Legal, and Social Implications (ELSI)-funded educational intervention designed to provide a unique genetics education program for Native American college and university students. A curriculum was developed and implemented in workshops in geographically diverse settings throughout the United States, primarily in conjunction with regional and national scientific conferences that include substantial numbers of Native American attendees. The original curriculum includes 24 objectives and has been offered in two formats, as a 16-hr "comprehensive" program and in briefer workshops (referred to as "customized" hereafter) that are designed to include objectives for selected audiences. Both formats teach sufficient genetics to allow discussion and understanding of the ELSI and cultural issues related to genetics science. This article describes the evaluation findings from our implementation of both formats of the GENA curriculum.

GENETIC Education for Native Americans (GENA; NHGRI R25 HG01866) was a 4-year project funded in 1998 by the Ethical, Legal, and Social Implications (ELSI) research program of the National Human Genome Research Institute (NHGRI) at the National Institutes of Health (NIH). The goal of GENA was to provide culturally sensitive genetics instruction to Native Americans to increase their awareness of genetics as a topic. This would include an understanding of genetics research and testing and careers in the field of genetics. As an overall goal, it was designed to help improve informed decision making about genetics and genetics research in Native American communities. Genetics has been a controversial issue among Native Americans during the past 20 years. The controversy was initially due to the lack of a sufficient informed consent process for the International Human Genome Diversity Project. Subsequent issues include, but are not limited to genetics research and tribal sovereignty, patenting of Native

intellectual knowledge, storage of genetic specimens, and sharing of genetic specimens without tribal notification (BURHANSSTIPANOV *et al.* 2001a,b, 2002).

The primary target population for GENA instruction was Native American college and university students. The decision to focus on students was based on recommendations from intertribal leaders on how to effectively integrate genetics education into Native American communities (BURHANSSTIPANOV *et al.* 2001a,b). The primary product from GENA was a culturally relevant and acceptable curriculum for teaching genetics to Native Americans. Development and implementation of the curriculum has been described previously (BURHANSSTIPANOV *et al.* 2001b, 2002). The original curriculum included 24 objectives and recommended specific teaching methods. The teaching methods were developed to emphasize interactive learning, hands-on participation of students, and extensive interactions with faculty. The GENA curriculum is taught by teams that usually include two members: at least one with substantial expertise in genetics and the other with cultural and scientific training. GENA is provided in workshops that are carried out in conjunction with scientific and cultural meetings that include large numbers of Native American

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TABLE 1
Original 24 GENA objectives, plus 5 new objectives

Objective 1	Examine selected Native American cultural/political issues (10 min)
Objective 2	Review basic principles of cell biology and genetics; <i>e.g.</i> , cell structure, location of DNA and RNA, protein expression, transcription, and translation (45 min)
Objective 3	Examine examples of ethical, legal, and social implications that humanity faces in genomic research (50 min)
Objective 4	Examine special concerns of indigenous people (40 min)
Objective 5	Identify the types of genetics research that are of interest/priority to Native communities (45 min)
Objective 6	Identify current scientific, cultural, ethical, social, and legal resources to clarify the patenting process (45 min)
Objective 7	Review genetics concepts (45 min)
Objective 8	Understand classical patterns of inheritance and cultural traditions related to these patterns (60 min)
Objective 9	Describe genetic testing (30 min)
Objective 10	Examine selected Native American cultural and ethical issues related to genetic testing (60 min)
Objective 11	Identify common misconceptions related to genetic testing (30 min)
Objective 12	Analyze the benefits and risks of genetic testing (30 min)
Objective 13	Determine factors that should be considered when deciding whether or not to take part in genetic testing (10 min)
Objective 14	Examine current genetics-research-related issues and discoveries and their potential impact for Native communities (60 min)
Objective 15	Understand the NIH Human Genome Project (50 min)
Objective 16	Describe benefits and drawbacks to pharmacogenetics (60 min)
Objective 17	Examine current botanical genomic research (30 min)
Objective 18	Examine Native American cultural issues that are related to contemporary genetics research (30 min)
Objective 19	Analyze the tribal research approval process relevant to genetics research (60 min)
Objective 20	Describe guidelines and ways that future genetics research could be conducted to be culturally respectful and allow for informed decision making by Indian communities (30 min)
Objective 21	Recognize the roles of the health care team involved with cancer genetic counseling (20 min)
Objective 22	Describe culturally acceptable methods of collecting a family history (45 min)
Objective 23	Examine selected ethical, legal, and cultural issues of genetic counseling (30 min)
Objective 24	Describe how other Native and Latino/Chicano/Hispanic scientists have addressed challenges in their (1) education, (2) careers, and (3) family life (video)
Objective 25 ^a	Identify advantages and limitations of selected models for human diseases (60 min)
Objective 26 ^a	Describe parts of a cell (45 min)
Objective 27 ^a	Describe components of the NHGRI HapMap Project (120 min)
Objective 28 ^a	Describe potential benefits and drawbacks regarding participation of tribal nations in the HapMap Project (40 min)
Objective 29 ^a	Distinguish between facts and myths of genetics issues of concern to Natives (60 min)

^a New objectives.

students. The workshops are provided in two formats: as “customized” 3- to 5-hr events or as “comprehensive” 16-hr events. The customized workshops are designed to provide instruction that is limited to specific GENA objectives. The objectives are selected to tailor the workshop to the needs of the audience. The comprehensive 16-hr events, on the other hand, include instruction for all 24 of the original GENA objectives. Table 1 shows the original 24 objectives that are included in GENA, as well as 5 objectives added since the grant officially ended.

MATERIALS AND METHODS

The GENA curriculum: Curriculum development for GENA included focus groups, extensive review of available curricula, and collection of information about genetics career opportunities (BURHANSSTIPANOV *et al.* 2001a,b, 2002; ROMERO *et al.* 2001). Special attention was focused on genetics research of current interest to identify key concepts, instructional methods, and potentially troublesome or sensitive issues for Native

Americans. The curriculum development process for GENA strongly reinforced the need to focus on cultural perspectives related to genetics. This approach was needed because for many Native Americans, cultural norms and values have an extraordinary level of influence on how information is perceived. For example, many tribal nations have cultural beliefs that prohibit the storage of genetic specimens as cell lines or supplemental research that is not designated in the original informed consent process.

GENA implementation: GENA workshops were implemented during national meetings, frequently as preconference workshops. The customized workshops were typically 3–5 hr on one day and the 16-hr comprehensive workshops provided 16 hr of instruction across 2 days. Selection of national scientific meetings for GENA presentations was based on the expected number of Native American students who would be attending. Meetings that were likely to include sufficient numbers of students from other populations who are underrepresented in the sciences were also of high priority. Table 2 shows the meetings and participation in GENA from 2000 to 2002.

GENA evaluation: Evaluation of GENA was concentrated on assessing the experience of the participants during the workshops. The GENA workshop evaluations were designed to capture changes in knowledge occurring during GENA

TABLE 2
GENA workshop implementation, 2000–2002

Date	Meeting	City	No. of participants	Native participants	Objectives	Hours
February 2000	7th Biennial Symposium, ICC	Washington, DC	75	15	5	5
March 2000	Indigenous People and Environment	Denver	53	53	3	2
March 2000	Wellness and Women	San Diego	15	15	4	3
August 2000	Association of American Indian Physicians	Tucson, AZ	12	12	4	3
October 2000	SACNAS ^a	Atlanta	73	11	23	16
March 2001	Wellness and Women	San Diego	25	23	3	3
August 2001	Association of American Indian Physicians	Albuquerque, NM	50	45	3	3
September 2001	SACNAS ^a	Phoenix, AZ	20	8	16	16
February 2002	8th Biennial Symposium on Cancer, Medically Underserved and Minorities, ICC	Washington, DC	30	8	4	5
February 2002	Native Women's Wellness Conference	Reno, NV	17	16	3	3
May 2002	Cancer, Culture, and Literacy	Clearwater, FL	25	5	2	1.5
July 2002	Association for American Indian Physicians	Anchorage, AK	15	7	3	3
Total			410	218		

^aComprehensive 16-hr workshops; all others are customized workshops.

workshops (*i.e.*, specific to the objectives presented) and to capture student perceptions of faculty performance. The latter was carried out using a summary evaluation instrument designed to collect information on appropriateness of teaching methods and the strengths and limitations of the particular workshop setting. To capture information on the application of the information after the workshops, additional assessment was carried out with a random sample of participants ~3 months later (see *Three-month postworkshop evaluation* in this section). This follow-up assessment collected information on recall of the workshop and any additional education in genetics planned or obtained and asked if the participant had recommended that others, particularly students, attend future workshops.

Pre- and post-test evaluations: Customized 3- to 5-hr workshops included administration of four pre- and four posteducation knowledge evaluation items (Table 3). In comparison, the 16-hr workshops included a total of 16 pre- and posteducation knowledge items administered at ~4-hr intervals throughout the workshop. Each knowledge item was developed to assess a specific workshop objective and is an open-ended question. Thus, the techniques used for both workshop formats were the same and evaluations were conducted at the same time interval (*i.e.*, four items approximately every 3–4 hr). Knowledge item scores ranged from 0 to 2. (A score of 0 was assigned for no response, 1 for an incorrect response, and 2 for a correct response.)

Three-month postworkshop evaluation: About 3 months after the workshop was held, ~10% of the attendees were sent a survey to assess actions taken, such as recommending the workshop to fellow students or colleagues. The survey was distributed by e-mail and asked the following: (1) whether attendees recalled the workshop; (2) to evaluate in terms of content, presentation methods, and cultural appropriateness; and (3) whether the workshop had been recommended to others.

RESULTS

GENA workshops were conducted at national meetings of organizations such as the Society for the Advancement of Chicanos and Native Americans in Science (SACNAS), the Association of American Indian Physicians, the biennial Symposium of the Intercultural Cancer Council (ICC), and National Native Wellness and Women Conference. The numbers of participants varied from workshop to workshop, and ranged from 12 to 75. Workshop participants came from 32 states, American Samoa, Puerto Rico, and Canada and included members of 27 Native American tribes. Over half (54%) were Native American. Of the non-Native American participants, 21%

TABLE 3
Examples of pre- and postworkshop knowledge items

What is a historical example of classical inheritance in everyday life?
Where would you find a centromere?
How would you refer to the short arm of chromosome 3?
What genetics research study is currently going on with the support/partnership of at least one Native American tribe?
What is one example of how a scientist should work with a local Native American community to demonstrate respect?
What type(s) of tribal approval are required for a research project to be conducted in a Native American community?
What is one of the issues concerning the use of "cell lines" among Native American communities?
What is one concern among Native communities regarding patenting?

TABLE 4
Responses to student evaluation items

1. How well did this workshop assist you in understanding ELSI issues in Indian communities?	Very well (57%)	Well (43%)	Not well (0%)	Not well at all (0%)
2. How high would you rank the need for this workshop in Indian communities?	Extreme need (100%)	Some need (0%)	Little need (0%)	No need (0%)
3. How high would you rank the need for this workshop in school and college curricula?	Extreme need (86%)	Some need (14%)	Little need (0%)	No need (0%)
4. Please indicate how appropriate you feel the level of this workshop would be for Indian communities.	Extremely appropriate (57%)	Very appropriate (36%)	Somewhat appropriate (7%)	Not appropriate (0%)

were Hispanic, 2% were African American, 5% were Pacific Islander, and 18% were Caucasian. About one-quarter of the participants (23%) were undergraduate students, 30% were graduate students (including medical students), and 47% were health professionals or administrators. Of the undergraduate and graduate students, over 80% were science majors.

Knowledge assessment: The pretest scores for 3- to 5-hr workshops ranged from 0.3 to 4.8 and averaged 2.16. For the post-tests, the mean was 4.78 and scores ranged from a low of 3.0 to a high of 7.3. For customized workshops, there was a 55% increase in mean score from pretest to post-test ($P < 0.05$). For the comprehensive 16-hr workshops, the mean pretest score was 19.9 compared with a mean post-test score of 27.5, a 38% increase ($P < 0.05$). Thus, both formats were effective ways to increase participants' knowledge.

Student evaluations: Student evaluations were conducted near the close of each workshop. As described previously, the evaluation focused on the content provided by the workshop. Four key questions were included in the evaluation. Table 4 shows the questions and summarizes the responses obtained from the student evaluations, summarized over all of the workshops.

As Table 4 shows, most participants rated the workshops very positively on most items. Over half of the respondents judged the workshop to be valuable in facilitating their understanding of ELSI issues in Native American communities. All of the respondents felt that the workshop was needed in Native American communities (*i.e.*, 57% thought the level at which this workshop was taught was "extremely appropriate," 36% ranked it "very appropriate," and 7% felt it was "somewhat appropriate").

Three-month postworkshop evaluations: Responses were received from ~80% of those included in the 3-month postworkshop surveys. Those who returned the e-mail surveys provided evaluations of the workshops, indicating approval of the presentation methods and cultural appropriateness. Comments on workshop content suggested that additional handout material should be provided for participants who wish to learn about topics in greater depth. Approximately 50% indicated

that the workshop had been recommended to other students or faculty.

DISCUSSION

Results from the GENA evaluation indicate that workshops providing genetics education can be successfully implemented during conferences and that Native American students, and students who are members of other racial/ethnic minority groups, can be reached through this method. The quantitative results from knowledge testing at the workshops revealed that the pretest scores were quite low, but that substantial increases could be observed at the post-test. Taken as a whole, the results strongly suggest that the approach used by GENA has been successful in recruiting participants and increasing their knowledge about genetics.

The two versions of GENA—the comprehensive 16-hr and the customized 3- to 5-hr workshops—produced essentially similar results, but were quite different in several important ways. The 16-hr comprehensive curriculum is demanding to implement for the staff, faculty, and participants. The advantages of the 16-hr curriculum include coverage of more content, provision of more printed materials to participants, and greater opportunity for participants to interact with one another and with workshop faculty. It also allows for more reinforcement of objectives throughout the workshop. The customized workshops are clearly easier to conduct in a conference setting and are less arduous for those involved. The drawback to this approach is that the amount of teaching and learning that can occur is more limited. The results from our evaluation suggest that both the 1- and 2-day workshops are appropriate for providing education about genetics to Native American students and workshop participants. The customized workshop is likely to have broader appeal, however, principally because it does not require as much time and is easily tailored to the needs of the participants.

From a cultural perspective, we found that participants were anxious to learn more about their own culture and how it may be affected by genetics research. Through GENA, the faculty has been able to refer stu-

dents to respected elders from their primary tribal Nation who can provide guidance and instruction. The students who requested cultural mentoring were not limited to those from urban settings; contrary to popular misconception, they included those raised on reservations and in rural settings as well. The integration and presentation of culture, genetics, and ethics through GENA are continually applauded by the students and other workshop participants (ROMERO *et al.* 2001).

Finally, each GENA workshop is followed by a debriefing meeting with faculty and staff to critique the workshop and identify areas that need refinement, new objectives or interactive activities, and new ways to encourage active learner interactions. These debriefings have led to an essential process evaluation that has resulted in a successful and flexible curriculum. As of 2003, GENA objectives are being modified to focus on increasing their acceptability at the community level. Workshop evaluations and debriefing meetings have led to the development, pretesting, and implementation of five new objectives:

GENA objective 25: “models of research”; for example, Why not conduct all genetics research on yeast?

GENA objective 26: What is a cell? (For example, community participants were beginning to understand that chromosomes are where genetic material resides, but still were uncertain that cells are the building blocks of tissues.)

GENA objective 27: What is the HapMap Project and how does it affect Native Americans?

GENA objective 28: What are potential benefits and drawbacks related to the Native American community’s involvement with the HapMap Project?

GENA objective 29: common facts and fallacies related to genetics issues of concern to Native communities.

During the summer of 2003, Native American Cancer Research (NACR) pretested audience response system (ARS) technology with Native community members to determine its usefulness and acceptability for collecting demographic data and more extensive knowledge and attitudinal items and for accurately accumulating data. On the basis of pretests, we currently implement ARS in all workshops. GENA continues to be available for implementation during conferences and is being adapted for community settings. Updates on GENA objectives are included on the NACR website approximately every 6 months (<http://www.NatAmCancer.org>).

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