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MAPPING AND SEQUENCING THE HUMAN GENOME: SCIENCE, ETHICS, AND PUBLIC POLICY

FINAL REPORT

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Final Project Report
Mapping and Sequencing the Human Genome: Science, Ethics, and Public Policy

Development of *Mapping and Sequencing the Human Genome: Science, Ethics, and Public Policy* followed the standard process of curriculum development at the Biological Sciences Curriculum Study (BSCS), the process is described below. The production of this module was a collaborative effort between BSCS and the American Medical Association (AMA). Appendix A contains a copy of the module. Copies of reports sent to the Department of Energy (DOE) during the development process are contained in Appendix B; all reports should be on file at DOE. Appendix B also contains copies of status reports submitted to the BSCS Board of Directors.

1. *First advisory committee meeting.* The advisory committee met for the first time at BSCS headquarters on 14, 15 March 1991 to develop the conceptual framework for the module. On 13 May 1991, we forwarded a summary of the conceptual framework the education committees of the American Society of Human Genetics (ASHG), the National Society of Genetic Counselors (NSGC), and the Council of Regional Networks for Genetic Services (CORN) and to prominent scientists in the genetics and ethics communities for review. We summarized the suggested revisions from these reviewers and made them available to the writers at the writing conference. This summary appears as Appendix C.

2. *First writing conference.* This conference was held 22 July through 2 August 1991, in Colorado Springs. The objective of the conference was to produce preliminary materials for an early 1992 field test that would help determine whether the materials were useful and instructive. The group produced background materials for teachers, annotated teacher activities, and five student activities.

3. *Orientation of field-test teachers.* Following the in-house, physical production of five activities, teacher materials, and evaluation instruments, BSCS staff, six selected field-test teachers, four writers, and a representative of the AMA met at BSCS headquarters on 1 and 2 November 1991 for orientation to the materials. The teachers reviewed the materials and completed each of the instructional activities that they were required to teach during the field test.

4. *Field test.* The official field-test teachers, as well more than 20 supplemental field-test teachers (recommended by Jon Hendrix at Ball State University, Indiana), used the module from December 1991 through February 1992 with 583 students. All teachers were required to complete evaluations of the materials (see Appendix D). Students were required to complete pre- and post-surveys (Appendix E), as well as a final evaluation of the module. The project director visited five field-test classes from 21-28 January 1992 to observe first-hand how the materials were received by the students. In addition to collecting data from the field test, we sent the experimental module and a content evaluation form (Appendix F) to specialists in genetics and ethics throughout the country, including members of the education committees of ASHG, CORN, and NSGC). Copies of the content evaluation results are in Appendix G. Results of the teacher evaluations are contained in Appendix H, and the results of the student evaluations appear in Appendix I. We currently are preparing the results of the student pre- and post-surveys for publication; one such document, recently submitted to the *Journal of Research in Science Teaching*, appears in Appendix J. A listing

of the supported field-test sites and supplemental field-test sites is in Appendix K.

5. *Second advisory committee meeting.* On 20-21 March 1992 the project advisory committee returned to BSCS to review the results of the field test and external reviews and to make recommendations for the final revision of the materials prior to publication. The committee gave high marks to the activities and proposed several revisions, including a complete rewrite of Activity 4 and substantial revisions to (now) Activity 2.

6. *Second field test.* As a result of the recommendations of the advisory committee, the two new activities were field tested by 5 teachers in 10 classrooms. The teachers completed evaluation forms similar to those used in the first field test (Appendix L). Both activities were well received by teachers and students alike.

7. *Production of final materials.* Between April 1992 and 6 August 1992, the BSCS project staff, in collaboration with several of the writers, revised the materials for final production. During this period, we solicited bids for the final printing and mailing and made preparations for the delivery of the materials to the selected printer.

8. *Publication and marketing.* We selected Hirschfeld Press to print the final materials and we delivered the camera-ready module to them on 6 August 1992. On 4 September 1992, the project director visited the printer to examine pages from module.

   The final module consists of 21 pages of background material for teachers on the science and technology of the genome project and on ethics and public policy. The module also contains a section on classroom management, a glossary, and reference section (a total of 29 pages). The last section of the module includes annotated versions of the final four activities for teachers as well as copymasters for the students (a total of 62 pages of teacher information).

   We mailed the module to more than 50,000 high school biology teachers and other educators nationwide free of charge in mid October 1992. The National Science Teachers Association (NSTA) provided the list of teachers and additional copies were delivered to the National Association of Biology Teachers (NABT) in Reston, Virginia, for further distribution. The copies at NABT are available for $4.00 per module to cover shipping and handling. Although we thought the list of teachers was up-to-date, approximately 850 copies (approximately 2 percent) of the module have been returned to BSCS because of closed schools, incorrect school addresses, or because the addressee no longer teaches at that school. We have compiled a list of names and schools for those modules that came back with corrected addresses, and this list will be forwarded to NSTA. Those modules that were returned as undeliverable have been sent to various schools at the recommendation of BSCS staff.

   BSCS staff have conducted several workshops at the annual meetings of NABT, and the principal investigator has used the module in numerous presentations nationwide. In addition, BSCS has given permission for many educators to use the module in teacher enhancement and other activities throughout the country (Appendix M). References to module have appeared in various newsletters, such *Splicer* and *Genesis*. An article about the module appeared in the January 1993 issue of the *American Journal of Human Genetics,* (vol. 52, no. 1, pp. 235-238). A reprint is attached as Appendix N. To date, the module has

been well-received, and BSCS continues to receive requests for the materials. We will continue to exhibit the module in the BSCS booth and future conventions. We also have received requests to adapt the materials for distribution in Japan and Canada.

APPENDIX A

Mapping and Sequencing the Human Genome:

Science, Ethics, and Public Policy

Cycled Separately
Copyright

APPENDIX B

Reports Submitted to the DOE and the

BSCS Board of Directors

Date: 15 September 1992

Mapping and Sequencing the Human Genome: Science, Ethics, and Public Policy

Purpose	BSCS produced and distributed an instructional monograph on the Human Genome Project that is designed for average, first-year students in high school biology.
Budget	$394,193
Funding Agency /Duration	Department of Energy/16 months - 10 March 1991 - 9 July 1993 (extended)
Marketing Activities	Monograph has been distributed to the more than 50,000 high school teachers in the United States free of charge. Other interested educators and scientists will receive copies. Press releases have been distributed to numerous magazines and newsletters.
Audience /Number Reached	More than 50,000 biology teachers, scientists, and educators
Product /Number Sold	N/A
Royalties Received	N/A
Success of the Project	Field test materials were well received and we have received a number of requests for final materials. The module was distributed September 15, 1992 and we anticipate a very favorable reception.
Commentary	Presentations made that addressed the BSCS Human Genome Project: NABT National Convention, Nashville, TX--November 1991, International Congress of Human Genetics, Washington, DC--November 1991, NSF Conference on Biotechnology Education (keynote address), University of Wisconsin, Madison--October 1991, University of Iowa Humanities Symposium, "Genes and Human Self-Knowledge"--April 1992, Workshop on Science, Ethics, and Public Policy-United States Office of Personnel Management, national workshop for senior managers in federal science agencies, Denver--March 1992, Keynote address Colorado/Wyoming Academy of Sciences, United States Air Force Academy--April 1992, NIH and DOE convocation for principal investigators for projects that deal with the ethical, legal, and social implications of the Human Genome Project--September 1992. Lane Conn, San Francisco State University conducted the revised activities with 100 pre-med students. Bill Horton, University of Texas Medical School, Houston, used information from Section II, Ethics & Public Policy with 200 pre-med students. Debbie Collins, Council of Regional Networks for Genetic Services, conducted a workshop for high school biology teachers using revised activities.

Date: 20 May 1992

Mapping and Sequencing the Human Genome: Science, Ethics, and Public Policy

Purpose	BSCS will produce and distribute an instructional monograph on the Human Genome Project that is designed for average, first-year students in high school biology.
Budget	$394,193
Funding Agency /Duration	Department of Energy/16 months - 10 March 1991 - 9 July 1993 (extended)
Marketing Activities	Monograph will be distributed to the more than 50,000 high school teachers in the United States free of charge.
Audience /Number Reached	More than 50,000 biology teachers
Product /Number Sold	N/A
Royalties Received	N/A
Success of the Project	N/A
Commentary	Presentations made that addressed the BSCS Human Genome Project: NABT National Convention, Nashville, TX--November 1991, International Congress of Human Genetics, Washington, DC--November 1991, NSF Conference on Biotechnology Education (keynote address), University of Wisconsin, Madison--October 1991, University of Iowa Humanities Symposium, "Genes and Human Self-Knowledge"--April 1992, Workshop on Science, Ethics, and Public Policy-United States Office of Personnel Management, national workshop for senior managers in federal science agencies, Denver--March 1992, Keynote address Colorado/Wyoming Academy of Sciences, United States Air Force Academy--April 1992. Lane Conn, San Francisco State University will conduct the revised activities with 100 pre-med students. Bill Horton, University of Texas Medical School, Houston, will use information from Section II, Ethics & Public Policy with 200 pre-med students.

1992 Quarterly Report
Mapping and Sequencing the Human Genome: Science, Ethics, and Public Policy

1 January 1992 - 1 March 1992
DOE: $394,193; 16 months

Purpose

BSCS will produce and distribute an instructional monograph on the Human Genome Project that is designed for average, first-year students in high school biology. The monograph, approximately 75 pages long, will include 30 pages of background information for teachers and 5 student-directed inquiry activities for the classroom. More than 50,000 high school teachers in the United States will receive a copy of the monograph free of charge and will have permission to reproduce the materials for classroom use. Additional copies will be distributed through the National Association of Biology Teachers at cost. BSCS is working in conjunction with the American Medical Association; other cooperating organizations include the American Society of Human Genetics (ASHG), the National Society of Genetic Counselors (NSGC), and the Council of Regional Networks for Genetic Services (CORN).

Relevance to BSCS Goals

With this monograph, BSCS has the opportunity to influence public perceptions of genetics and genetic technology, increase the exposure of students and teachers to sound, conceptually based content, and introduce a workable model for teaching ethics and ethical analysis in the biology classroom. BSCS also will increase its visibility among new teachers as an organization that is committed to accurate and current content and inquiry-oriented instruction.

Staffing

Joseph D. McInerney, Principal Investigator
Katherine A. Winternitz, Project Director
Jean Milani, Senior Staff Associate
Jenny Stricker, Staff Associate
Dee Miller, Project Executive Assistant
Wilbur Bergquist, Project Evaluator
Pam Van Scotter, Project Editor

Progress from 1 September 1991

- Revised materials from writing conference
- Prepared field-test materials, student and teacher editions
- Arranged for "unofficial" field test sites--Jon Hendrix (Ball State University, Indiana) master teachers; total of 17 additional sites
- Conducted telephone interviews with teachers not receiving a site visit
- Made four site visits to Minneola, KS, Coldwater, KS, St. Louis MO, and Niwot, CO. (total of five teachers, 8 classes)
- Distributed content review materials to members of ASHG, NSGC, and CORN, as well as to Dr. Neil Holtzman, Dr. Thomas Murray, and Mr. Mark Rothstein. Project advisory board members, writers, and other interested parties also received review copies.
- Began analysis of field test and content review data

Tasks for next quarter

- Complete analysis of field test and content review data
- Conduct project advisory board meeting
- Incorporate field-test data, content review suggestions, and advisory board recommendations
- Determine final format of materials
- Solicit current bids from printers
- Prepare materials for final edition
- Allocate extra copies of final modules to NABT
- Distribute final materials to teachers

1991 Quarterly Report

Mapping and Sequencing the Human Genome: Science, Ethics and Public Policy--Development and Distribution of Educational Materials for Use in High School Biology Courses

1 May 1991 - 1 September 1991
DOE: $394,193; 16 months

Purpose

BSCS will produce and distribute a 75-page instructional monograph on the Human Genome Projects, designed for use with average, first-year students in high school biology. The monograph will consist of 25 pages of background materials for the teacher and at least 5 inquiry-oriented activities for the classroom. Each high school teacher in the United States will receive one free copy of the monograph and will have permission to reproduce the materials for classroom use. BSCS will work in conjunction with the American Medical Association; cooperating organizations include the American Society of Human Genetics (ASHG), the National Society of Genetic Counselors (NSGC), and the Council of Regional Networks for Genetic Services (CORN).

Relevance to BSCS Goals

In developing this monograph, BSCS will have an opportunity to influence public perceptions of genetics and genetic technology, increase the exposure of students and teachers to sound, conceptually based content, and introduce a workable model for teaching ethics and ethical analysis in the biology classroom. BSCS also may increase its visibility among younger teachers as an organization committed to accurate and current content and inquiry-oriented instruction.

Staffing

Joe McInerney - principal investigator (.2 FTE)
Jenny Stricker - project director (1 FTE)*
Dee Miller - secretary (.5 FTE)
Wilbur Bergquist - evaluator (.2 FTE)
Pam Van Scotter - editor (.25 FTE)

* As of 1 November 1991, Kathy Winternitz, BSCS staff associate on the Green Version revision project, will assume the role of project director.

Progress since 1 May 1991

- summarized and evaluated reviews of conceptual framework (submitted by the education committees of ASHG, NSGC, and CORN, and by Drs. Neil Holtzman and Thomas Murray)
- conducted writing conference
- selected five field-test sites
- developed preliminary public relations and promotions plan
- began production of experimental materials

Tasks for next quarter

- complete production of experimental materials
- conduct teacher orientation
- begin field-test process
- conduct workshop at the national meeting of the National Association of Biology Teachers

APPENDIX C

Summary of Suggested Revisions

ADVISORY COMMITTEE SUMMARY
Summary of Reviewers' Comments

The following represent the average answers of 21 reviewers.

1. **Are the major concepts accurate?** (avg = 1.34)

very accurate		generally accurate	generally inaccurate	completely inaccurate
1	(1.34)	2	3	4

2. **Are the major concepts appropriate for first year biology courses?** (avg = 1.64)

very appropriate		somewhat appropriate	inappropriate
1	(1.64)	2	3

3. **Do the proposed teacher background materials include the major scientific, ethical, and public policy issues raised by the Human Genome Project?** (avg = 1.68)

all		most	some	none
1	(1.68)	2	3	4

4. **Are the proposed classroom activities at the appropriate level for first-year biology courses?** (avg = 1.73)

too difficult		about right	too easy
1	(1.73)	2	3

5. **Is the proposed treatment of ethics and public policy appropriate for first-year biology courses?** (avg = 1.32)

very appropriate		somewhat appropriate	inappropriate
1	(1.32)	2	3

The following are general comments of the reviewers. Please note that this is not a comprehensive list.

1. Overall design of the classroom activities

- may take more than 5 classes to do justice to all HGP issues
- 5 day student project is a good idea
- teacher narrative translates into a lecture 3 to 4 days long--when would this fit in?
- will teachers be willing to spend 5 days?
- too many complex issues to be resolved in 5 periods; it is irresponsible of us to encourage the students to decide on the future of the genome projects in this amount of time
- classroom activities seem a bit difficult; would depend on class, of course
- would biology teachers be willing to devote 5 class periods to this?
- appears to be out of balance--are 2 days sufficient to bring the average high school student up to speed on how the information is generated and possibilities for its application?

2. Major concepts

- some concepts may be a bit beyond most high school students
- major concepts seem difficult for first year biology courses
- stay away from discussions of normal/abnormal
- (several reviewers had strong opinions--positive and negative--about our use of metaphors such as the genetic code as a "map")
- (two reviewers contended that the HGP *will* raise new categories of ethical issues--first because it will provide information on the range of human variation, not just diseases which impact lives, and second because the ability to diagnose or predict diseases will be a much more general phenomenon)
- we are not sequencing the human genome to understand human variation...we are doing it to find and maybe fix, disease genes...if we learn something about how polygenic traits are determined--fine...but to imply that this is the goal is wrong...Congress is not allocating several billion dollars to determine why we all don't look or think alike

3. Treatment of science and technology

- make sure we give teachers resources (e.g., supplemental programs on genetics) for basic genetics that would precede this unit
- there is a danger in presenting too much science in 2 class periods
- teachers may not have adequate background in techniques and issues of genetic counseling
- (several reviewers had strong opinions about including explanations of DNA technology; the gist of these comments was that we need a simplified explanation that describes *what* the techniques do, not an in-depth treatment of *how* the techniques work; some suggested we model our explanation after those used by genetics counselors or physicians)

4. Treatment of ethics and public policy:

- it is questionable whether high school students as concrete thinkers can handle the proposed decision-making model or ethics grid
- treatment of ethics seems challenging for both student and teacher
- the students and teacher must have a basic understanding of science and technology; if they don't, the ethics and public policy may be too difficult
- treatment of ethics and public policy may be too difficult for first year classes
- what about political issues?
- the treatment of ethics and public policy is appropriate as long as it doesn't detract from treatment of science/technology
- biology teachers need to expand their skills to embrace social science principles--are biology teachers willing to approach science in this manner?
- if students have already used ethical models then the proposed sequence of activities is ok; if not, then too much time will be spent helping the student through the process and not enough time will be spent helping them understand the Human Genome Project
- I am worried about the formal approach to ethical analysis--it seems difficult and unfamiliar to teachers; I suggest using a more practical approach; the discussion and appreciation of the problem is more likely to be valuable to the students
- treatment of ethics is perhaps too extensive--requires too much knowledge of ethics
- both appendices are excellent but seem far too extensive and complex for a first year biology course/teacher
- the curriculum seems to address the major concepts of ethics/public policy better than it addresses the major concepts of science/technology
- the distinction between ethics and moral codes may not be an important issue for this module

- students and teachers will need preparation to do the proposed decision-making models/ethical analysis
- will the students have the necessary background to interpret and understand the case studies and testimonials?
- the proposed treatment of ethics is unsuitable for high school biology teachers without ethics training--too theoretical; needs concrete examples to illustrate how to actually lead the discussion--what to do in class
- (several reviewers suggested alternative case studies for the students to evaluate/discuss during day 2)

APPENDIX D

Teacher's Evaluation Instruments

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Evaluation of Teacher Narrative

Name _____

Circle the number that best indicates your response to the following questions.

Text and Figures

1. Is there enough information in the teacher narrative?

   too much -2 -1 0 1 2 not enough

2. What should we omit or add?

3. Are there too few or too many figures in the narrative?

   too few -2 -1 0 1 2 too many

4. Which figures are most helpful?

5. Which figures are least helpful? Should these figures should be omitted or modified?

6. Does the narrative give you enough background to help connect the five activities in a meaningful manner?

   not enough -2 -1 0 1 2 enough

7. Does the narrative give you enough background to help make the transition from scientific inquiry to ethical inquiry?

   not enough -2 -1 0 1 2 enough

8. Is the teacher narrative clear and easy to read?

confusing	-2	-1	0	1	2	clear
difficult to read	-2	-1	0	1	2	easy to read

9. Are the references useful and available?

not useful	-2	-1	0	1	2	useful
not available	-2	-1	0	1	2	available

10. What other references should we include?

Please rate the following aspects of the teacher narrative. For any low ratings, please suggest improvements.

		poor				excellent
11.	The glossary is	1	2	3	4	5
12.	The accuracy of the information in the narrative is	1	2	3	4	5
13.	The sequence of information in the narrative is	1	2	3	4	5
14.	The timeliness of the information is the narrative is	1	2	3	4	5
15.	The appropriateness of the information in the narrative is	1	2	3	4	5
16.	The writing style of the narrative is	1	2	3	4	5
17.	The layout of the narrative is	1	2	3	4	5
18.	The size of type used in the narrative is	1	2	3	4	5
19.	The quality of blackline masters is	1	2	3	4	5

Comments or suggestions for the previous items:

20. In general, this teacher narrative:

is poor	**-2**	**-1**	**0**	**1**	**2**	**is excellent**
is confusing	**-2**	**-1**	**0**	**1**	**2**	**is clear**
lacks information	**-2**	**-1**	**0**	**1**	**2**	**contains sufficient information**

21. Did the narrative help you teach each activity? **yes** **no**
Comments:

22. Were the teacher annotations complete enough to support you during class discussions? **yes** **no**
Comments:

23. Would the cost of duplicating student materials inhibit other teachers from using these activities? **yes** **no**
Comments:

24. Were the brochures *Career Opportunities in Genetics* and *Careers in Genetic Counseling*, helpful? **yes** **no**
Comments:

25. Would the electrophoresis activity, DNA Fingerprinting, be an appropriate extension of this module? **yes** **no**
Comments:

26. Would the cost of this activity (@ $800) prevent you from using it? **yes** **no**
Comments:

27. Would the simulation activity, Gel Electrophoresis Simulation, be an appropriate extension of this module? **yes** **no**
Comments:

28. Would the cost of this activity (@ $50) prevent you from using it? **yes** **no**
Comments:

29. Does the Human Genome Poster enhance the module? **yes** **no**
Comments:

30. Is the Human Genome Poster (@ $15) necessary for this module? **yes** **no**
Comments:

31. Does the Collaborative Research advertisement on cystic fibrosis screening enhance the module? **yes** **no**
Comments:

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Teacher's Evaluation of Activity 1: Our Genetic Future?

Name _____

Circle the number that best indicates your response to the following questions.

Student Materials

1. Is the amount of prior knowledge of genetics required for this activity appropriate?

   inappropriate -2 -1 0 1 2 appropriate

2. Did this activity help your students understand that environmental factors as well as genetic factors influence the expression of traits?

   did not help -2 -1 0 1 2 helped

3. Students are expected to know the difference between having the gene for a trait (the genotype) and expressing the trait (the phenotype). Is this expectation appropriate for your class?

   not appropriate -2 -1 0 1 2 appropriate

4. Was the distinction between the *Human Genome Project* and an individual's genetic profile clear by the end of this activity?

   not clear -2 -1 0 1 2 clear

5. Did your students understand that genetic profiles might be used to make employment decisions?

   did not understand -2 -1 0 1 2 understood

6. Is the use of pop-it beads appropriate for this activity?

   inappropriate -2 -1 0 1 2 appropriate

7. Did your students make the connection that the pop-it beads were used to model the genetic traits?

   missed the connection -2 -1 0 1 2 made the connection

Student Instructions and Discussion Questions

8. The directions for the students are

hard to follow	-2	-1	0	1	2	clear
not useful	-2	-1	0	1	2	useful

9. The information provided to the student is

not enough	-2	-1	0	1	2	too much
not useful	-2	-1	0	1	2	useful

10. The discussion and test questions are

poor	-2	-1	0	1	2	excellent
confusing	-2	-1	0	1	2	clear

11. In general, participation in class discussion about the various questions was

low	-2	-1	0	1	2	high
unenthusiastic	-2	-1	0	1	2	enthusiastic

Please rate the coverage of the following concepts:	poor				excellent
12. Everyone has a genetic profile.	1	2	3	4	5
13. Traits are the result of both genes and environment.	1	2	3	4	5
14. Determining an individual's genetic profile soon will be possible.	1	2	3	4	5
15. Employers may use genetic profiles to decide who to hire.	1	2	3	4	5
16. Human variation results from genetic differences that interact with environmental variables.	1	2	3	4	5
17. Genes code for inherited traits.	1	2	3	4	5
18. Genetic profiles could become public record.	1	2	3	4	5

Other issues

19. After reading the advertisement, were your students able to identify all of the characteristics given in the teacher's annotations? **yes** **no**

20. Please list any characteristics we overlooked.

21. Was the concept of variation well developed? **yes** **no**

22. Did your students give appropriate responses to discussion questions 4 and 5? **yes** **no**
If so, please explain.

23. Did you have sufficient pop-it beads for all your classes? **yes** **no**

General Questions (please explain your answer).

24. Is the reading level appropriate for high school students? **yes** **no**
Comments:

25. Do we provide enough background information for the teacher? **yes** **no**
Comments:

26. Are the suggestions for teaching this activity clear? **yes** **no**
Comments:

27. Is this activity appropriate for high school students? **yes** **no**
Comments:

28. Are the concepts important for your students? **yes** **no**
Comments:

29. Are the concepts relevant to your students? **yes** **no**
Comments:

30. Were the students engaged and excited during this activity? **yes** **no**
Comments:

31. How might we make this activity more interactive?

32. What suggestions do you have for modifying or changing this activity?

33. Which, if any, of the student objectives for this activity are not adequately covered?

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Teacher's Evaluation of Activity .. DNA Sequences

Name _____

Circle the number that best indicates your response to the following questions.

Student Materials

1. Was the amount of prior knowledge required for this activity appropriate?

   too much -2 -1 0 1 2 right amount

2. Did this activity help your students understand that different codons can code for the same amino acid?

   did not help -2 -1 0 1 2 helped

3. Did this activity help your students understand that a mutation is a variation in the DNA sequence, and that some mutations do not result in genetic disorders?

   did not help -2 -1 0 1 2 helped

4. We expect that students already know the difference between transcription and translation and are familiar with the genetic code. Is this expectation appropriate for your class?

   not appropriate -2 -1 0 1 2 appropriate

5. Did your students make the transition from Activity 1 to Activity 2, in other words, did they connect the two activities?

   missed the connection -2 -1 0 1 2 made the connection

6. Did your students make the distinction between mapping (Activity 1) and sequencing (Activity 2)?

   missed the distinction -2 -1 0 1 2 made the distinction

7. Can students complete this activity if they are not familiar with codons, transcription, and translation? **yes** **no**
   Please explain your answer.

8. Did your students seem frustrated by this activity? yes no
If so, please suggest ways we can change the activity.

9. Did your students have difficulty in determining how Rico's DNA sequence was different than the others? yes no
If so, please suggest ways we can change the activity.

10. Did your students have difficulty in proposing a hypothesis to question 6? yes no

11. Please lit student responses to question 6.

12. Is the metaphor of a map helpful for your students? yes no
Please explain your answer.

Student Instructions and Discussion Questions

13. Is the format we use to show the DNA sequence data appropriate or inappropriate for the activity?

inappropriate	-2	-1	0	1	2	appropriate

14. If inappropriate, what changes do you suggest?

15. The student directions are

hard to follow	-2	-1	0	1	2	clear
not useful	-2	-1	0	1	2	useful

16. The information provided to the student is

not enough	-2	-1	0	1	2	too much
not useful	-2	-1	0	1	2	useful

17. The discussion and test questions are

poor	-2	-1	0	1	2	excellent
confusing	-2	-1	0	1	2	clear

18. In general, participation in class discussion about the various questions was

low	-2	-1	0	1	2	high
unenthusiastic	-2	-1	0	1	2	enthusiastic

Please rate the coverage of the following concepts:	poor				excellent
19. It is possible to determine DNA sequence.	1	2	3	4	5
20. A change in the DNA sequence is a mutation.	1	2	3	4	5
21. Not all mutations result in a genetic disorder.	1	2	3	4	5
22. By comparing DNA sequences of people who have a genetic disorder with those who do not, it might be possible to determine what the code for the disorder is.	1	2	3	4	5
23. Human errors do occur in the reading of sequence data.	1	2	3	4	5

General Questions (please explain your answer).

24. Is the reading level appropriate for high school students? **yes** **no**
Comments:

25. Do we provide enough background information for the teacher? **yes** **no**
Comments:

26. Are the suggestions for teaching this activity clear? **yes** **no**
Comments:

27. Is this activity appropriate for high school students? **yes** **no**
Comments:

28. Are the concepts important for your students? **yes** **no**
Comments:

29. Are the concepts relevant to your students? **yes** **no**
Comments:

30. Were the students engaged and excited during this activity? **yes** **no**
Comments:

31. How might we make this activity more interactive?

32. What suggestions do you have for modifying or changing this activity?

33. Which, if any, of the student objectives for this activity are not adequately covered?

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Teacher's Evaluation of Activity 2 Extension: The PCR

Name _____

Circle the number that best indicates your response to the following questions.

Student Materials

1. Did this activity help your students understand that our bodies have a limited amount of DNA?

   did not help -2 -1 0 1 2 helped

2. Did this activity help your students understand that testing for genetic disorders is costly in terms of dollars, time, and personal anguish?

   did not help -2 -1 0 1 2 helped

3. Did this activity help your students understand that the benefits gained by testing for less common mutations reaches a point of diminishing returns when compared to the cost of the additional test?

   did not help -2 -1 0 1 2 helped

4. Did your students make the distinction that genetic disorders can have many different causes?

   missed the distinction -2 -1 0 1 2 made the distinction

5. Students are expected to take the position of a parent whose child might have cystic fibrosis and write about how they might feel in such a position. Is this expectation appropriate for your class?

   not appropriate -2 -1 0 1 2 appropriate

6. Did this activity help your students understand that the Human Genome Project will generate issues that affect individual families?

   did not help -2 -1 0 1 2 helped

7. Was the amount of prior knowledge of genetics required for this activity appropriate?

   inappropriate -2 -1 0 1 2 appropriate

8. Did your students connect this activity with the previous two activities?

missed the connection	-2	-1	0	1	2	made the connection

Student Instructions and Discussion Questions

9. Is the use of paper strips for the strands of DNA an appropriate or inappropriate model for multiplying and screening genetic material?

inappropriate	-2	-1	0	1	2	appropriate

10. If inappropriate, what changes do you suggest?

11. The student directions are

hard to follow	-2	-1	0	1	2	clear
not useful	-2	-1	0	1	2	useful

12. The information provided to the student is

not enough	-2	-1	0	1	2	too much
not useful	-2	-1	0	1	2	useful

13. The discussion and test questions are

poor	-2	-1	0	1	2	excellent
confusing	-2	-1	0	1	2	clear
lacking in information	-2	-1	0	1	2	provide enough information

14. In general, student participation in class was

low	-2	-1	0	1	2	high
unenthusiastic	-2	-1	0	1	2	enthusiastic

Please rate the coverage of the following concepts:	poor				excellent
15. The amount of DNA in our bodies is limited.	1	2	3	4	5
16. Scientists can produce large amounts of DNA using the polymerase chain reaction.	1	2	3	4	5
17. Genetic disorders can have many different causes.	1	2	3	4	5
18. DNA screening is expensive, so the benefits gained should help decide how many tests are appropriate.	1	2	3	4	5

19. Increasing the number of tests used for screening DNA fragments does not always give a significant increase in the amount of information gained. 1 2 3 4 5

Other Issues

20. Did your students have any difficulty understanding the trade-offs between the costs and benefits of increasing the number of tests? **yes** **no**
If so, please explain.

21. Did your students have any difficulty with the procedures in Part II? **yes** **no**
If so, please explain.

22. Did your students have difficulty understanding that the PCR allows scientists to increase the amount of DNA exponentially? **yes** **no**
If so, please explain.

23. Did your students indicate that instruction in exponential growth repeats instruction from other courses? **yes** **no**
If so, please explain.

24. Did your students need additional background in genetics, ethics, or mathematics before they could complete this activity? **yes** **no**
If so, please explain.

25. There is concern that use of cystic fibrosis as an example of a genetic disorder might offend or embarrass students who have the disorder, or who know someone who does. Should we not worry about the problem, or should we avoid such examples?
a) What is your opinion on this issue?
b) Have you experienced similar situations? If so, how did you handle the situation?

General Questions (please explain your answer).

26. Is the reading level appropriate for high school students? **yes no**
Comments:

27. Do we provide enough background information for the teacher? **yes no**
Comments:

28. Are the suggestions for teaching this activity clear? **yes no**
Comments:

29. Is this activity appropriate for high school students? **yes no**
Comments:

30. Are the concepts important for your students? **yes no**
Comments:

31. Are the concepts relevant to your students? **yes no**
Comments:

32. Were the students engaged and excited during this activity? **yes no**
Comments:

33. How might we make this activity more interactive?

34. What suggestions do you have for modifying or changing this activity?

35. Which, if any, of the student objectives for this activity are not adequately covered?

Mapping and Sequencing the Human Genome:
Science, Ethics, and Public Policy

Teacher's Evaluation of Activity 3: The Case of Nathaniel Wu

Name _____

Circle the number that best indicates your response to the following questions.

Student Materials

1. Did this activity help your students understand that genetic screening can detect certain genetic disorders?

   did not help -2 -1 0 1 2 helped

2. Did this activity help your students understand that decision making should include identifying both the costs and benefits of each choice?

   did not help -2 -1 0 1 2 helped

3. Was this activity successful in making students articulate reasons both for and against hiring Nathaniel Wu?

   not successful -2 -1 0 1 2 successful

4. Did your students make the distinction between justified and unjustified discrimination?

   missed the distinction -2 -1 0 1 2 made the distinction

5. We assume that students can take and defend a position on whether or not employers should consider a genetic predisposition when making employment decisions. Is this assumption appropriate for your class?

   not appropriate -2 -1 0 1 2 appropriate

6. Did your students make the transition from Activities 1 and 2 to Activity 3? In other words, did they connect this activity with the first two activities?

   missed the connection -2 -1 0 1 2 made the connection

7. If students do not know how to make and analyze arguments, can they complete this activity successfully?
   Please explain your answer. **yes** **no**

Please rate the coverage of the following concepts:		**poor**				**excellent**
8.	We need to identify both costs and benefits when making decisions.	1	2	3	4	5
9.	Discrimination can be both justified and unjustified.	1	2	3	4	5
10.	Ethical inquiry is a logical and systematic process.	1	2	3	4	5
11.	The skills of information gathering, evaluation of information, and making and analyzing arguments are the tools of ethical inquiry.	1	2	3	4	5
12.	It is possible to detect a predisposition for genetic disorders through genetic screening.	1	2	3	4	5
13.	That ethical decision making is complicated by the uncertainties introduced by genetic variation.	1	2	3	4	5

Student Instructions and Discussion Questions

14. Is the use of an employment hearing as a forum for the discussion appropriate or inappropriate for this activity?

inappropriate	**-2**	**-1**	**0**	**1**	**2**	**appropriate**

15. If inappropriate, what changes do you suggest?

16. The student directions are

hard to follow	**-2**	**-1**	**0**	**1**	**2**	**clear**
not useful	**-2**	**-1**	**0**	**1**	**2**	**useful**

17. The information provided to the student is

not enough	**-2**	**-1**	**0**	**1**	**2**	**too much**
not useful	**-2**	**-1**	**0**	**1**	**2**	**useful**

18. The discussion and test questions are

poor	**-2**	**-1**	**0**	**1**	**2**	**excellent**
confusing	**-2**	**-1**	**0**	**1**	**2**	**clear**

19. In general, student participation in class was

low	**-2**	**-1**	**0**	**1**	**2**	**high**
unenthusiastic	**-2**	**-1**	**0**	**1**	**2**	**enthusiastic**

Other Issues

20. Were students able to list several reasons for hiring Nathaniel Wu? **yes** **no**

21. Were students able to list several reasons for not hiring Nathaniel Wu? **yes** **no**

22. Did the decision makers have any difficulty performing their role? **yes** **no**
If so, please explain.

23. Did the use of role-playing help your students understand the process of ethical inquiry? **yes** **no**
If not, please explain.

24. Did your students find if difficult to complete the questions for Part I? **yes** **no**
If so, please explain.

25. Was the homework assignment for Part I appropriate? **yes** **no**
If not, please explain.

26. Did your students find it difficult to make appropriate arguments for Part II? **yes** **no**
If so, please explain.

27. Was the four-step process of ethical inquiry well developed? **yes** **no**
If not, please explain.

28. Did your students need additional background in ethics before they could complete this activity? **yes** **no**
If so, please explain.

General Questions (please explain your answer).

29. Is the reading level appropriate for high school students? **yes no**
Comments:

30. Do we provide enough background information for the teacher? **yes no**
Comments:

31. Are the suggestions for teaching this activity clear? **yes no**
Comments:

32. Is this activity appropriate for high school students? **yes no**
Comments:

33. Are the concepts important for your students? **yes no**
Comments:

34. Are the concepts relevant to your students? **yes no**
Comments:

35. Were the students engaged and excited during this activity? **yes no**
Comments:

36. How might we make this activity more interactive?

37. What suggestions do you have for modifying or changing this activity?

38. Which, if any, of the student objectives for this activity are not adequately covered?

Mapping and Sequencing the Human Genome:
Science, Ethics, and Public Policy

Teacher's Evaluation of Activity 4: Public Policy

Name _____

Circle the number that best indicates your response to the following questions.

Student Materials

1. Did this activity help your students understand that public policy is one method society uses to protect the public's welfare?

   did not help -2 -1 0 1 2 helped

2. Did this activity help your students understand that sound public policy must meet the conditions of urgency, means, and effectiveness?

   did not help -2 -1 0 1 2 helped

3. Did this activity provide enough background information on ethical inquiry so that students can complete the activity?

   too much -2 -1 0 1 2 not enough

4. Did this activity provide enough information about public policy so that students can complete the activity?

   too much -2 -1 0 1 2 not enough

5. This activity addresses legislative protection against discrimination. We expect students to take and defend a position on this issue. Is this expectation appropriate for your class?

   not appropriate -2 -1 0 1 2 appropriate

6. Did this activity help your students construct arguments both for and against the proposed amendment to the Disabilities Act of 1990?

   did not help -2 -1 0 1 2 helped

7. Did your students make the distinction between being predisposed to a genetic disorder and having a disability?

   missed the distinction -2 -1 0 1 2 made the distinction

8. Did your students make the transition to Activity 4? In other words, did they connect this activity with the previous activities?

missed the connection	-2	-1	0	1	2	made the connection

9. Did this activity help your students understand the differences between urgency, means, and effectiveness?

did not help	-2	-1	0	1	2	helped

10. Did this activity help your students understand that the Human Genome Project will generate many controversial issues that must be addressed through public policy?

did not help	-2	-1	0	1	2	helped

Student Instructions and Discussion Questions

11. The student directions are

hard to follow	-2	-1	0	1	2	clear
not useful	-2	-1	0	1	2	useful

12. The information we provided to the student is

not enough	-2	-1	0	1	2	too much
not useful	-2	-1	0	1	2	useful

13. The discussion and test questions are

poor	-2	-1	0	1	2	excellent
confusing	-2	-1	0	1	2	clear

14. In general, student participation in class was

low	-2	-1	0	1	2	high
unenthusiastic	-2	-1	0	1	2	enthusiastic

Please rate the coverage of the following concepts:	poor				excellent
15. Our society uses public policy to regulate public behavior.	1	2	3	4	5
16. Having a predisposition to a genetic disorder may result in discrimination.	1	2	3	4	5
17. A person with a predisposition to a genetic disorder might be a classified as having a disability and be protected by law from discrimination.	1	2	3	4	5

18. Public policy must address three conditions: urgency, means, and effectiveness. 1 2 3 4 5

19. The Human Genome Project will generate social issues that students must address in their lifetimes. 1 2 3 4 5

Other Issues

20. Are the five issues used for the small group discussion and presentations appropriate or inappropriate for this activity?

inappropriate -2 -1 0 1 2 appropriate

21. If inappropriate, what changes do you suggest?

22. Were the issues presented on the overheads clearly written? **yes** **no**

23. Were your students able to list several questions for each issue? **yes** **no**

24. Did your students have difficulty in establishing the difference between ethics and public policy? **yes** **no**
If so, please explain.

25. Did your students have difficulty in identifying the various meanings of fairness? **yes** **no**
If so, please explain.

26. Did your students have difficulty understanding the importance of urgency in establishing public policy? **yes** **no**
Please explain.

27. Did your students have difficulty with understanding the importance of means in establishing public policy? **yes** **no**
If so, please explain.

28. Did your students have difficulty with understanding the importance of effectiveness in establishing public policy? **yes** **no**
If so, please explain.

29. Did your students understand that society sometimes responds to ethical dilemmas by enacting public policy through legislation and sometimes responds by not enacting any legislation? **yes** **no**
If so, please explain.

30. Did you use test items 6 through 8? **yes** **no**
Why or why not?

31. If you used newspaper articles to test student learning, did your students find it difficult to judge the quality of the ethical reasoning? **yes** **no**
If so, please explain.

32. Did your students need additional background in ethics, public policy, or the disability act before they could complete this activity? **yes** **no**
If so, please explain.

General Questions (please explain your answer).

33. Is the reading level appropriate for high school students? **yes** **no**
Comments:

34. Do we provide enough background information for the teacher? **yes** **no**
Comments:

35. Are the suggestions for teaching this activity clear? **yes** **no**
Comments:

36. Is this activity appropriate for high school students? **yes** **no**
Comments:

37. Are the concepts important for your students? **yes** **no**
Comments:

38. Are the concepts relevant to your students? **yes** **no**
Comments:

39. Were the students engaged and excited during this activity? **yes** **no**
Comments:

40. How might we make this activity more interactive?

41. What suggestions do you have for modifying or changing this activity?

42. Which, if any, of the student objectives for this activity are not adequately covered?

Mapping and Sequencing the Human Genome:
Science, Ethics, and Public Policy

Teacher's Final Evaluation

Name _____

Please respond to the following questions about the five activities in this module.

1. Rank the activities from **most difficult** to **least difficult** for your students to complete. (It is possible to assign the same rank to two different activities.) Then indicate which activities your students seemed to find **most interesting** and **least interesting**. Use the scale provided with 1 = most and 4 = least.

	Interesting	Difficult
Activity 1: Our Genetic Future?	1 2 3 4	1 2 3 4
Activity 2: DNA Sequences	1 2 3 4	1 2 3 4
Extension Activity: The PCR	1 2 3 4	1 2 3 4
Activity 3: The Case of Nathaniel Wu	1 2 3 4	1 2 3 4
Activity 4: Public Policy	1 2 3 4	1 2 3 4

2. For each of the activities, indicate whether most of your students **understood the ideas**. Then indicate whether you needed to provide **more information** before students could complete the activity.

	Students understood the ideas	Students needed more information
Activity 1: Our Genetic Future?	*yes* *no*	*yes* *no*
Activity 2: DNA Sequences	*yes* *no*	*yes* *no*
Extension Activity: The PCR	*yes* *no*	*yes* *no*
Activity 3: Case of Nathaniel Wu	*yes* *no*	*yes* *no*
Activity 4: Public Policy	*yes* *no*	*yes* *no*

3. If you needed to provide additional information for any of the activities, what additional information did you provide and what format did you use?

_____

_____

4. Did your students have difficulty completing any of these activities? *yes* *no*
If so, please explain.

_____

_____

_____

_____

5. Did your students have difficulty reading this material? *yes* *no*
If so, please explain.

_____

_____

_____

6. Each activity assumes that students are familiar with genetics. Indicate whether you felt we expected **too much** or **too little knowledge** of genetics. Then indicate whether the six-day schedule resulted in the students' spending **too much** or **too little time** on each activity.
Use the scale provided, with 1 = too little, 2 = enough, and 3 = too much.

	Knowledge of genetics expected	Time spent
Activity 1: Our Genetic Future?	1 2 3	1 2 3
Activity 2: DNA Sequences	1 2 3	1 2 3
Extension Activity: The PCR	1 2 3	1 2 3
Activity 3: The Case of Nathaniel Wu	1 2 3	1 2 3
Activity 4: Public Policy	1 2 3	1 2 3

7. Were any activities difficult to teach? If so, explain why you found them difficult.

_____

_____

_____

8. Was the time you needed to prepare for any activity excessive? Was it difficult to find or prepare materials for any activity? Please explain any problems you encountered.

_____

_____

_____

9. Did you teach these activities as written? *yes no*
If not, please explain how you changed any activity.

_____

_____

_____

10. Did you use all of the student test questions? *yes no*
Please comment on the quality and appropriateness of the questions.

_____

_____

_____

_____

11. As written, did the daily schedule provide enough time for each activity? *yes no*
If not, please suggest how the time schedule should be changed.

_____

_____

_____

_____

12. If you only have five days for this module, which activities are the best to use. *yes* *no*

_____

_____

_____

_____

13. Could this module be used effectively by delaying longer between each activity, or is it better to do all activities in one week? *yes* *no*

14. Did you write any additional test questions? *yes* *no*
If so, please share these with us.

15. Would you do more activities like these? *yes* *no*

16. Would your students enjoy more activities like these? *yes* *no*

17. Will other high school students enjoy this module? *yes* *no*

18. Will other high school teachers enjoy this module? *yes* *no*

19. Please provide any additional suggestions that might help improve this module.

APPENDIX E

Student's Surveys and Final Evaluation

Mapping and Sequencing the Human Genome:
Science, Ethics, and Public Policy

Student Survey 1

Please indicate whether you are:

Male ____ Female ____

Name of your school _____

Name of your teacher _____

Today's date _____

DO NOT GIVE YOUR NAME

This is NOT a test. You will NOT receive a grade on this survey. Please respond to the statements on the basis of your current knowledge.

Please decide whether you agree or disagree with the following statements. Then, circle the number on the scale provided. Please circle only one number.

1 = strongly disagree 2 = disagree 3 = don't know 4 = agree 5 = strongly agree

Strongly disagree				Strongly agree	
1	2	3	4	5	1. The public should be involved in regulating the Human Genome Project.
1	2	3	4	5	2. Public policy should be determined only by weighing the benefits, costs, and risks involved.
1	2	3	4	5	3. The scientists working on the Human Genome Project are doing very exciting work.
1	2	3	4	5	4. The federal government should regulate the Human Genome Project.
1	2	3	4	5	5. The best support for any ethical argument is that most people agree with the stated position.
1	2	3	4	5	6. The Human Genome Project will make it possible to know everyone's genetic profile.
1	2	3	4	5	7. An individual's genetic profile should be available to employers and insurance companies.
1	2	3	4	5	8. Ethics is a way to deal with and solve social problems.
1	2	3	4	5	9. Everyone should have access to the information that results from the genome project.
1	2	3	4	5	10. Students should discuss ethical issues in science classes.
1	2	3	4	5	11. DNA carries the information for the traits a new baby will inherit.
1	2	3	4	5	12. The more scientists understand about how genes carry genetic information, the more they will be able to prevent disease.
1	2	3	4	5	13. One purpose of the genome project is to find cures for genetic disorders.
1	2	3	4	5	14. Once the human genome is mapped it will be possible to know everyone's genetic profile.
1	2	3	4	5	15. We need laws to protect people with a genetic predisposition to a disease from discrimination.
1	2	3	4	5	16. The scientists working on the Human Genome Project are doing very important work.

1 2 3 4 5 17. One purpose of the genome project is to learn about human variation.

1 2 3 4 5 18. The Human Genome Project is an attempt to map the location of every gene in the human genome.

1 2 3 4 5 19. The abilities and skills I will have as an adult depend both on my genetic information and environment.

1 2 3 4 5 20. If most of the people in the country feel that they have a right to a safe and healthy environment, then we should make laws to protect that right.

1 2 3 4 5 21. Doctors may be able to use my genetic profile to know whether or not I have a predisposition to certain diseases.

1 2 3 4 5 22. The Human Genome Project will make it possible to know exactly what skills and abilities someone will have when he or she becomes an adult.

1 2 3 4 5 23. Once a genetic profile is available, it will be possible to predict exactly how someone will look and behave.

1 2 3 4 5 24. The traits I will have as an adult depend only on my genetic information.

1 2 3 4 5 25. Passing new laws is the only way to make public policy.

1 2 3 4 5 26. If you have a genetic predisposition to a disease, you will develop that disease, no matter what.

1 2 3 4 5 27. Employers should have access to genetic profiles so they can hire the best person for the job.

1 2 3 4 5 28. I should have a genetic profile prepared so I will know whether I will have any health problems when I grow older.

1 2 3 4 5 29. All of my genetic information is contained in the chromosomes of my cells.

1 2 3 4 5 30. Ethics is a method of deciding how we should behave.

1 2 3 4 5 31. Knowing which genes are responsible for a trait will make it possible to design organisms that have desirable traits.

1 2 3 4 5 32. A new law should be enacted only when everyone agrees the law is necessary.

1 2 3 4 5 33. Ethical inquiry is a method of solving problems.

1 2 3 4 5 35. Good public policy must fulfill the conditions of urgency, means, and effectiveness.

1 2 3 4 5 36. We should introduce new technology only if there is no risk of harm to individuals or the public.

37. What do you think the term *genome* means?

38. What do you think the term *ethics* means?

39. What do you think the term *public policy* means?

40. What do you think distinguishes opinions from reasoned arguments about ethical issues?

41. What do you think is the relationship between genotype and phenotype?

Mapping and Sequencing the Human Genome:
Science, Ethics, and Public Policy

Student's Final Evaluation

Please respond to the following questions about the five activities in this module.

1. Rank each activity from **most interesting** to **least interesting**. Then rank each activity from **most difficult** to **least difficult**. (It is possible to assign the same rank to two different activities.) Use the scale provided with 1 = most and 4 = least.

	Interesting				Difficult			
Activity 1: Our Genetic Future?	1	2	3	4	1	2	3	4
Activity 2: DNA Sequences	1	2	3	4	1	2	3	4
Extension Activity: The PCR	1	2	3	4	1	2	3	4
Activity 3: The Case of Nathaniel Wu	1	2	3	4	1	2	3	4
Activity 4: Public Policy	1	2	3	4	1	2	3	4

2. For each of the activities, indicate whether you **understood the ideas**. Then indicate whether you wanted or **needed more information** to complete the activity.

	I understood the ideas		I needed more information	
Activity 1: Our Genetic Future?	*yes*	*no*	*yes*	*no*
Activity 2: DNA Sequences	*yes*	*no*	*yes*	*no*
Extension Activity: The PCR	*yes*	*no*	*yes*	*no*
Activity 3: Case of Nathaniel Wu	*yes*	*no*	*yes*	*no*
Activity 4: Public Policy	*yes*	*no*	*yes*	*no*

3. If you needed more information for any of the activities, what additional information did you need to know?

_____

_____

_____

4. Would you like to do more activities like these? *yes* *no*

5. Will other high school students enjoy this set of activities? *yes* *no*

6. Do you think it is important to learn about genetics? *yes* *no*
Why or why not?

_____

_____

7. Do you think it is important to learn about ethics and public policy? *yes* *no*
Why or why not?

_____

_____

8. Did you have difficulty reading this material? *yes* *no*
If so, please explain.

_____

_____

9. Do you think research on the Human Genome Project is worth the effort? *yes* *no*
Why or why not?

_____

_____

_____

10. Each activity assumes that you know something about genetics. Indicate whether you felt we expected **too much** or **too little knowledge** about genetics. Then indicate whether you spent **too much** or **too little time** doing each of the five activities. Use the scale provided with 1 = too little, 2 = enough, and 3 = too much.

	Knowledge of genetics expected			Time spent		
Activity 1: Our Genetic Future?	1	2	3	1	2	3
Activity 2: DNA Sequences	1	2	3	1	2	3
Activity 3: The Case of Nathaniel Wu	1	2	3	1	2	3
Activity 4: Public Policy	1	2	3	1	2	3
Activity 5: The PCR	1	2	3	1	2	3

11. The best part of this module was _____

_____

_____

_____

_____

12. The worst part of this module was _____

_____

_____

_____

_____

13. The most important thing I learned from doing activities in this module is_____

_____

_____

_____

_____

_____

14. Please give us any suggestions that might help improve this module.

_____

_____

_____

_____

_____

Mapping and Sequencing the Human Genome:
Science, Ethics, and Public Policy

Student Survey 2

Please indicate whether you are:

Male ____ Female ____

Name of your school _____

Name of your teacher _____

Today's date _____

DO NOT GIVE YOUR NAME

This is NOT a test. You will NOT receive a grade on this survey. Please respond to the statements on the basis of your current knowledge.

Please decide whether you agree or disagree with the following statements. Then, circle the number on the scale provided. Please circle only one number.

1 = strongly disagree 2 = disagree 3 = don't know 4 = agree 5 = strongly agree

Strongly disagree				Strongly agree	
1	2	3	4	5	1. The public should be involved in regulating the Human Genome Project.
1	2	3	4	5	2. Public policy should be determined only by weighing the benefits, costs, and risks involved.
1	2	3	4	5	3. The scientists working on the Human Genome Project are doing very exciting work.
1	2	3	4	5	4. The federal government should regulate the Human Genome Project.
1	2	3	4	5	5. The best support for any ethical argument is that most people agree with the stated position.
1	2	3	4	5	6. The Human Genome Project will make it possible to know everyone's genetic profile.
1	2	3	4	5	7. An individual's genetic profile should be available to employers and insurance companies.
1	2	3	4	5	8. Ethics is a way to deal with and solve social problems.
1	2	3	4	5	9. Everyone should have access to the information that results from the genome project.
1	2	3	4	5	10. Students should discuss ethical issues in science classes.
1	2	3	4	5	11. DNA carries the information for the traits a new baby will inherit.
1	2	3	4	5	12. The more scientists understand about how genes carry genetic information, the more they will be able to prevent disease.
1	2	3	4	5	13. One purpose of the genome project is to find cures for genetic disorders.
1	2	3	4	5	14. Once the human genome is mapped it will be possible to know everyone's genetic profile.
1	2	3	4	5	15. We need laws to protect people with a genetic predisposition to a disease from discrimination.
1	2	3	4	5	16. The scientists working on the Human Genome Project are doing very important work.

1 2 3 4 5 17. One purpose of the genome project is to learn about human variation.

1 2 3 4 5 18. The Human Genome Project is an attempt to map the location of every gene in the human genome.

1 2 3 4 5 19. The abilities and skills I will have as an adult depend both on my genetic information and environment.

1 2 3 4 5 20. If most of the people in the country feel that they have a right to a safe and healthy environment, then we should make laws to protect that right.

1 2 3 4 5 21. Doctors may be able to use my genetic profile to know whether or not I have a predisposition to certain diseases.

1 2 3 4 5 22. The Human Genome Project will make it possible to know exactly what skills and abilities someone will have when he or she becomes an adult.

1 2 3 4 5 23. Once a genetic profile is available, it will be possible to predict exactly how someone will look and behave.

1 2 3 4 5 24. The traits I will have as an adult depend only on my genetic information.

1 2 3 4 5 25. Passing new laws is the only way to make public policy.

1 2 3 4 5 26. If you have a genetic predisposition to a disease, you will develop that disease, no matter what.

1 2 3 4 5 27. Employers should have access to genetic profiles so they can hire the best person for the job.

1 2 3 4 5 28. I should have a genetic profile prepared so I will know whether I will have any health problems when I grow older.

1 2 3 4 5 29. All of my genetic information is contained in the chromosomes of my cells.

1 2 3 4 5 30. Ethics is a method of deciding how we should behave.

1 2 3 4 5 31. Knowing which genes are responsible for a trait will make it possible to design organisms that have desirable traits.

1 2 3 4 5 32. A new law should be enacted only when everyone agrees the law is necessary.

1 2 3 4 5 33. Ethical inquiry is a method of solving problems.

1 2 3 4 5 35. Good public policy must fulfill the conditions of urgency, means, and effectiveness.

1 2 3 4 5 36. We should introduce new technology only if there is no risk of harm to individuals or the public.

37. What do you think the term *genome* means?

38. What do you think the term *ethics* means?

39. What do you think the term *public policy* means?

40. What do you think distinguishes opinions from reasoned arguments about ethical issues?

41. What do you think is the relationship between genotype and phenotype?

Which adjectives best express your feelings about using these modules to learn about the Human Genome Project?
Please circle only one number.

exciting	3	2	1	0	1	2	3	boring
easy	3	2	1	0	1	2	3	hard
useless	3	2	1	0	1	2	3	useful
clear	3	2	1	0	1	2	3	muddled
important	3	2	1	0	1	2	3	not important
threatening	3	2	1	0	1	2	3	comforting
unpleasant	3	2	1	0	1	2	3	pleasant
irrelevant	3	2	1	0	1	2	3	relevant
fun	3	2	1	0	1	2	3	not fun
challenging	3	2	1	0	1	2	3	not challenging
worthless	3	2	1	0	1	2	3	valuable
understandable	3	2	1	0	1	2	3	confusing
dull	3	2	1	0	1	2	3	stimulating
complex	3	2	1	0	1	2	3	simple

APPENDIX F

Content Evaluation Form

Mapping and Sequencing the Human Genome:
Science, Ethics, and Public Policy

Content Review Response Form

Reviewer_____

Date Reviewed_____

Please circle the number that corresponds to your evaluation of the accuracy and appropriateness of the information presented in this program. Also note that this form is two-sided.

Overall Rating

1. Are the major concepts accurate?

very accurate **generally accurate** **generally inaccurate** **completely inaccurate**

2. Are the major concepts appropriate for first-year biology courses?

very appropriate **somewhat appropriate** **inappropriate**

3. Do the proposed teacher background materials include the major scientific, ethical, and public policy issues raised by the Human Genome Project?

all **most** **some** **none**

4. Are the proposed classroom activities at the appropriate level for first-year biology courses?

too difficult **about right** **too easy**

5. Is the proposed treatment of ethics and public policy appropriate for first-year biology courses?

very appropriate **somewhat appropriate** **inappropriate**

TEACHER NARRATIVE (Section I): ***The Science and Technology of the Human Genome Project***

I. Objectives of the Human Genome Project (pages 1-4)

1. The factual information in this section is

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
out-dated	1	2	3	4	5	very current

2. Please comment on whether any factual information in this section should be changed, deleted, or supplemented.

3. The figures and tables in this section are

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
out-dated	1	2	3	4	5	very current

4. Please comment on whether or not any figures or tables used in this section should be changed, deleted, or supplemented.

5. The concepts developed in this section are

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
obscure	1	2	3	4	5	very clear

6. In general, this section is

poor fair good excellent

TEACHER NARRATIVE (Section I): ***The Science and Technology of the Human Genome Project***

II. Techniques for Mapping Genes (pages 4-12)

1. The factual information in this section is

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
out-dated	1	2	3	4	5	very current

2. Please comment on whether any factual information in this section should be changed, deleted, or supplemented.

3. The figures and tables in this section are

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
out-dated	1	2	3	4	5	very current

4. Please comment on whether any figures or tables used in this section should be changed, deleted, or supplemented.

5. The concepts developed in this section are

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
obscure	1	2	3	4	5	very clear

6. In general, this section is

poor fair good excellent

TEACHER NARRATIVE (Section I): ***The Science and Technology of the Human Genome Project***

III. Human Genetic Variation (pages 13-15)

1. The factual information in this section is

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
out-dated	1	2	3	4	5	very current

2. Please comment on whether any factual information in this section should be changed, deleted, or supplemented.

3. The figures and tables in this section are

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
out-dated	1	2	3	4	5	very current

4. Please comment on whether any figures or tables used in this section should be changed, deleted, or supplemented.

5. The concepts developed in this section are

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
obscure	1	2	3	4	5	very clear

6. In general, this section is

poor fair good excellent

TEACHER NARRATIVE (Section I): ***The Science and Technology of the Human Genome Project***

IV. Expected Results form the Human Genome Project (pages 15-17)

1. The factual information in this section is

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
out-dated	1	2	3	4	5	very current

2. Please comment on whether any factual information in this section should be changed, deleted, or supplemented.

3. The concepts developed in this section are

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
obscure	1	2	3	4	5	very clear

4. In general, this section is

poor fair good excellent

TEACHER NARRATIVE (Section I): ***The Science and Technology of the Human Genome Project***

V. Limits and Opportunities (pages 17-18)

1. The factual information in this section is

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
out-dated	1	2	3	4	5	very current

2. Please comment on whether any factual information in this section should be changed, deleted, or supplemented.

3. The concepts developed in this section are

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
obscure	1	2	3	4	5	very clear

4. In general, this section is

poor fair good excellent

TEACHER NARRATIVE (Section I): ***The Science and Technology of the Human Genome Project***

VI. Concerns about the Human Genome Project (pages 18-19)

1. The factual information in this section is

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
out-dated	1	2	3	4	5	very current

2. Please comment on whether any factual information in this section should be changed, deleted, or supplemented.

3. The concepts developed in this section are

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
obscure	1	2	3	4	5	very clear

4. In general, this section is

poor fair good excellent

TEACHER NARRATIVE (Section II): ***Ethical and Public Policy Dimensions of the Human Genome Project***

VII. Uses of Data from the Human Genome Project (pages 20-25)

1. The factual information in this section is

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
out-dated	1	2	3	4	5	very current

2. Please comment on whether any factual information in this section should be changed, deleted, or supplemented.

3. The concepts developed in this section are

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
obscure	1	2	3	4	5	very clear

4. In general, this section is

poor fair good excellent

TEACHER NARRATIVE (Section II): ***Ethical and Public Policy Dimensions of the Human Genome Project***

VIII. Ethics (pages 25-27)

1. The factual information in this section is

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
out-dated	1	2	3	4	5	very current

2. Please comment on whether any factual information in this section should be changed, deleted, or supplemented.

3. The concepts developed in this section are

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
obscure	1	2	3	4	5	very clear

4. In general, this section is

poor fair good excellent

TEACHER NARRATIVE (Section II): ***Ethical and Public Policy Dimensions of the Human Genome Project***

IX. Public Policy (pages 27-30)

1. The factual information in this section is

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
out-dated	1	2	3	4	5	very current

2. Please comment on whether any factual information in this section should be changed, deleted, or supplemented.

3. The concepts developed in this section are

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
obscure	1	2	3	4	5	very clear

4. In general, this section is

poor fair good excellent

Student Activity 1: *Our Genetic Future?*

1. The factual information in this activity is

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
out-dated	1	2	3	4	5	very current

2. Please comment on whether any factual information in this activity should be changed, deleted, or supplemented.

3. The concepts developed in this activity are

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
obscure	1	2	3	4	5	very clear

4. The teacher's annotation in this activity are

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
out-dated	1	2	3	4	5	very current

5. Please comment on whether any annotations in this activity should be changed, deleted, or supplemented.

6. The figures and tables used in this section are

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
out-dated	1	2	3	4	5	very current

7. Please comment on whether any figures or tables used in this section should be changed, deleted, or supplemented.

8. The activities chosen for this lesson are poor fair good excellent

9. The presentation of the concepts is poor fair good excellent

10. In general, this student section is poor fair good excellent

Student Activity 2: *DNA Sequencing*

1. The factual information in this activity is

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
out-dated	1	2	3	4	5	very current

2. Please comment on whether any factual information in this activity should be changed, deleted, or supplemented.

3. The concepts developed in this activity are

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
obscure	1	2	3	4	5	very clear

4. The teacher's annotation in this activity are

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
out-dated	1	2	3	4	5	very current

5. Please comment on whether any annotations in this activity should be changed, deleted, or supplemented.

6. The figures and tables used in this section are

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
out-dated	1	2	3	4	5	very current

7. Please comment on whether any figures or tables used in this section should be changed, deleted, or supplemented.

8. The activities chosen for this lesson are poor fair good excellent

9. The presentation of the concepts is poor fair good excellent

10. In general, this student section is poor fair good excellent

Student Optional Activity: *The PCR*

1. The factual information in this activity is

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
out-dated	1	2	3	4	5	very current

2. Please comment on whether any factual information in this activity should be changed, deleted, or supplemented.

3. The concepts developed in this activity are

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
obscure	1	2	3	4	5	very clear

4. The teacher's annotation in this activity are

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
out-dated	1	2	3	4	5	very current

5. Please comment on whether any annotations in this activity should be changed, deleted, or supplemented.

6. The figures and tables used in this section are

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
out-dated	1	2	3	4	5	very current

7. Please comment on whether any figures or tables used in this section should be changed, deleted, or supplemented.

8. The activities chosen for this lesson are **poor fair good excellent**

9. The presentation of the concepts is **poor fair good excellent**

10. In general, this student section is **poor fair good excellent**

Student Activity 3: *The Case of Nathaniel Wu*

1. The factual information in this activity is

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
out-dated	1	2	3	4	5	very current

2. Please comment on whether any factual information in this activity should be changed, deleted, or supplemented.

3. The concepts developed in this activity are

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
obscure	1	2	3	4	5	very clear

4. The teacher's annotation in this activity are

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
out-dated	1	2	3	4	5	very current

5. Please comment on whether any annotations in this activity should be changed, deleted, or supplemented.

6. The figures and tables used in this section are

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
out-dated	1	2	3	4	5	very current

7. Please comment on whether any figures or tables used in this section should be changed, deleted, or supplemented.

8. The activities chosen for this lesson are poor fair good excellent

9. The presentation of the concepts is poor fair good excellent

10. In general, this student section is poor fair good excellent

Student Activity 4: *Public Policy*

1. The factual information in this activity is

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
out-dated	1	2	3	4	5	very current

2. Please comment on whether any factual information in this activity should be changed, deleted, or supplemented.

3. The concepts developed in this activity are

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
obscure	1	2	3	4	5	very clear

4. The teacher's annotation in this activity are

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
out-dated	1	2	3	4	5	very current

5. Please comment on whether any annotations in this activity should be changed, deleted, or supplemented.

6. The figures and tables used in this section are

inaccurate	1	2	3	4	5	accurate
inappropriate	1	2	3	4	5	appropriate
too simplified	1	2	3	4	5	too technical
out-dated	1	2	3	4	5	very current

7. Please comment on whether any figures or tables used in this section should be changed, deleted, or supplemented.

8. The activities chosen for this lesson are **poor** **fair** **good** **excellent**

9. The presentation of the concepts is **poor** **fair** **good** **excellent**

10. In general, this student section is **poor** **fair** **good** **excellent**

APPENDIX G

Results of the Content Evaluation

Mapping and Sequencing the Human Genome:
Science, Ethics, and Public Policy

Analysis of Responses from Field-test Sites and Content Review Committee

Submitted by
Wilbur Bergquist
BSCS Project Evaluator

10 March 1992

Mapping and Sequencing the Human Genome:
Science, Ethics, and Public Policy

CONTENT REVIEW

Overall Rating (18 reviewers)

Values marked with * are the mean of the responses while a † indicate the median response. A large difference between the mean and median indicate possible strong dissenting opinions.

1. Are the major concepts accurate?

4.0 † very accurate	**3.4 *** generally accurate	generally inaccurate	completely inaccurate

2. Are the major concepts appropriate for first-year biology courses?

3.0 † very appropriate	**2.6 *** somewhat appropriate	inappropriate

3. Do the proposed teacher background materials include the major scientific, ethical, and public policy issues raised by the Human Genome Project?

all	**3.2 *** **3.0 †** most	some	none

4. Are the proposed classroom activities at the appropriate level for first-year biology course?

too difficult	**2.2 *** **2.0 †** about right	too easy

5. Is the proposed treatment of ethics and public policy appropriate for first-year biology courses?

3.0 † very appropriate	**2.6 *** somewhat appropriate	inappropriate

Content Review: Teacher's Narrative 18 reviewers

* means † medians	accurate	appropriate	technical	clear	current	general rating
Part I factual information	3.9 * 5.0 †	3.7 5.0	3.1 3.0	- -	3.8 4.5	3.0 * 3.0 †
concept developed	4.2 5.0	4.1 4.5	3.3 3.0	3.6 4.0	- -	
Part II factual information	4.0 5.0	4.0 4.0	3.3 4.0	- -	4.1 4.0	2.9 3.0
concept developed	4.2 5.0	4.4 5.0	3.5 3.0	3.6 4.0	- -	
Part III factual information	4.4 5.0	4.5 5.0	3.5 3.0	- -	4.1 4.0	2.9 3.0
concept developed	4.1 5.0	4.1 5.0	3.3 3.0	3.4 4.0	- -	
Part IV factual information	4.4 5.0	4.4 5.0	3.1 3.0	- -	4.1 4.5	3.2 3.0
concept developed	4.7 5.0	4.6 5.0	3.4 3.0	4.0 4.0	- -	
Part V factual information	3.8 5.0	4.6 5.0	2.8 3.0	- -	4.0 4.0	3.2 3.0
concept developed	3.9 4.5	4.4 4.5	3.1 3.0	3.9 4.0	- -	
Part VI factual information	4.4 5.0	4.4 5.0	3.1 3.0	- -	4.6 5.0	3.3 3.0
concept developed	4.3 5.0	4.4 5.0	3.1 3.0	4.1 4.5	- -	

* means (first five columns use a 5-point scale (last column uses
† medians 1 = lowest and 5 = highest rating) a 4.0 scale
1 = low; 4 = high)

A large difference between the two measures indicates possible strong dissenting opinions.

Content Review: Public Policy and Ethics 18 reviewers

(first five columns use a 5-point scale 1 = lowest and 5 = highest rating) (4.0 scale 4 = high)

* means † medians	accurate	appropriate	technical	clear	current	general rating
Ethics factual information	4.4 * 5.0 †	4.3 5.0	3.3 3.0	- -	3.8 4.5	3.2 * 3.0 †
concept developed	4.2 4.5	4.2 4.5	3.3 4.0	3.4 3.0	- -	
Public Policy factual information	4.3 5.0	4.3 5.0	3.1 3.0	- -	4.1 4.5	3.2 3.0
concept developed	4.6 5.0	4.4 5.0	3.5 3.0	3.9 4.0	- -	

Content Review: Student Activities 18 reviewers

#1 Our Genetic Future?

(Section rated on a 5-point scale: 1 = lowest and 5 = highest)

* means † medians	accurate	appropriate	technical	clear	current
factual information	3.8 * 5.0 †	3.8 5.0	2.7 3.0	- -	3.8 5.0
concept developed	4.3 5.0	4.2 5.0	3.0 3.0	3.9 5.0	- -
teacher's annotations	4.0 5.0	4.0 5.0	2.9 3.0	- -	3.9 5.0
figures and tables	3.2 4.0	3.5 4.0	2.9 3.0	- -	3.1 4.0

(Section rated on a 4-point scale) poor fair good excellent

choice of activities	3.2 * 3.0 †
presentation of concepts	3.1 * 3.0 †
general rating of section	3.3 * 3.5 †

#2 DNA Sequencing

(Section rated on a 5-point scale: 1 = lowest and 5 = highest)

* means † medians	accurate	appropriate	technical	clear	current
factual information	4.1 * 5.0 †	4.6 5.0	3.4 3.0	- -	4.4 5.0
concept developed	4.1 5.0	4.4 5.0	3.3 3.0	4.1 4.0	- -
teacher's annotations	4.4 5.0	4.6 5.0	3.2 3.0	- -	4.6 5.0
figures and tables	4.1 5.0	4.4 5.0	2.9 3.0	- -	4.4 5.0

(Section rated on a 4-point scale)

	poor	fair	good	excellent
choice of activities			3.5 * 4.0 †	
presentation of concepts			3.3 * 3.0 †	
general rating of section			3.4 * 3.5 †	

#3 The Case of Nathaniel Wu

(Section rated on a 5-point scale: 1 = lowest and 5 = highest)

* means † medians	accurate	appropriate	technical	clear	current
factual information	4.4 * 5.0 †	4.5 5.0	3.2 3.0	- -	4.5 5.0
concept developed	4.5 5.0	4.7 5.0	3.1 3.0	4.5 5.0	- -
teacher's annotations	4.3 5.0	4.3 5.0	3.2 3.0	- -	4.3 5.0
figures and tables	3.6 4.0	3.4 5.0	2.3 3.0	- -	3.1 4.0

(Section rated on a 4-point scale)

	poor	fair	good	excellent
choice of activities				3.8 * 4.0 †
presentation of concepts			3.6 * 4.0 †	
general rating of section			3.7 * 4.0 †	

#4 Public Policy

(Section rated on a 5-point scale: 1 = lowest and 5 = highest)

* means † medians	accurate	appropriate	technical	clear	current
factual information	4.4 * 5.0 †	4.6 5.0	3.2 3.0	- -	4.6 5.0
concept developed	4.4 5.0	4.5 5.0	3.1 3.0	4.0 4.0	- -
teacher's annotations	4.4 5.0	4.4 5.0	3.2 3.0	- -	4.6 5.0

(Section uses a 4-point scale)

	poor	fair	good	excellent
choice of activities			3.1 * 3.0 †	
presentation of concepts			3.1 * 3.0 †	
general rating of section			3.2 * 3.0 †	

Optional Activity: The PCR

(Section rated on a 5-point scale: 1 = lowest and 5 = highest)

* means † medians	accurate	appropriate	technical	clear	current
factual information	4.2 * 5.0 †	4.2 5.0	3.6 3.0	- -	4.7 5.0
concept developed	4.4 5.0	4.1 5.0	3.5 3.0	3.6 4.0	- -
teacher's annotations	4.4 5.0	4.3 5.0	3.5 3.0	- -	3.6 4.0
figures and tables	4.4 5.0	4.3 4.0	3.4 3.0	- -	4.3 5.0

(Section uses a 4-point scale)

	poor	fair	good	excellent
choice of activities			3.0 * 3.0 †	
presentation of concepts			3.0 * 3.0 †	
general rating of section		2.8 *	3.0 †	

APPENDIX H

Results of the Teachers' Evaluation

Teacher's Evaluation: Teacher Narrative (16 responses)

ratings based on a 5.0 scale, anchors are given.

question about the narrative		mean	median	
enough information	too much	2.7	3.0	not enough
# of figures in narrative	too few	2.8	3.0	too many
gives enough background to connect activities	not enough	4.1	5.0	enough
enough background to help make transition from scientific inquiry to ethical inquiry	not enough	4.2	4.5	enough
easy to read	difficult	3.7	4.0	easy
written clearly	confusing	4.0	5.0	clear
references useful	not useful	3.3	4.0	useful
references available	not available	2.9	3.5	available
glossary is	poor	3.7	4.0	excellent
accuracy of information is	poor	4.1	4.0	excellent
sequence of information is	poor	4.2	4.0	excellent
timeliness of the information	poor	4.4	5.0	excellent
appropriateness of information	poor	4.2	4.5	excellent
writing style	poor	4.1	4.0	excellent
layout	poor	3.8	4.0	excellent
size of type	poor	4.1	4.0	excellent
quality of blackline masters	poor	3.8	4.5	excellent
in general narrative is	poor	4.6	5.0	excellent
in general narrative is	confusing	4.6	5.0	clear
in general narrative is	lacks information	4.4	5.0	has sufficient information

A large difference between the mean and the median indicates possible strong dissenting opinions.

Teacher's Evaluation: Activity #1 *Our Genetic Future* (16 responses)

General Questions:

Responses based on either 2 = yes; 1 = no

	mean	median
reading level appropriate	1.5	yes
provide enough information for the teacher	1.8	yes
suggestions for teaching clear	1.8	yes
activity appropriate	1.7	yes
concepts important	1.8	yes
concepts relevant	1.8	yes
student engaged and excited	1.3	yes

Coverage of Concepts:

ratings based on a 5.0 scale, anchors are given.

		mean	median	
everyone has a genetic profile	poor	4.8	5.0	excellent
traits are the result of both environment and genes	poor	4.3	5.0	excellent
soon it will be possible to determine genetic profiles	poor	4.0	4.0	excellent
employers may use profiles to make personnel decisions	poor	4.5	5.0	excellent
human variation results from genetic difference interacting with environment	poor	4.2	4.5	excellent
genes code for inherited traits	poor	4.4	5.0	excellent
genetic profiles could become public record	poor	3.8	4.0	excellent

Teacher's Evaluation: Activity #1 *Our Genetic Future*

Other Issues of Concern:

ratings based on a 5.0 scale, anchors are given.

		mean	median	
prior knowledge required	inappropriate	4.5	5.0	appropriate
help students understand both environmental and genetic factors influence	did not help	4.4	5.0	helped
expected to know difference between genotype and phenotype	inappropriate	4.9	5.0	appropriate
distinction clear between HGP and individual's genetic profile	not clear	4.1	5.0	clear
students understand genetic profiles might be used to make decisions	did not understand	3.8	4.0	understood
see pop-it beads as a model of gene	missed connection	4.2	4.0	made connection
directions clear	hard to follow	4.1	4.0	clear
directions useful	not useful	4.1	4.0	useful
information for student is	not enough	2.9	3.0	enough
information for student is	not useful	4.2	4.0	useful
questions are	poor	3.9	4.0	excellent
questions are	confusing	3.9	4.0	clear
participation in class was	low	3.9	4.0	high
participation is class was	unenthusiastic	4.2	4.0	enthusiastic

Teacher's Evaluation: Activity #2 *DNA Sequences* (16 responses)

General Questions:

Responses based on either 2 = yes; 1 = no

	mean	median
possible to complete activity if not familiar with codons, transcription, and translation	1.3	no
map is a useful metaphor	1.6	yes
reading level appropriate	1.8	yes
provide enough information for the teacher	1.8	yes
suggestions for teaching clear	1.8	yes
activity appropriate	1.7	yes
concepts important	1.9	yes
concepts relevant	1.8	yes
student engaged and excited	1.4	yes

Coverage of Concepts:

ratings based on a 5.0 scale, anchors are given.

		mean	median	
it is possible to determine DNA sequence	poor	4.4	5.0	excellent
a mutation is a change in the DNA sequence	poor	4.0	4.0	excellent
not all mutations result in a genetic disorder	poor	4.1	4.0	excellent
comparison of DNA sequences is the process used to determine the code for the disorder	poor	3.8	4.0	excellent
human errors do occur when reading the sequence data	poor	3.4	3.5	excellent

Teacher's Evaluation: Activity *#2 DNA Sequences*

Other Issues of Concern:

ratings based on a 5.0 scale, anchors are given.

		mean	median	
prior knowledge required	too much	4.2	5.0	right amount
help students understand different codons can code for same amino acid	did not help	4.8	5.0	helped
help students understand mutation is a variation in DNA sequence and does not always result in genetic disorder	did not help	4.4	5.0	helped
appropriate to expect students to know transcription, translation, an the idea of a genetic code	inappropriate	3.3	4.0	appropriate
students see the connection between first two activities	missed connection	3.8	4.0	made the connection
make distinction between mapping and sequencing	missed distinction	3.7	4.0	made distinction
format for DNA data appropriate	inappropriate	4.6	5.0	appropriate
directions clear	hard to follow	4.2	4.5	clear
directions useful	not useful	4.1	4.5	useful
information for student is	not enough	3.0	3.0	enough
information for student is	not useful	3.7	4.0	useful
questions are	poor	3.8	4.0	excellent
questions are	confusing	3.5	4.0	clear
participation in class was	low	3.5	4.0	high
participation is class was	unenthusiastic	3.6	4.0	enthusiastic

Teacher's Evaluation: Activity #3 *Case of Nathaniel Wu* (16 responses)

General Questions:

Responses based on either 2 = yes; 1 = no

	mean	median
reading level appropriate	1.9	yes
provide enough information for the teacher	1.9	yes
suggestions for teaching clear	2.0	yes
activity appropriate	2.0	yes
concepts important	2.0	yes
concepts relevant	2.0	yes
student engaged and excited	2.0	yes

Coverage of Concepts:

ratings based on a 5.0 scale, anchors are given.

		mean	median	
need to identify both cost and benefits when making decisions	poor	4.3	4.0	excellent
discrimination can be both justified and unjustified	poor	4.3	4.0	excellent
ethical inquiry is a logical and systematic process	poor	3.6	4.0	excellent
teaching the tools of ethical inquiry	poor	3.7	4.0	excellent
possible to detect predisposition for genetic disorders	poor	4.8	5.0	excellent
ethical decision making is complicated by genetic variation	poor	3.9	4.0	excellent

Teacher's Evaluation: Activity #3 *Case of Nathaniel Wu*

Questions about Activity:

Responses based on either 2 = yes; 1 = no

	mean	median
able to list reasons to hire Nathaniel	2.0	yes
able to list reasons not to hire Nathaniel	2.0	yes
difficulty to perform role of decision makers	1.4	no
role-playing help students understand ethical inquiry	1.8	yes
can complete activity without knowing how to make and analyze arguments	1.3	no
difficult to complete questions	1.0	no
homework assignment appropriate	1.8	yes
difficult to make arguments for Part II	1.2	no
process of ethical inquiry well developed	1.6	yes
student need more background in ethics	1.5	1.5

Teacher's Evaluation: Activity #3 *Case of Nathaniel Wu*

Other Issues of Concern:

ratings based on a 5.0 scale, anchors are given.

		mean	median	
help students understand genetic screening can detect genetic disorders	did not help	4.8	5.0	helped
help students understand decision making should include both costs and benefits	did not help	4.2	5.0	helped
made students articulate reasons both for and against hiring Wu	not successful	4.3	5.0	successful
make distinction between justified and unjustified discrimination	missed distinction	4.3	5.0	made distinction
appropriate to expect students to take and defend a position	inappropriate	4.4	5.0	appropriate
students connected all three activities	missed connection	4.0	4.0	made connection
use of employment hearing appropriate	inappropriate	4.9	5.0	appropriate
directions clear	hard to follow	4.8	5.0	clear
directions useful	not useful	4.6	5.0	useful
information for student is	not enough	2.9	3.0	enough
information for student is	not useful	4.1	5.0	useful
questions are	poor	3.7	4.0	excellent
questions are	confusing	3.4	4.0	clear
participation in class was	low	4.9	5.0	high
participation is class was	unenthusiastic	4.6	5.0	enthusiastic

Teacher's Evaluation: Activity #4 *Public Policy* (16 responses)

General Questions:

Responses based on either 2 = yes; 1 = no

	mean	median
reading level appropriate	1.6	yes
provide enough information for the teacher	1.7	yes
suggestions for teaching clear	1.5	yes
activity appropriate	1.6	yes
concepts important	1.7	yes
concepts relevant	1.7	yes
student engaged and excited	1.2	no

Coverage of Concepts:

ratings based on a 5.0 scale, anchors are given.

		mean	median	
society uses public policy to regulate behavior	poor	3.5	4.0	excellent
predisposition to genetic disorder might result in discrimination	poor	4.4	4.0	excellent
predisposition to genetic disorder may be classified as a disability	poor	3.8	4.0	excellent
public policy must address three conditions	poor	4.1	4.0	excellent
HGP will generate social issues	poor	4.6	5.0	excellent

Teacher's Evaluation: Activity #4 *Public Policy*

Questions about Activity:

Responses based on either 2 = yes; 1 = no

	mean	median
issues presented on overheads clearly written	1.4	no
able to list questions for each issue	1.8	yes
difficulty in seeing difference between ethics and public policy	1.2	no
difficulty in identifying various meanings of fairness	1.1	no
difficulty in understanding the importance of urgency	1.1	no
difficulty in understanding the importance of means	1.2	no
difficulty in understanding the importance of effectiveness	1.4	no
understand that not enacting legislation is a response to ethical dilemmas	1.7	yes
did you use our test items	1.1	no
student need more background on the disability act in order to successfully complete this activity	1.3	no

Other Issues of Concern:

ratings based on a 5.0 scale, anchors are given.

		mean	median	
help students understand public policy is method to protect public welfare	did not help	4.0	4.0	helped
help students understand public policy must meet 3 conditions	did not help	4.3	4.0	helped
provided enough background on ethical inquiry to complete activity	too much	3.8	3.5	not enough
provided enough background on public policy to complete activity	too much	3.7	3.5	not enough
appropriate to expect students to take and defend a position	inappropriate	4.1	4.0	appropriate
help students argue both for and against the disabilities act	did not help	3.4	4.0	helped
5 issues used for group discussion appropriate	inappropriate	3.5	4.0	appropriate
students make distinction between being predisposed to a genetic disorder and having a disability	missed distinction	4.1	4.5	made distinction
connect all activities together	missed connection	3.8	5.0	made connection
help students understand difference between urgency, means, and effectiveness in public policy	did not help	3.6	4.0	helped
help students understand that HGP will generate issues that must be addressed through public policy	did not help	4.5	5.0	helped
directions clear	hard to follow	3.7	4.0	clear
directions useful	not useful	3.5	4.0	useful
information for student is	not enough	3.1	3.0	enough
information for student is	not useful	3.8	4.0	useful
questions are	poor	2.7	3.0	excellent
questions are	confusing	2.5	2.0	clear
participation in class was	low	3.5	4.0	high
participation is class was	unenthusiastic	3.4	4.0	enthusiastic

Teacher's Evaluation: Laboratory Materials 16 reviewers

* means † medians	interesting (first two columns rated on 4.0 scale 1 = most, 4 = least)	difficult	expected knowledge of genetics (uses a 3.0 scale 1 = too little 3 = too much)	time spent on activity	students understood ideas (uses scale with 1 = no 2 = yes)	needed more information
Activity 1	2.4 * 2.0 †	2.9 3.0	1.8 2.0	1.9 2.0	1.9 2.0	1.2 1.0
Activity 2	2.4 2.0	2.3 2.0	2.0 2.0	1.1 1.0	1.8 2.0	1.6 2.0
Activity 3	1.7 1.0	2.3 2.0	1.8 2.0	1.6 2.0	1.8 2.0	1.1 1.0
Activity 4	2.4 2.0	2.3 2.0	1.8 2.0	1.6 2.0	1.5 2.0	1.4 2.0
Activity Optional	- -	- -	- -	- -	- -	- -

Student's Evaluation: Laboratory Materials 295 reviewers

means only	interesting (first two columns rated on 4.0 scale 1 = most, 4 = least)	difficult	expected knowledge of genetics (uses a 3.0 scale 1 = too little 3 = too much)	time spent on activity	understood ideas (uses scale with 1 = no 2 = yes)	needed more information
Activity 1	2.4	2.5	1.9	1.8	1.9	1.1
Activity 2	2.5	2.4	2.0	1.8	1.7	1.1
Activity 3	2.0	2.3	2.0	1.9	2.0	1.1
Activity 4	2.2	2.1	1.9	1.7	1.6	1.2
Activity Optional	- -	- -	- -	- -	- -	- -

Teacher's Responses to *YES / NO* questions based on 16 responses.

	(1 = no and 2 = yes) mean	median
Did the narrative **help you teach** each activity?	1.8	2.0
Did the schedule provide **enough time** for each activity?	0.8	1.0
Could this module be effective with a **break between activities**?	1.7	2.0
Did your students have **difficulty completing** any activities?	1.4	1.0
Did your students have **difficulty reading** this material?	1.6	2.0
Would your students **enjoy more activities** like these?	1.8	2.0
Was the brochure *Career Opportunities in Genetics* helpful?	1.1	1.0
Did the *Human Genome Poster* enhance the module?	1.6	2.0
Is the *Human Genome Poster* necessary?	1.3	1.0
Did the Advertisement on cystic fibrosis screening enhance the module?	1.7	2.0
Would an electrophoresis activity be an appropriate extension?	1.7	2.0
Would the cost prevent you from using an electrophoresis activity?	1.7	2.0
Would a simulation of gel electrophoresis be an appropriate extension?	1.7	2.0
Would the cost prevent you from using a simulation activity?	1.3	1.0
Did you use all of the student test questions?	1.3	1.0
Did you teach these activities as written?	1.5	2.0
Would you do more activities like these?	2.0	2.0
Would other high school students enjoy these modules?	1.8	2.0
Would other high school teachers enjoy these modules?	2.0	2.0

Student's Responses to *YES / NO* questions based on 295 responses.

	(1 = no and 2 = yes) mean
Did you have any **difficulty reading** this material?	1.2
Would you like to **do more activities** like these?	1.7
Will other high school students **enjoy this set** of activities?	1.6
Do you think it is important to **learn about genetics**?	1.9
Do you think it is important to **learn about ethics and public policy**?	1.6
Do you think research on the Human Genome Project is **worth the effort**?	1.7

Mapping and Sequencing the Human Genome:
Science, Ethics, and Public Policy

Summary of Teacher Comments

Submitted by
Katherine A. Winternitz
BSCS Project Director

10 March 1992

Evaluation of Teacher Narrative

There were not many unfavorable comments. Many teachers thought we should add additional information on how to teach ethics and public policy, and how to foster good classroom discussions. Some teachers wanted to have more technical information on testing. Figures 2, 3, and 4 were the most helpful and Figure 9 was the least helpful. One teacher thought the pie chart should be omitted; another thought Figures 4a and 4b should be omitted.

Activity 1
Our Genetic Future?

Overall, teachers liked this activity. Some students had difficulty with questions 5 and 6--they did not understand how the term *variability* was being used and some did not understand multifactorial traits. Some teachers thought we should change the job (one suggested and AIDS research scientist). Several teachers thought we should personalize the activity more either by increasing the emphasis on the ownership of the profiles or assigning identities to students. One teacher suggest that we have a mock interview with candidates 3, 5, 7, and 9 to underscore the importance of the interview and to emphasize that having certain genes does not necessarily translate into those traits coded for. A few teachers thought we should emphasize the relationship between genes and the environment more. Student objectives were adequately covered.

Activity 2
DNA Sequences

Generally, teachers liked this activity. Most teachers, however, recognize that students should know about codons, transcription, and translation before they begin this activity. Without this information, they feel the students could complete the activity, but it would be meaningless. Some students were frustrated by Rico 2 and some had difficulty determining how Rico's DNA was different from the others. Some classes had difficulty proposing a hypothesis to step 6--most students responded by saying "There are some bases missing." Some students are not familiar with the term *deletion*. The metaphor of a map generally was helpful. To make the activity more interactive, some teachers suggested we have some students act as lab techs, that we pair students as couples, that we assign a persona to students, and that we increase the amount of time we allow for the activity. Only two teachers had minor suggestions on how to improve the activity. Student objectives are covered adequately, but one teacher thought we should develop #1 more.

Activity 3
The Case of Nathaniel Wu

This was the most popular activity with the teachers. Most teachers thought students could complete the activity, although some thought we should instruct teachers to take additional time to prepare the students to analyze information and develop their ability to formulate well-reasoned thoughts. Most students did not have difficulty performing their roles as decision makers. Some teachers commented that students wound up arguing against their personal opinion, which is good. Role playing generally was helpful for students. Many teachers thought

that students need more background in ethics, mainly because this is not covered in any other subject area. One teacher had her classes arguing against other biology classes with the principal and 2 seniors as the decision makers. Some teachers thought we could provide additional information on Huntington disease. Objectives were covered.

Activity 4
Public Policy

Teachers feel the issues used for small group discussion are vague. Some students had difficulty distinguishing between ethics and public policy, some students did not understand *means* and *urgency*--most did better with *effectiveness*. In general, students did not understand that society may react to ethical dilemmas by enacting legislation or by *not* enacting legislation. Teachers did not use test items 6 through 8, either because there was not enough time or because students were not interested in this part of the activity. Most teachers felt students need additional background in ethics, public policy, and the disability act before they could complete the activity and understand it. Teachers thought the student objectives were adequately covered.

Optional Activity
The PCR

Most teachers did not have enough time to do this activity. Using the paper strips for strands of DNA may not be an appropriate model--students think that PCR cuts DNA into smaller pieces. Teachers think that students need additional background in ethics. We should not worry about using cystic fibrosis as an example in this activity. To make the activity more interactive, teachers suggested that we pair up students as couples or that we have students deliver their DNA to the lab, a lab tech doubles, doubles, and doubles the DNA and passes it to lab tech 2, who matches it for CF. One teacher thought we should decrease the number of students who end up with CF. One teacher thought we should use metric measures (mL or cm^3 instead of ounces and pints.

Teacher's Final Evaluation

Most teachers thought Activity 4 was the most difficult. It was a let-down after Nathaniel Wu and students were bored. Activity 4 also was the most difficult to teach. Most prep time was expended in sorting beads; most did not have time to look for articles for Activity 4. Most teachers taught the activities as they are written, although some did not use all the test questions. One teacher had students do the reading in small groups out loud so they could help each other with comprehension. Most teachers thought Activity 4 had too many questions, particularly for the amount of time. Almost all teachers agree that we have not provided enough time to complete the activities so that students adequately understand the material. Most thought Activity 4 should take 2 class periods. Most teachers took 10 days to complete all the activities (if they did #4), otherwise they needed about 8 days. Most teachers agree that Activities 1,2, and 3 are the most crucial, followed by Activity 4. Activity 5 received 1 vote.

APPENDIX I

Results of the Students' Evaluation

To sample student responses, we selected 5 evaluation forms at random from 19 classes of differing abilities and locales. All official field-test sites are included, as well as sites where teachers did not have the benefit of orientation. There does not appear to be any great difference in student responses between the two types of sites. The following summaries reflect overall student responses, as well as some of the negative replies.

Activity 1
Our Genetic Future?

In general, students felt this was a good activity, although some higher-ability students did not like the pop-it beads. Many students did not relate well to the space trip scenario--they did not feel it was likely to happen to them. They also have a problem conceptualizing a 20-year time span. Some students suggested we chose a job that relates more closely to their age level.

Activity 2
DNA Sequences

Again, most students liked this activity, but they found it confusing and some felt they needed more information. Many students wanted more information on cystic fibrosis.

Activity 3
The Case of Nathaniel Wu

Most students enjoyed this activity more than any other. In general, they liked the group discussion format and being able to discuss their opinions with others. Many students liked finding out how an apparently easy decision could become difficult. Many students changed their minds after debating the pro and cons of hiring Nathaniel. The tone and wording of their comments, however, suggest that we have not done a good job at presenting discrimination on the basic of a genetic profile as a *possibility*, not a *certainty*.

Activity 4
Public Policy

This activity presented the most problems for both teachers and students. Students did not feel they had enough information and did not understand the material very well. Most negative comments are that it was boring and dry, mostly because of the structure of the activity and the presentation. Some students had difficulty understanding the five issues. Some students suggested that we reformat the activity to use a group discussion, such as in Activity 3 (they like debating).

Optional Activity
The PCR

This was the least favorite activity of the students. Many students did not understand it and they did not like the math. They felt we did not provide enough information and that we did not allot enough time for the activity. Some students observed that it seemed out of place with the other activities. There are some problems using strips of paper as a model of DNA in PCR. One class thought that PCR cuts DNA into shorter strips to multiply the number of strands.

Opinions on the Human Genome Project

Comments are polarized. Most students feel the research is important to help scientists locate genes, help cure genetic diseases, and prevent disorders. Those students with negative comments feel the HGP will cause discrimination. Very few students express mixed feelings. Of 95 written student responses, only 14 replied that the HGP might help people, but also that it may have negative effects. We may not have done a good job at indicating there could be both benefits and risks, and these are possibilities, not certainties.

Suggestions for improving this module

Most students would like to have more opportunities for group discussion and more hands-on activities. Many students would like to have more information on cystic fibrosis, Huntington disease, and similar genetic disorders. Students also would like more explanation for some of the activities, such as PCR, Public Policy, and DNA Sequences. Students also would like more information on the HGP itself, similar to what is contained in the teacher narrative. Many students wanted more time to complete the activities.

APPENDIX J

Analysis of Data from Student Pre- and Post-surveys

Student Understanding of the
Science, Ethics, and Public Policy Issues Raised by
Mapping and Sequencing the Human Genome

Student Understanding of the Science, Ethics, and Public Policy Issues Raised by Mapping and Sequencing the Human Genome

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5 January 1993

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Mapping and Sequencing the Human Genome: Science, Ethics, and Public Policy

Introduction

In 1991 and 1992, BSCS developed a series of activities designed to improve student understanding of the Human Genome Project. We developed these materials to increase student awareness of some of the ethical issues that might arise as a result of this national effort to map and sequence the human genome and to increase student understanding of the process by which public policy is determined. BSCS developed and field tested five activities during the 1991-1992 academic year. Although we provided all field test sites with the student modules and a teacher's guide, only six teachers received training by the BSCS staff in the use and philosophy of the materials. At all of the field-test sites teachers gave their students a survey both before and after using the modules. The students were to indicate whether they agreed or disagreed with 35 statements about the Human Genome Project. The statements in the survey are clustered into four categories: an understanding of genetics, an understanding of the purpose of the Human Genome Project, an understanding of ethics as a way to solve social problems, and an understanding of public policy as a process of legislating social behavior. See Appendix A for a copy of the survey instrument.

We analyzed the data on student attitudes from ten field-test sites, five randomly selected from the six that received staff development and five randomly selected from the sites that received only the instructional materials through the mail. A total of 583 students returned the pre-survey and 577 students returned the post survey. The survey presented the students with the following five point scale on which to mark their choices: 1 = strongly disagree, 2 = agree, 3 = I don't know, 4 = agree, and 5 = strongly agree. We determined the median response to each question and used the Kruskal-Wallis one-way analysis of variance test to determine whether there was any significant change in the median student response prior to the students using our materials to after using the modules.

Attitudes Toward Ethics and Understanding of Public Policy

The survey included seventeen questions about ethics and public policy. As shown in Table 1,. thirteen of these questions resulted in a statistically significant change in student responses. These results indicate that these educational materials are fairly successful in making students more aware of some of the ethical and public policy issues associated with the Human Genome Project. Note, however, that providing staff development for teachers before they use the materials appears to increase the effectiveness of the materials. The surveys returned by the students whose teachers received staff development before using the materials showed a statistically significant change in the median response to twelve of these questions while those students whose

top number is the mean, bottom number is the median.	Received Staff Development		No Staff Development	
Question	pre	post	pre	post
The public should be involved in regulating the Human Genome Project.	3.33 3.00	3.97 4.00	3.42 4.00	3.66 4.00
The federal government should regulate the Human Genome Project.	3.00 3.00	3.30 3.00	3.09 3.00	3.28 3.00
Everyone should have access to the information that results from the genome project.	3.24 4.00	2.34 2.00	2.88 2.00	2.45 2.00
Employers should have access to genetic profiles so they can hire the best person for the job.	1.94 2.00	2.26 2.00	2.42 3.00	2.71 2.00
We need laws to protect people with a genetic predisposition to a disease from discrimination.	4.07 4.00	4.24 5.00	3.89 4.00	3.98 4.00
Good public policy must fulfill the conditions of urgency, means, and effectiveness.	3.73 4.00	4.24 4.00	3.49 4.00	3.65 4.00
Passing new laws is the only way to make public policy.	2.70 3.00	2.88 3.00	2.82 3.00	3.09 3.00
Public policy should be determined only by weighing the benefits, costs, and risks involved.	3.37 3.00	3.06 3.00	results are not statistically significant	
Ethics is a way to deal with and solve social problems.	3.31 3.00	3.88 4.00		
Ethical inquiry is a method of solving problems.	3.27 3.00	3.61 4.00		
Ethics is a method of deciding how we should behave.	3.28 3.00	3.50 4.00		
Students should discuss ethical issues in science classes.	3.74 4.00	3.86 4.00		
If most of the people in the country feel that they have a right to a safe and healthy environment, then we should make laws to protect that right.	pre mean = 4.04 median = 4.00		post 3.91 4.00	

Table 1. *Ethical and public policy questions showing a statistically significant response (Kruskal-Wallis Test, $\alpha = 0.05$).*

teachers received the materials through the mail showed a statistically significant change in the median response to only seven of the questions. One question (the last one in the table concerning the need to pass laws when people feel they have a right to a safe and healthy environment) did not appear to be statistically significant for either group, but when we combined the responses from both groups this question shows a significant change in response from the pre-survey to the post survey. This result might indicate that regardless of teacher preparation, these educational materials produce a change in the students' attitudes about the need to legislate public policy for the common good.

A review of the information in Table 1 reveals a discrepancy in student responses about who should have access to the information that might be generated as a result of mapping and sequencing the human genome. Observe that for the third question listed in the table, the students' attitudes shift away from agreeing towards disagreeing that everyone should have access to the information, but for the fourth question, the students' responses shift towards being more neutral on whether employers should have access to the information. Perhaps this discrepancy is resolved by factoring in the results to the fifth question, where students strongly agree that we need laws to protect against discrimination. One might infer from these results that employers can use the information, but that they should be prohibited from practicing any type of discrimination as a result of knowing the genetic profile of an individual.

This survey indicated that students' attitudes changed in the following areas. The students tended to agree that there is a need to regulate the Human Genome Project. They shifted away from disagreeing that the only way to make public policy is to pass new laws toward being more neutral about this aspect. The students at all of the sites showed an increased agreement that good public policy must fulfill the conditions of urgency, means, and effectiveness.

Understanding of Genetics and the Human Genome Project

Eighteen questions in the survey dealt with the students' understanding of the Human Genome Project and related genetic concepts. Once again, we observed a statistically significant change in student response for eleven of these questions (see Table 2). The influence of staff development on student response is even more striking for this set of questions than for the previous set of questions. For the students whose teachers received staff development, there was a statistically significant difference in student responses to nine questions. Only three questions, however, showed a significant difference in student responses for students whose teachers did not have any training with the materials before using the modules in their classroom.

Students in both groups showed a statistically significant change in their responses to the item about whether the Human Genome Project was exciting (the students agreed it is) and to the questions about the creation of a genetic profile (the students agreed that the genome project will make it possible). Although there was the anticipated shift

top number is the mean, bottom number is the median.	Received Staff Development		No Staff Development	
Question	pre	post	pre	post
The scientists working on the Human Genome Project are doing very exciting work.	3.56 4.00	3.77 4.00	3.38 3.00	3.52 4.00
The Human Genome Project will make it possible to know everyone's genetic profile.	3.62 4.00	3.74 4.00	3.48 4.00	3.72 4.00
Once the human genome is mapped, it will be possible to know everyone's genetic profile.	3.56 4.00	3.73 4.00	3.43 3.00	3.63 4.00
The Human Genome Project will make it possible to know exactly what skills and abilities someone will have when he or she becomes an adult.	2.62 2.00	2.38 2.00	results are not statistically significant	
Once a genetic profile is available, it will be possible to predict exactly how someone will look and behave.	2.60 3.00	2.17 2.00		
The traits I will have as an adult depend only on my genetic information.	2.51 2.00	2.30 2.00		
The abilities and skills I will have as an adult depend both on my genetic information and environment.	3.75 4.00	4.14 4.00		
Doctors may be able to use my genetic profile to know whether I have a predisposition to certain diseases.	4.19 4.00	4.41 4.00		
One purpose of the genome project is to learn about human variation.	3.77 4.00	4.03 4.00		
The Human Genome Project is an attempt to map the location of every gene in the human genome.	pre mean = 3.85 median = 4.00		post 3.90 4.00	
The scientists working on the Human Genome Project are doing very important work.	mean = 4.05 median = 4.00		4.18 4.00	

Table 2. *Genetics and genome project questions that show a statistically significant response (Kruskal-Wallis Test, $\alpha = 0.05$).*

in the students' understanding that knowing someone's genetic profile does not make it possible to predict exactly how someone will look or behave, only those students in the staff development group showed the desired shift (see the fourth, fifth, and sixth questions in Table 2).

These same students also showed a shift towards agreeing that a genetic profile might make it possible to identify a predisposition to certain diseases, that an additional benefit of the genome project is to learn more about human variation, and that both genetic information and the environment influence what skills and abilities someone will have as an adult. Note that when one compares student responses before and after using these materials, there is a statistically significant increase in the number of students agreeing that the purpose of the Human Genome Project is to map the location of every gene in the human genome and that this effort is very important work.

Effectiveness of the Modules

For 24 of the 35 questions, the students' median response changed from "I don't know" towards either agree or disagree with the statement. Because the Kruskal-Wallis analysis of variance test identifies whether there is a change in the median scores obtained, this large number of statistically significant results suggests that these materials were effective in producing the desired change in students' awareness and understanding of the topics covered. In summary, this module on the Human Genome Project appears to be effective in the following areas: 1) students became aware that the Human Genome Project will make it possible to produce a genetic profile for an individual, 2) students became aware that knowing someone's genetic profile might result in possible discrimination, and 3) students understand that good public policy must fulfill three essential conditions of urgency, means, and effectiveness.

The positive implications of these findings are tempered by the discrepancy in student responses between those teachers who attended staff development workshops and those teachers that did not have any training in the use and philosophy of the materials. When teachers attend staff development workshops about the use of these materials, the overall effectiveness of the module is even greater. We observed the influence of this training most frequently in 1) an increase in the student's awareness of the role of ethics and ethical inquiry in dealing with social issues, and 2) the teachers' willingness to allow students to discuss ethical issues in the science classroom. A third area in which we observed the influence of staff development was the increase in students' understanding of the interplay between genetic information and the environment in the expression of traits in an adult.

Implications for In-service and Pre-service Teacher Education

Overall this student module achieves the developers' goal of increasing student awareness about some of the ethical problems that will arise as we know more about the

human genome, especially the issue of discrimination. It might be possible to obtain the same gains shown by those students whose teachers received training in the use and philosophy of the educational materials in other classrooms if we could revise the teacher's guide in a manner that emphasizes the ethical and public policy training that the teachers received during the staff development sessions. The BSCS has consistently received feedback from teachers, however, that the more there is to read in the teacher's guide, the less useful the guide becomes. Thus, it is more likely that providing additional written information in the teacher's guide will not help teachers use the materials better but might inhibit teachers from using the module. The significant change in students' attitudes that we observed in this study was the direct result of providing teachers the opportunity to practice with materials and reflect on the objectives of the lessons. The results of this study indicate that useful curriculum materials are more effective when the teacher is given training and support in the use and philosophy of the materials.

APPENDIX K

Supported and Supplemental Field-Test Teachers and Sites

Supported Field-Test Teachers

Fran Crowley, Bell High School, South Gate, California

Dan Daniels, Minneola High School, Minneola, Kansas

Janice A. Fisher, Niwot High School, Longmont, Colorado

Elmer Kellmann, Parkway Central High School, Washington, Missouri

Carl Raab, Forth Hamilton High School, Brooklyn, New York

Patricia Chandler Smith, Socastee High School, Myrtle Beach, South Carolina

Raymond Urbanski, Oak Park and River Forest High School, Oak Park, Illinois

Supplemental Field-Test Teachers

Lynn Altwerger, Fort Hamilton High School, Brooklyn, New York

Richard N. Anderson, Lake Oswego High School, Lake Oswego, Oregon

Jonathan Bealer, Buena High School, Sierra Vista, Arizona

Carol Beckham, Socastee High School, Myrtle Beach, South Carolina

Ken Bingman, Shawnee Mission West High School, Shawnee Mission, Kansas

Mary B. Boldon, Maryville High School, Walland, Tennesee

Dwight Brown, Bountiful High School, Bountiful, Utah

Elizabeth Carvellas, Colchester High School, Colchester, Vermont

Charles Couchman, Coldwater High School, Coldwater, Kansas

Beth Cox, Socastee High School, Myrtle Beach, South Carolina

Peter F. DeDecker, Hastings High School, Hastings, Minnesota

Edward Drexler, Pius XI High School, Milwaukee, Wisconsin

Carolyn P. Hammond, Eastern Guilford High School, Gibsonville, North Carolina

William Hayes, Socastee High School, Myrtle Beach, South Carolina

Tim Henson, Niwot High School, Longmont, Colorado

Allen M. Jaggi, Lyman High School, Lyman, Wyoming

Sister Mary Carroll McCaffrey, Mt. St. Joseph Academy, Flourtown, Pennsylvania

Kevin McCarty, Socastee High School, Myrtle Beach, South Carolina

Karen E. O'Neil, The Annie Wright School, Tacoma, Washington

Spencer E. Reames, Benjamin Logan High School, Bellefontaine, Ohio

Leonard C. Smith, Lake Oswego High School, Lake Oswego, Oregon

Stephen Streff, Linn-Mar High School, Marion, Iowa

APPENDIX L

Teachers' Evaluation Instruments

Second Field Test

Mapping and Sequencing the Human Genome:
Science, Ethics, and Public Policy

Teacher's Evaluation of Activity 2
Do Genes Determine Our Genetic Future?

Name _____

Circle the number that best indicates your response to the following questions.

Student Materials

1. Is the amount of prior knowledge of genetics required for this activity appropriate?

   inappropriate -2 -1 0 1 2 appropriate

2. Did this activity help your students understand that environmental factors as well as genetic factors influence the expression of traits?

   did not help -2 -1 0 1 2 helped

3. Students are expected to know the difference between having the allele for a trait (the genotype) and expressing the trait (the phenotype). Is this expectation appropriate for your class?

   not appropriate -2 -1 0 1 2 appropriate

4. Was the distinction between the Human Genome Project and an individual's genetic profile clear by the end of this activity?

   not clear -2 -1 0 1 2 clear

5. Did your students understand that genetic profiles might be used to make employment decisions?

   did not understand -2 -1 0 1 2 understood

6. Did your students understand the importance of different alleles in a genetic profile?

   did not understand -2 -1 0 1 2 understood

7. Did your students understand that lifestyle can affect phenotype?

   did not understand -2 -1 0 1 2 understood

8. Did your students understand that the profiles showed 3 chromosome pairs and not 6 different chromosomes?

   did not understand -2 -1 0 1 2 understood

9. Were your students comfortable with the absence of a hands-on model?

uncomfortable	**-2**	**-1**	**0**	**1**	**2**	**comfortable**

Student Instructions and Discussion Questions

10. The directions for the students are

hard to follow	**-2**	**-1**	**0**	**1**	**2**	**clear**
not useful	**-2**	**-1**	**0**	**1**	**2**	**useful**

11. The information provided to the student is

not enough	**-2**	**-1**	**0**	**1**	**2**	**too much**
not useful	**-2**	**-1**	**0**	**1**	**2**	**useful**

12. The discussion questions are

poor	**-2**	**-1**	**0**	**1**	**2**	**excellent**
confusing	**-2**	**-1**	**0**	**1**	**2**	**clear**

13. In general, participation in class discussion was:

low	**-2**	**-1**	**0**	**1**	**2**	**high**
unenthusiastic	**-2**	**-1**	**0**	**1**	**2**	**enthusiastic**

Please rate the coverage of the following concepts:		**poor**				**excellent**
14.	Everyone has a genetic profile.	1	2	3	4	5
15.	Traits are the result of both genes and environment.	1	2	3	4	5
16.	Determining an individual's genetic profiles soon will be possible.	1	2	3	4	5
17.	Genetic profiles may influence career decisions.	1	2	3	4	5
18.	Human variation results from genetic differences that interact with environmental variables.	1	2	3	4	5
19.	Genes code for inherited traits.	1	2	3	4	5
20.	Genetic profiles could become public record.	1	2	3	4	5

General Questions (please explain your answer).

21. Is the reading level appropriate for high school students? **yes** **no**
Comments:

22. Do we provide enough background information for the teacher? **yes** **no**
Comments:

23. Are the suggestions for teaching this activity clear? **yes** **no**
Comments:

24. Is this activity appropriate for high school students? **yes** **no**
Comments:

25. Are the concepts important for your students? **yes** **no**
Comments:

26. Are the concepts relevant to your students? **yes** **no**
Comments:

27. Were the students engaged and excited during this activity? **yes** **no**
Comments:

28. How might we make this activity more interactive?

29. What suggestions do you have for modifying or changing this activity?

30. Which, if any, of the student objectives for this activity are not adequately covered?

31. Should we propose a hands-on model (pop-it beads or paper clips, for example) as an alternative for teachers who feel their students will benefit from it?

Mapping and Sequencing the Human Genome:
Science, Ethics, and Public Policy

Teacher's Evaluation of Activity 4
Public Policy: Genetics and Alcoholism

Name _____

Circle the number that best indicates your response to the following questions.

Student Materials

1. Did this activity help your students understand that public policy is one method society uses to protect the public's welfare?

   did not help -2 -1 0 1 2 helped

2. Did this activity help your students understand that sound public policy must meet the conditions of urgency and effectiveness?

   did not help -2 -1 0 1 2 helped

3. Did this activity provide enough background information on ethical inquiry so that students can complete the activity?

   too much -2 -1 0 1 2 not enough

4. Did this activity provide enough information about public policy so that students can complete the activity?

   too much -2 -1 0 1 2 not enough

5. This activity addresses legislation that affects individual rights. We expect students to take and defend a position on this issue. Is this expectation appropriate for your class?

   not appropriate -2 -1 0 1 2 appropriate

6. Did this activity help your students construct arguments both for and against the proposed legislation to prohibit the sale of alcohol to certain individuals based on their genetic profile?

   did not help -2 -1 0 1 2 helped

7. Did your students make the distinction between being genetically predisposed to alcoholism and actually being an alcoholic?

missed the distinction	**-2**	**-1**	**0**	**1**	**2**	**made the distinction**

8. Did your students understand that the proposed law is made more complex by the uncertainty of the genetic environmental contributions to alcoholism?

did not understand	**-2**	**-1**	**0**	**1**	**2**	**understood**

9. Did the background information about alcoholism from the U.S. Department of Health and Human Services help your students in their consideration of the proposed legislation?

did not help	**-2**	**-1**	**0**	**1**	**2**	**helped**

10. Did this activity help your students understand the differences between urgency and effectiveness?

did not help	**-2**	**-1**	**0**	**1**	**2**	**helped**

11. Did this activity help your students understand that the Human Genome Project will generate many controversial issues that must be addressed through public policy?

did not help	**-2**	**-1**	**0**	**1**	**2**	**helped**

Student Instructions and Discussion Questions

12. The student directions are

hard to follow	**-2**	**-1**	**0**	**1**	**2**	**clear**
not useful	**-2**	**-1**	**0**	**1**	**2**	**useful**

13. The information we provided to the student is

not enough	**-2**	**-1**	**0**	**1**	**2**	**too much**
not useful	**-2**	**-1**	**0**	**1**	**2**	**useful**

14. The discussion questions are

poor	**-2**	**-1**	**0**	**1**	**2**	**excellent**
confusing	**-2**	**-1**	**0**	**1**	**2**	**clear**

15. In general, student participation in class was

low	**-2**	**-1**	**0**	**1**	**2**	**high**
unenthusiastic	**-2**	**-1**	**0**	**1**	**2**	**enthusiastic**

Please rate the coverage of the following concepts?	**poor**				**excellent**
16. Our society uses public policy to regulate public behavior.	1	2	3	4	5
17. Having a predisposition to a genetic disorder may result in discrimination.	1	2	3	4	5
18. Public policy must address two conditions: urgency and effectiveness.	1	2	3	4	5
19. The Human Genome Project will generate social issues that students must address in their lifetimes.	1	2	3	4	5

Other Issues

20. Did your students have difficulty in establishing the difference between ethics and public policy? **yes** **no**
If so, please explain.

21. Did your students have difficulty in identifying the various meanings of fairness? **yes** **no**
If so, please explain.

22. Did your students have difficulty understanding the importance of urgency in establishing public policy? **yes** **no**
Please explain.

23. Did your students have difficulty with understanding the importance of effectiveness in establishing public policy? **yes** **no**
If so, please explain.

24. Did your students understand that society sometimes responds to ethical dilemmas by enacting public policy through legislation and sometimes responds by not enacting any legislation? **yes** **no**
If so, please explain.

25. Did your students need additional background in ethics, public policy, or alcoholism before they could complete this activity? **yes** **no**
If so, please explain.

General Questions (please explain your answer).

26. Is the reading level appropriate for high school students? **yes** **no**
Comments:

27. Do we provide enough background information for the teacher? **yes** **no**
Comments:

28. Are the suggestions for teaching this activity clear? **yes** **no**
Comments:

29. Is this activity appropriate for high school students? **yes** **no**
Comments:

30. Are the concepts important for your students? **yes** **no**
Comments:

31. Are the concepts relevant to your students? **yes** **no**
Comments:

32. Were the students engaged and excited during this activity? **yes** **no**
Comments:

33. How might we make this activity more interactive?

34. What suggestions do you have for modifying or changing this activity?

35. Which, if any, of the student objectives for this activity are not adequately covered?

APPENDIX M

Additional Users of the Module

Users of HGN Experimental Materials, *Mapping and Sequencing the Human Genome: Science, Ethics, and Public Policy*

Dr. William Horton
Director, Division of Medical Genetics
University of Texas Medical School
Dept. of Pediatrics
Houston, TX

202 medical school students used parts of the module in a medical genetics course, spceifically Acitivity 3, Nathaniel Wu, and ethical issues/questions raised in the Section II of the teacher's narrative.

Dr. Lane Conn
San Francisco State University
Department of Biology
16 Holloway Ave.
San Francisco, CA 94132

100 plus medical students used parts of the module during an ethics course.

Karen O'Neil
The Annie Wright School
Tacoma, WA

Using module as part of a teacher-enhancement workshop on ethics and science.

Dr. Kenneth Garver
Dept. of Medical Genetics
West Penn Hospital
4800 Friendship Ave.
Pittsburg, PA 15224

Using HGN experimental materials as part of a course in medical genetics and ethics.

Dr. LeRoy Hood (Susan Grether)
Science and Technology Center
Beckman Institute, Room 260
CalTech, Pasadena, CA 91125

Using module as part of a workshop on ethics and technology at Caltech.

Ken Bingman, Debbie Collins, Tom Heintz
University of Kansas
Kansas City, KS 66208

Using materials as part of a teacher workshop on ethics, technology, and genetics

Susan Tinley (genetic counselor)
Boys Town Research Hospital
55 N. 30th
Omaha, NE 68131

Using materials as reference in DOE proposal for teacher-enhancement workshops in genetics and ethics. If proposal is funded, will use materials during course.

Ben Wilfong
University of Wisconsin

Materials will be used during a week-long teacher workshop on the ethical issues associated with the HGP.

Gordon Mendenhall
Ball State University
Muncie, IN

Using HNG materials with teachers in Michigan in workshop dealing with ethics and genetics.

APPENDIX N

The Human Genome Project
Relevant to Genetics Education in High School

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