Presidential Commission
for the Study of Bioethical Issues

Teacher Companion for *Deliberative Scenario: Law Enforcement Access to a University's Genetic Database*

This teacher companion provides instructors with step-by-step instructions for facilitating deliberation. The deliberative scenario, "Law Enforcement Access to a University's Genetic Database," is particularly well suited for science or government classes in high school and college, and can be used in a variety of other settings.

Phase 1: Before the Deliberation

Provide Background and Context

Provide students with "Deliberative Scenario: Law Enforcement Access to a University's Genetic Database" and with "Guide to Classroom Deliberation for Students and Teachers." Both are available on bioethics.gov in the *Education* section. If desired, assign additional readings on deliberation from the *Additional Resources* section in "Guide to Classroom Deliberation for Students and Teachers." Ask students to think about the differences between deliberation and debate or discussion, and the goals and method of deliberation.

Clearly state the goal of the deliberation: to develop a consensus on a practical policy for the requests from law enforcement to access the University's extensive genetic database developed primarily for biomedical research that is conducted on campus.

Provide all students with the following readings (available online) to learn about genetic privacy.
- Hayden, E.C. (2012, June 20). Informed consent: A broken contract. *Nature*. Retrieved April 19, 2016 from http://www.nature.com/news/informed-consent-a-broken-contract-1.10862.
- Presidential Commission for the Study of Bioethical Issues (PCSBI). (2012, October). Privacy and Progress in Whole Genome Sequencing. Washington, DC: PCSBI, pp. 1-11. Available at: http://bioethics.gov/node/764.

Assign Roles

Option 1: Assign each student a role from among the following stakeholders who might serve on the special purpose committee: institutional review board members, members of the genetic database governance board, students, research participants, researchers, university lawyers, law enforcement officers, and university administrators.

Option 2: Ask students to generate a list of stakeholders who would serve on the special purpose committee and assign roles from that list. The list should include participants with a wide variety of perspectives on the matter.

Note: You can also assign multiple students to the same role, as even people in the same role can have different perspectives. These readings provide additional perspective for each role.

Assign Role-based Readings

Based on a student's specified role, assign role-specific readings from the additional reading section at the end of this document.

Phase 2: During the Deliberation

Questions to Guide and Focus Deliberation

Remind students of the goal of this exercise: To practice democratic deliberation by considering many different perspectives, providing reasons for their arguments, listening respectfully to opposing viewpoints, and finding a way forward.

Instruct students to begin the deliberation by introducing themselves and stating which role they will play.

During the deliberation, ensure that the following questions have received sufficient attention. If a question has not been answered, pose the question to the group.
- Are there other ways in which this genetic information could be accessed? (Empirical question: provides factual evidence)
- How does the language of the informed consent document inform the considerations? (Empirical question: provides factual evidence)
- What effects might this have on future research recruitment? (Empirical question: provides factual evidence)
- When can expectations of privacy be overcome? (Normative question: provides answer to question of what we *should* do)
- What other values might be at stake? (Normative question: provides answer to question of what we *should* do)
- In what ways should the consent process be changed? (Normative question: provides answer to question of what we *should* do)
- If law enforcement wanted to use familial matching, would the considerations be different? (Normative question: provides answer to question of what we *should* do)
- How might we balance individual interests and societal interests in research and safety? (Normative question: provides answer to question of what we *should* do)

- What if the records being sought by law enforcement were not genetic—would this be meaningfully different? (Thought exercise: includes possible factual and moral consequences)

Strategies to Improve the Deliberative Process

If some students are quiet or refrain from contributing, ask the class: Are there any views that have been left out? Whose views might those be?

If there is a swift and seemingly straightforward answer or a premature dominant view developing that could crowd out other views, ask the class: What are some other perspectives that we have not heard or considered yet?

Strategies to Improve Content

If students come up with recommendations without justification, ask the class: How does justice relate to research? Are the recommendations compromising the research enterprise?

Scenario Shift

If the students reach consensus on recommendations with time leftover, you might introduce a shift in the scenario. Pick one or more of the following scenario shifts and ask students to discuss how this new information changes things.

- The murderer has struck again. There is increasing evidence that the murderer is a member of the university, or surrounding, community. Does this new information alter your policy? If so, how will you update it?
- An independent researcher who has access to a subset of samples from the biobank has offered to run the sample against his own database. Does your policy recommendation speak to this issue?
- Law enforcement tells you that they will be using familial matching to see if they can find a relative of the alleged perpetrator. Would you change your policy recommendation based on this new request? If so, what would you change?

Developing a Policy Recommendation

Ask the students to develop recommendations that reflect the consensus-driven process of deliberation. The recommendations should include mutually acceptable reasons for a policy choice.

Phase 3: After the Deliberation

Presenting the Policy Recommendation

Instruct students to write a half-page press brief for the local newspaper stating their recommendations and their justifications for them. Alternatively, ask students to present this information orally.

Assessment and Reflection

Ask the class to reflect on the process and outcome of the deliberation using the following questions.

- Do the recommendations provide reasons for a policy choice?
- Are all of the deliberators satisfied with the outcome? If not, was a dissenting statement included?
- Does this policy recommendation seem more legitimate than one decided by majority vote? By elected representatives? Why or why not?
- What are the strengths of deliberative decision making? What are the weaknesses?
- Is the set of recommendations contingent upon new facts or values coming to light? When would a new deliberation be needed?

Additional Role-based Readings

If the role assigned is an *institutional review board member*, assign the following reading:
- Office of Research, Florida State University. (n.d.). Human Subjects. Retrieved on April 19, 2016 from https://www.research.fsu.edu/research-offices/human-subjects/. (First three sections only).

If the role assigned is a *member of the genetic database governance board*, assign the following reading:
- Vanderbilt Research. (n.d.). What is BioVU? Retrieved April 19, 2016 from https://victr.vanderbilt.edu/pub/biovu/.

If the role assigned is a *student*, assign the following reading:
- Pollack, A. (2016, March 8). Genetic Test Firm to Make Customers' Data Publicly Available. *The New York Times*. Retrieved April 19, 2016 from http://www.nytimes.com/2016/03/08/business/genetic-test-firm-to-put-customers-data-in-public-domain.html.

If the role assigned is a *research participant*, assign the following reading:
- Williams, R. (2015, October 29). Toward Protecting Participants' Privacy. *The Scientist*. Retrieved April 19, 2016 from http://www.the-scientist.com/?articles.view/articleNo/44369/title/Toward-Protecting-Participants--Privacy/.

If the role assigned is a *researcher*, assign the following reading:

- Duke Biobank. (n.d.). Index of Biospecimens. Retrieved April 19, 2016 from http://biobank.duke.edu/index-biospecimens.

If the role assigned is a *university lawyer*, assign the following reading:

- Maldarelli, C. (2015, October 16). Could Having Your DNA Tested Land You In Court? *Popular Science*. Retrieved April 19, 2016 from http://www.popsci.com/could-submitting-your-dna-to-private-genetics-companies-land-you-in-court.

If the role assigned is a *law enforcement officer*, assign the following reading:

- Cale, C.M. (2015, October 28). Forensic DNA evidence is not infallible. *Nature*. Retrieved April 19, 2016 from http://www.nature.com/news/forensic-dna-evidence-is-not-infallible-1.18654.
- Cannon, H.B. (2013, January 10). First Cost-Benefit Analysis of DNA Profiling Vindicates 'CSI' Fans. *UVA Today*. Retrieved April 19, 2016 from https://news.virginia.edu/content/first-cost-benefit-analysis-dna-profiling-vindicates-csi-fans.

If the role assigned is a *university administrator*, assign the following reading:

- Petrone, J. (2015, May 28). Ancestry.com Shutters SMGF Database Amid Murder Case Controversy. *Genomeweb*. Retrieved April 19, 2016 from https://www.genomeweb.com/applied-markets/ancestrycom-shutters-smgf-database-amid-murder-case-controversy.

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Relevant National Educational Standards

Standards	Category	Sub-Category	Grade levels & bullets/skills	Page(s)
Next Generation Science Standards	Science and Engineering Practices in the NGSS (Appendix F)[1]	Practice 7	**Grades 9-12:** bullets 1, 6	13-14
		Practice 8	**Grades 9-12:** bullets 3-5	15
	Science, Technology, Society, and the Environment (Appendix J)[2]	Core Idea 2	**Grades 9-12:** bullets 3, 4	3-4
Common Core[3]	English Language Arts	Reading Standards for Informational Text	**Grades 9-10:** Skills 1-8	40
			Grades 11-12: Skills 1-7	
		Speaking and Listening	**Grades 9-10:** Skills 1-4, 6	50
			Grades 11-12: Skills 1-4, 6	
	Literacy in History/Social Studies, Science, and Technical Subjects	Reading Standards for Literacy in History/Social Studies	**Grades 9-10:** Skills 1, 2, 4-6, 8	61
			Grades 11-12: Skills 1, 2, 4-6, 8	
		Reading Standards for Literacy in Science and Technical Subjects	**Grades 9-10:** Skills 1, 2, 4, 5, 8, 9	62
			Grades 11-12: Skills 1, 2, 4, 5, 8, 9	

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[1] Next Generation Science Standards. (2013). APPENDIX F – Science and Engineering Practices in the NGSS. Retrieved April 19, 2016 from
http://www.nextgenscience.org/sites/default/files/Appendix%20F%20%20Science%20and%20Engineering%20Practices%20in%20the%20NGSS%20-%20FINAL%20060513.pdf.
[2] Next Generation Science Standards. (2013). APPENDIX J – Science, Technology, Society and the Environment. Retrieved April 19, 2016 from
http://www.nextgenscience.org/sites/default/files/APPENDIX%20J_0.pdf.
[3] Common Core State Standards Initiative. (2010). Common Core State Standards for English Language Arts & Literacy in History/Social Studies, Science, and Technical Subjects. Retrieved April 19, 2016 from http://www.corestandards.org/wp-content/uploads/ELA_Standards1.pdf.