Deliberative Democracy: Genetics

Alignment with Course Content

This module can be used to reinforce understanding of genetics, cell structure and function, and gene expression.

Necessary Background Knowledge

- Genetics
- Cell structure and function
- Cell cycle
- Central dogma
- Gene expression

Policy Question

Your group is being asked to make a policy recommendation regarding direct-to-consumer (DTC) genetic tests such as 23 and Me. These widely-available kits usually involve sending in a vial of saliva to receive "health and trait reports" that provide information about a person's genetic variants for particular genes, as well as genealogical information. However, there has been some controversy surrounding these kits, particularly with regard to regulation by the US Food and Drug Administration. As scientists, your group must answer the following question: Should results from DTC tests be used to inform medical decisions? Please briefly explain the reasoning behind your consensus.

Module Goals

- Understand how genetic information can be collected and applied
- Describe how genes can affect structure or function
- Address a problem with consideration of multiple variables both scientific and socioeconomic factors

Deliberation Scaffolding

Students should consider

- What are direct-to-consumer (DTC) genetic tests? What kinds of data do they produce?
- How are DTC tests currently regulated in the US?
- What are some of the genetic variants that DTC tests are capable of testing?
- What are some of the problems with DTC genetic tests?
- How is genetic counseling typically applied in medical diagnoses?
- What populations might be positively affected by DTC genetic tests? Negatively?
- Who typically uses DTC tests?
- Are DTC test results valuable?
- What does it mean to carry variants of a gene?

Instructor Notes

Implementation Suggestions

- The module topic and peer-reviewed article can be tied to ecological concepts through a discussion of sources of anthropogenic pollution and various effects on different environments, communities, and populations
- The peer-reviewed assignment in an open-ended format can be completed as an in-class activity rather than outside of class
- For wrapping up on the final discussion day, choose several groups that investigated different aspects of the problem (e.g. socioeconomic, environmental, etc.) to make a very short (2 minute) presentation of the key points that led to their science advisory statement

Articles

Media:

NPR 2018-Questions Rise About Shortcoming of DNA Tests for Dogs

Peer reviewed:

<u>British Journal of Sports Medicine 2015-Direct-to-consumer genetic testing for predicting sports performance</u> and talent identification: Consensus statement

Informative Articles Students Might Find

Media-23andMe Is Terrifying, but Not for the Reasons the FDA Thinks

Peer Review-Home DNA test kits cause controversy

Peer Review-False-positive results released by direct-to-consumer genetic tests highlight the importance of clinical confirmation testing for appropriate patient care

Media-Dog DNA Testing Market Grows As Vendors Target Consumers, Breeders, Vets

Media-The rise and fall and rise again of 23andMe

Media-Before you send your spit to 23andMe, what you need to know

Media-Here's what kind of data genetics testing companies can share

Media-What consumer DNA data can and can't tell you about your risk for certain diseases

Media Article (Multiple-Choice Assignment Ideas)

NPR 2018-Questions Rise About Shortcoming of DNA Tests for Dogs

Questions Rise About Shortcomings Of DNA Tests For Dogs by Carey Goldberg

Example question topics:

- Why should consumers be concerned about pet genetic testing?
- What types of data are produced by pet genetic testing?
- What is one of the major problems with interpreting pet genetic test results?

Peer Reviewed Article (Multiple-Choice Assignment Ideas)

British Journal of Sports Medicine 2015-Direct-to-consumer genetic testing for predicting sports performance and talent identification: Consensus statement

Direct-to-consumer genetic testing for predicting sports performance and talent identification: Consensus statement by Nick Webborn, Alun Williams, Mike McNamee, Claude Bouchard, Yannis Pitsiladis, Ildus Ahmetov, Euan Ashley, Nuala Byrne, Silvia Camporesi, Malcolm Collins, Paul Dijkstra, Nir Eynon, Noriyuki Fuku, Fleur C Garton, Nils Hoppe, Søren Holm, Jane Kaye, Vassilis Klissouras, Alejandro Lucia, Kamiel Maase, Colin Moran, Kathryn N North, Fabio Pigozzi, Guan Wang.

Example question topics:

- The purpose of different sections within a peer-reviewed article (e.g., introduction and experimental)
- Describing the central motivating factors behind the work
- Describing how the results might be applied or built upon
- Describing the importance of a consensus statement in the literature

Peer Reviewed Article (Alternate Open-Ended Assignment Ideas)

Science 1997-The Complete Genome Sequence of Escherichia coli K-12

DOI: 10.1126/science.277.5331.1453

The Complete Genome Sequence of Escherichia coli K-12 by Frederick R. Blattner, Guy Plunkett III, Craig A. Bloch, Nicole T. Perna, Valerie Burland, Monica Riley, Julio Collado-Vides, Jeremy D. Glasner, Christopher K. Rode, George F. Mayhew, Jason Gregor, Nelson Wayne Davis, Heather A. Kirkpatrick, Michael A. Goeden, Debra J. Rose, Bob Mau, Ying Shao

- 1. What was the central motivating factor behind the work? That is, why did the authors start the work?
- 2. If the paper is hard to understand (at first), what would be your next step?
- 3. Why would annotation be important for genomic sequencing?
- 4. Why is it important to sequence the genome of an organism like *E. coli*? How is it relevant to humans?
- 5. What is the importance of Table 3? Why are CTAG sequences significant?
- 6. What type of genes make up the bulk of the *E. coli* genome?

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Deliberative Democracy: Genetics

| Leader First & Last Name | Facilitator/Spokesperson First & Last Name | |
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| Recorder First & Last Name | Devil's Advocate/Summarizer First & Last Name | |

Your group is being asked to make a policy recommendation regarding direct-to-consumer (DTC) genetic tests such as 23andMe. These widely-available kits usually involve sending in a vial of saliva to receive "health and trait reports" that provide information about a person's genetic variants for particular genes, as well as genealogical information. However, there has been some controversy surrounding these kits, particularly with regard to regulation by the US Food and Drug Administration. As scientists, your group must answer the following question: Should results from DTC tests be used to inform medical decisions? Please briefly explain the reasoning behind your consensus.

| Why does this missing piece of information matter? (include social and science rationales) | Who will find 2-3 peer-reviewed articles about this concept? |
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| | Why does this missing piece of information matter? (include social and science rationales) |

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Before doing background research, what is your group's initial stance on how DTC genetic test results are used in medical decisions?

| Leader First & Last Name AND Exam Number | Facilitator/Spokesperson First & Last Name AND Exam Number | |
|--|---|--|
| Recorder First & Last Name AND Exam Number | Devil's Advocate/Summarizer First & Last Name AND Exam Number | |

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| Evidence to support your science advisory recommendation: | Source title and journal (with initials of who contributed this article): | Which lecture topics or textbook chapters cover this material? |
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| Science Advisory Statement (group consensus): | | | |
| Colonice Advisory Statement (group consensus). | | | |
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End of Day 2. Thank you for investing your time and energy on this activity!