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Medical Genetics Ethics Cases Facilitator's Guide

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Resource Files

1. Ethics Cases in Genomics PowerPoint: Clicker questions and discussion cases
2. Student handout of discussion cases and facilitator version with question prompts, notes, and references

Conceptual Background and Learning Objectives

As our understanding of the genetic basis of human disease has grown, genetic testing applications for these conditions have grown in parallel. Discussion of the nuances of these testing strategies in the context of direct-to-consumer genetic testing, identification of incidental findings in genomic strategies, and other ethically complex scenarios is imperative for trainees to fully consider responsible use of genomic technologies.

The case collection was developed for use in a first year Genomic Medicine course for medical students at the Boston University School of Medicine. Although this was initially piloted with medical students, it would be appropriate to use with advanced undergraduate students as well as graduate students with an interest in the clinical applications of the science they are studying.

Learning Objectives

At the end of this section, the student should be able to:

1. Consider the potential advantages and disadvantages of widespread use of whole genome sequencing approaches and direct-to-consumer initiatives.
2. Identify the critical need to protect individual privacy of genetic test results and genetic databases to safeguard their impact on a patient's family relationships, their employment status, and their ability to secure health insurance.
3. Appraise the nuances and consequences of the current recommendations around reporting of genetic test results with respect to whole genome sequencing.

4. Recognize the economic ramifications of genetic technology for precision medicines and patented inventions.

Implementation Advice

1. Materials

- The cases are provided in two groups: clicker questions and discussion cases.
- Classroom equipped with an LCD projector and an audience response system: Instructors can use electronic audience response systems such as Turning Point or iClicker, or if their institution doesn't have this technology available, class polling of answers can be accomplished using colored sheets of paper that students hold up in class to share their opinions. The advantage to using the electronic solution is that responses are anonymous to peers in this set up, and when discussing nuanced and sometimes personal ethics topics, anonymity can be an advantage.

2. Length

If an instructor was planning to use the full set of cases in one session, 2 hours of class time is recommended. However, the cases are independent and can be sprinkled throughout multiple sessions where the relevant science is introduced.

3. Educational context

The in-class discussion does not necessarily need to be limited to use in a medical school, but students should be experienced in the concepts of direct-to-consumer genetic testing, whole exome/genome sequencing, mitochondrial manipulation, privacy of genetic information, and patenting of genetic material. These topics can be introduced as translational or clinical examples in advanced undergraduate or even high school courses as well, since the extent to which the technical science is the focus can vary without impacting the relevance of the ethical discussion.

4. Logistics

- In terms of using the clicker cases, the facilitator leads an interactive case discussion employing the Powerpoint slides and audience response technology. Clicker-based audience response technology allows students to submit their responses to questions posed on the slides to allow for immediate polling of student understanding of topics. These responses can be displayed in real time and anonymously. Responses can also be collected by distributing colored sheets of paper or index cards to students for them to hold up in class for each answer choice. These clicker questions can be used in large format classes, and students can report individual opinions before engaging in “think-pair-share” exercises within the larger room. Sample clicker data is included from use of these cases with first year medical students. Notably, there is generally not an overwhelming consensus of opinions on these cases which is the perfect starting point for a discussion highlighting differing perspectives on the same cases.
- The discussion cases can be used with live discussion in a large lecture hall with similar techniques to above or can be used in smaller case discussion groups or even as writing prompts for essay-based assignments. The discussion cases are available in the Powerpoint collection but can also be handed out in advance of a small group discussion, for which the facilitator has discussion prompts.

Conclusions

We were able to successfully implement the interactive cases in our class of 180 first year medical students. Our tips for success in facilitating a discussion of approximately 180 students include:

- Break students in auditorium into groups and ask for student opinions for discussion questions from within each group; this prevents a select group of students from dominating the discussion. This might be better accomplished in a large hall that can be filled with round tables, seating 6-8 students per table.
- Repeat questions and comments from the students so that all students in a large hall can hear the contributions of their peers. Alternatively, set the room up conference style with microphones in the aisles where students can move to be amplified for the discussion.

Student engagement with the material during the discussions were high, and they raised many complex points related to the cases. There was rich discussion on the influence of for-profit genetic testing companies, the nature of incidental findings, and the limited preventative options available in genetic conditions. Feedback from course evaluations was strongly positive, and representative quotes are included below.

- *"The best section of the course for me was the lecture on the historical and emerging issues in ethics in genetics, and I think the points brought to light are very real challenges most of us will encounter in the future in practice."*
- *"Small group discussions between students were always engaging as they touched on ethics, future technology, and prompted us to reflect on our value systems & future practice."*
- *"Dr. Dasgupta has done a great job in organizing this course the topics were relevant and the information was current and genetics as a social, political, ethical issue was also covered which was really informative."*
- *"The repeated references to the socioeconomic considerations around testing, screening, and access were greatly appreciated as a way to tie the knowledge to the clinical and societal applications/implications of genetic medicine."*
- *"She recognized the relevance of race, ethnicity, sexuality, and cultural difference on what she was teaching, and...addressed these topics in a respectful way that enhanced our overall understanding of the material and our ability to provide good care to diverse patient populations. This course should provide the standard for teaching diversity in our other courses."*
- *"I really appreciated how Dr. Dasgupta brought in real-world applications of the material and pushed us to think about the issues that we will face in our practice of medicine."*
- *"...it's been one of my favorite classes thus far. A lot of that has to do with how you emphasized the fact that medical genetics is fraught with ethical issues that force us to consider what it truly means to be human – one of the fundamental questions that got me interested in medicine in the first place."*