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Discussion Questions

Stem Cells & Policy: Values & Religion Module

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General Questions

1. What sort of specific words and concepts are used when individuals construct arguments concerning the ethical and social issues surrounding human embryonic research (hESCR) and technology?
2. Where do individuals derive their understanding of these words and concepts? Do they necessarily hold the same meaning and emotional weight for all groups and individuals? If not, should those differences be resolved, and if so how?
3. What shapes the division between arguments that are considered religious and those that are considered secular in the U.S.? How does this affect public discussion of hESCR and technology?
4. How does the first amendment of the US Constitution protecting the right to freedom of religion and freedom of expression play a role in human embryonic stem cell research policy?
5. What kinds of approaches are available in trying to understand religious and cultural pluralism across nations?
6. Do individuals within a given religious or cultural community necessarily share the same attitudes and opinions concerning hESCR?
7. What strategies can a group or individual employ when speaking about a contentious issue in hESCR to a mixed group? How will those strategies be different when speaking before a more homogeneous group?
8. What is the role of an ethics advisory committee in public debate about critical bioethical issues like hESCR?
9. How are ethics advisory committees established and what are the principles for selecting their members?
10. How do ethics advisory committees conduct their work and what particular challenges do they face?
11. Consider in the US, the role of the executive, legislative, and judicial branches of government in directing, supporting, and regulating hESCR.
12. In discussing embryonic stem cell research the notion of “inalienability” is raised, to what does this term refer? Consider whether current US policy regarding bodily goods is consistent with the notion of keeping sacred that which is inalienable. Use evidence to address this question by reviewing the US policies regarding compensation for eggs, sperm, and bone marrow stem cells as well as patent law governing genetics research.
13. Two recent publications, one by Ikemoto concerning the troubled past of hESCR (2014 [Link](#)) and another Caulfield et al. (2015 [Link](#)) proposing that stem cell research exceptionalism should end, seem to be diametrically opposed with respect to ethical oversight of hESCR. What is Ikemoto’s argument, and does it seem to matter whether ESCROs were involved with the three recent advances in human SCNT cloning?

US Federal Injunctions, States Rights, and Federal Funding Policies

14. In 2010, Peter Boyer published “The Covenant” in the *New Yorker*, an article centered on the ways that

religion, ethics, and policy are brought together in the court case Sherley v. Sebelius. Boyer in this piece interviews Francis Collins, director of the National Institutes of Health.

- a. Comment on the ways in which the author presented these three perspectives.
 - b. Consider the Vannevar Bush Report “Science, The Endless Frontier?” published in 1945 ([Link](#)) and notice that one of the proposals laid out in this report was self regulation of science and federal funding of science; in the “Covenant” piece there is an example of where this might be worth considering given the political maneuver around “taxpayer blues”- freezing sperm etc. What would you say to Vannevar Bush, can you argue both sides?
15. In Sherley v. Sebelius a federal injunction was brought forth because two adult (ASC) stem cell researchers argued that federal funding for human embryonic stem cell research violated the intent of the Dickey Wicker Appropriations Rider. Interestingly, the case was originally brought forward by embryos, pro-life groups, and ASC researchers, but thrown out. The second time it was presented, plaintiffs were the ASC researchers. Judge Royce Lamberth filed the injunction because he felt that the plaintiffs had a good chance of winning against the Obama Administration based on their lenient interpretation of the Dickey Wicker Amendment.
- a. What do you make of the arguments that the ESC research funded by federal monies is only a “piece of the research”? Develop an argument that supports this interpretation and consider a rebuttal for counter arguments that would oppose your stance.
 - b. Diana Degette, a congressional representative of Colorado, has said that forty pieces of legislation have been put forth to avoid the loose interpretation of the Dickey Wicker Rider. Does her framing and approach for a law permitting federal funding for research using surplus embryos created through in vitro fertilization allow for measured discourse regarding human embryonic stem cell research?
16. Reflect on the idea that the US is a pluralistic society, yet, much of the federal policy claims to uphold human dignity and prohibit research on human embryos using public monies. Given the trajectory of the injunction, is “the moral status of the embryo” what we, as a country, value? Where do other countries draw the line and what secular and religious values inform their national policies?
17. The Empire State Stem Cell Board’s NYSTEM site is rich with information on Ethics Committee and Funding Committee membership and activities, including funded projects.
- a. Where does the private foundation NYSCF appear on this site, and why?
 - b. What are the state monies used for in NYSTEM?
 - c. How is NYSTEM regulated?
 - d. Are there interstate projects that take money from this program?
 - e. Can you locate the NYSTEM model templates for human subjects research, oocyte provision, and research using animal-human hybrids? If so, do you feel the hyperlinked information is adequate?
 - f. Can you access meeting minutes or video playback of past public meetings and are there ways for you to engage with the ethics committee members?

- Moral Status of the Embryo, Saviour Siblings, Human-Animal Chimeras, & Reproductive Technologies**
18. During July 2003, five papers were prepared for the meeting of the President’s Council on Bioethics. All five papers were intended to sum up the state of current work on human stem cell research for non-experts. Four of them explain recent scientific developments, while one of them is a review and critique of writing on the ethical issues surrounding that research written by Paul Lauritzen. (Lauritzen, P. 2003. The Ethics of Stem Cell Research. Background Materials for the President’s Council on Bioethics [Link](#)). In this piece Lauritzen uses an academic argument as well as art to advise the Council. What do you make of

Lauritzen's choice to include artwork by Patricia Piccinini and Eduardo Kac in his article? Though he chooses interesting works, there are those that bring the notion of human-animal chimeras and our ability to create them to the fore, such as "The Young Family" ([Link](#)) and " Genesis" ([Link](#)) by Piccinini and Kac respectively.

19. In 2010, the weekly program *Religion and Ethics Weekly* aired the story of the Trevino family's success in conceiving a saviour sibling to save the life of their son (VIDEO: [Link](#))
- a. Do you feel the case study serves as a good vehicle for fostering discussion of potentially controversial applications of technology?
 - b. Is IVF regulated by the government in any way?
 - c. Who should make decisions about the surplus embryos, unwanted embryos, and "dead" embryos created through IVF/ PGD technologies?
 - d. Where does the social justice perspective come in?

Informed Consent and Commodification

20. In considering state and federal policy, the ethics around informed consent are introduced in the context of "reconsent", presumed consent, broad consent, or exculpatory consent. What does this mean in the context of available federal funds for hESCR? Why do people caution against focusing too narrowly on the moral status of the embryo- what other ethical issues are raised by stem cell research?
21. In the article published by Elie Dolgin entitled "Profiting from pluripotency" in *The Scientist* ([Link](#)) we are reminded of the industry that emerged not too long after the HeLa cell line was established and the ways in which this industry excludes research participants from benefiting from commercialization down the road. What do you make of this system? How does the financial risk of being an enabler, or a company that makes reagents for stem cell culture, compare to being a company that develops therapies? What are the hidden costs?
22. Consider the Dolgin article in the context of a communication between the presidential press secretary and a journalist at the press conference shortly after Obama signed the executive order to allow federal funds for research on hESC lines generated with private money. Press Secretary Gibbs was asked "Why the urgency to sign this order given our financial crisis?" Gibbs began talking about healthcare costs ([Link](#)). What talking points might you have suggested for Gibbs to better his response, given your read of the Dolgin article?
23. In her article [Race for Cures](#), sociologist Ruha Benjamin raises important issues related to informed consent that are often overlooked or taken for granted. She details the ways in which particular charismatic characters, powerful policy makers, and clinical staff influence policies regarding recruitment of tissue donors and clinical trial participants, and ultimately access to the downstream products of stem cell research funded by public monies. How can systemic policy changes address her concerns regarding community participation and biomedical trust? Comment on the efforts being made to address these concerns as detailed in the blog post by Katayoun Chamany regarding the New Rules Proposed to Address Privacy and Trust in the Precision Medicine Initiative ([Link](#)).