Discussion Questions
HeLa & HPV: Immortality & Cancer Module

by Katayoun Chamany

Biology

1. Why was the HeLa cell line established?
2. What research questions were biomedical researchers asking in 1951, and what role did tissue culture play in answering them? How is tissue culture used to answer more contemporary biomedical research questions?
3. What was unique about Henrietta Lacks' cells? What biological characteristics contributed to their immortality in cell culture? What biological characteristics make them useful for cell culture research?
4. What is HPV and how is it related to immortality? Since we have diagnostics for HPV infection, can we screen for cancer; explain your reasoning?
5. To what do "contamination" and "aggressive" mean in the context of cell culture, and do they carry different meanings in this context as opposed to conversational language outside the lab.
6. In the early years of cell culture, scientists used race as a proxy for a cell line's origin. Can this be done today? Why or why not?
7. Why must cells be immunologically matched between donor and recipient in transplant therapy? What challenges do people of mixed race present with respect to immunocompatibility and how does this relate to human evolution?
8. Genomic instability is a hallmark of early cancer development and also a sign of viral infection. How does this information relate to evolutionary concepts and changing environments?
9. What is being done about the cell contamination problem in existing cell lines used today?

Capitalism v. Public Goods (Tissue Policy & Social Justice)

1. Who decides how biospecimens are obtained, regulated, stored, disseminated, and marketed?
2. Are there any policies regarding compensation for bodily goods (gametes, blood, tissues), incentives for public biobanking, and cost coverage for stem cell transplant therapies?
3. What are the ethical concerns regarding equity, diversity, access, and exploitation as they relate to cell cultures and biobanking?
4. Who funds public biobanks such as bone marrow, cord blood, and breast milk banks?
5. Are some bodies and biospecimens considered more valuable than others, and if so, why?
6. Is it appropriate for the US government to provide tax relief via the Family Cord Blood Banking Act for those who can afford to bank their child's cord blood in private banks rather than donating to the public bank system?
7. Why do we need a diverse supply of cell lines for research?

Compensation & Incentives

1. What stance does the US federal government take on payment for bone marrow, and what is the

reasoning and is it warranted?

2. Do research participants or biospecimen "donors" have a right to compensation, payment, or some other form of acknowledgement for their services and time and who should decide if there will be a cap?
3. What is the Wage Payment Model? What other models exist for payment for participation in research?
4. Can non-cash incentives address the concerns of those who feel bodily goods should be "gifted?"
5. Should incentives to diversify public tissue and cell banks be implemented to address health inequities? What are the advantages of such programs and what can be done to mitigate the potential drawbacks?
6. How would a Biotrust or charitable trust model work to ensure sustainability of biobanks, control over research directions, and access to goods and knowledge produced from the biobank?

Choice (Nation, State, or Individual Agency & Autonomy)

1. Should people have a choice in how their individual bodies may serve biomedical research, or should tissue banking be considered a social good in which opt-out models for collection of biospecimens are used?
2. When is the choice to participate in biomedical research taken away from individuals? Are there special provisions in federal law to address vulnerable populations?
3. Who is involved in moving cells from a clinic, to the lab, and ultimately to the market?
4. Under states' rights should public funding or taxes be used in biobanking research, as in the case of the NY Blood Spot Program?
5. Given that many individuals seek medical care that results in the creation of biospecimens, should these specimens be permitted to enter the research sector? This "dual use" specimen is highly contentious and may require "reconsent" procedures and require that the researcher and the clinician be separate individuals to avoid a conflict of interest. Comment on the notion of dual use.
6. Some parents of children living with disease/disability utilize Assisted Reproductive Technologies to produce "savior siblings," or siblings where cord blood or bone marrow stem cells are an immunological match. Should parents have the right to choose this course of action?
7. In 2011, two sisters convicted of a crime, were granted clemency from prison on the stipulation that one "donate" a kidney to the other. Is this an appropriate "price for freedom"? Ridgeway, J. 2011. The Scott Sisters' 'Debt to Society' and The New Jim Crow. Solitarywatch.com A short video reviews this case in Mississippi on NBC Nightly News (2:16")
8. In the late 1990s, patient advocates Sharon and Patrick Terry established PXE International as a non-profit organization designed to protect the DNA of volunteers with a history of PXE and to secure rights to any profits made from their rare genetic genotypes conferring pseudoxanthoma elasticum (PXE). In 1999, Charles Boyd, a researcher at the University of Hawaii isolated the gene variant responsible for PXE and named Sharon Terry as a co-discoverer. For the 2000 individuals who had donated DNA to this database, and used contract law to establish control over the access, use and commercialization of their DNA samples, the fact that the University owned their material and the patent proved challenging, but PXE offered to cover the costs of filing the patent, in exchange for control over the licensing and the university accepted. Given that this situation involves a tightly knit community with a common goal for discovering the genetic basis of their inherited disease risk and ultimately drugs to treat it, explain whether you believe that this model would be applicable to biobanking projects for which there is no specific disease focus, or hypothesis driven research question, and rather a data mining approach to address a range of questions would be applied? See Solovitch, S. Sept 2, 2001. Citizen Scientists. Wired.com

Ethics (Informed Consent: Risk-Benefit and Cost-Benefit)

1. What are the central tenets of informed consent?
2. Which historical events shaped policies and practices regarding research with human subjects?
3. What policies should be implemented to clarify or change the way people are recruited, monitored, and acknowledged for biospecimens used in research?
4. Who should be able to provide informed consent? A government or tribal leader for its people in the case of genome banks? A parent in the case of saviour siblings? A patient with a terminal illness?
5. Given the open nature of basic scientific research, how does one provide consent for future uses or applications, or understand the scope of unknown health risks associated with a procedure or drug?
6. Are patients or donors adequately informed about benefits and risks of tissue collection and donation?
7. What kinds of information or data need to be made available for individuals to consider participating in biomedical research? Do protections for privacy and anonymity exist?
8. Consider laws, guidelines, and structures that are in place for human subjects research, gamete research, blood/organ research, and stem cell research; consider these at the state, national, and international level. Are these enforceable and if so how?
9. Should there be some regulation of biospecimen procurement? If so, who provides oversight, regulation, and punishment for violations?
10. Should practices surrounding biospecimen research differ based on purpose; profit v. non-profit research?
11. What are the policies regarding DNA or cell donation outside of the clinical setting as seen with the Genographic, 23andMe, UK National Biobank, and Apple's Research Kit projects?