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### **Learning Activity 3: Teaching Notes for Case Study Role-Play**

#### **HeLa Cells & HPV Genes: Immortality & Cancer Module**

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This case uses a combination of textual and visual resources to explore the unique biological characteristics of HeLa cells and the social context that led to the establishment of cell culture techniques and biobanks.

The case centers on the real-world narrative of Henrietta Lacks and the establishment of the HeLa cell line to demonstrate how biology and social justice can be intimately intertwined. The Lacks' family story captured national attention since the publication and film adaptation of *The Immortal Life of Henrietta Lacks* and many colleges and universities adopted the book as a first-year common reading. The story raises questions regarding procedural justice with respect to who participates in life science research, as a scientist, research subject, tissue donor, policy maker, activist, or lobbyist. The narrative also highlights a lack of distributive justice providing examples that showcase which communities benefit from biomedical research and policy and which are marginalized as a consequence of shifting societal values and systemic inequity. To dive deeper into these aspects of the case, I have contextualized the case using an intersectionality framework. Intersectionality is a term that was proposed by Kimberle Crenshaw in the late 1980s to describe the situations in which identity politics can be destructive. Crenshaw posits that multiple social categories (e.g., race, ethnicity, gender, sexual orientation, socioeconomic status, ability) intersect at the micro level of individual experience to reflect multiple interlocking systems of privilege and oppression at the macro, social-structural level (e.g., racism, sexism, heterosexism, ableism) ([Bowleg, AJPH 2012](#)). The approach seeks to move away from conflating, or ignoring, aspects of a person's lived experience and, rather, uses a multidimensional perspective that highlights the additive effect of multiple forms of oppression.

This case is one of four in the [Stem Cells Across the Curriculum](#) project and can be used with biology majors and non-majors at the undergraduate and graduate level. Collectively, the cases trace the trajectory of cell biological research and tissue culture techniques that support biomedical research. A central theme of the cases is the trade offs involved in conducting research involving human subjects and biospecimens to advance life science research. The four cases (in italics) span six decades of scientific research on human cells beginning with the establishment of the first human cell line (*HeLa Cells & HPV Genes: Immortality & Cancer*), to the derivation and use of blood and embryonic stem cells (ESCs) (*Eggs & Blood: Gifts & Commodities*), to differentiation of adult stem cells (ASCs) in culture (*Disease & Disability: Hope & Hype*), and culminating with induced pluripotent stem cells (iPSCs) and their relative scientific and therapeutic potential as compared to ASCs and ESCs (*Stem Cells & Policy: Values & Religion*). The cases deliberately move from a historical case study that provides students with emotional distance and a rich array of resources to arrive at a decision, to contemporary and contentious cases for which precedent and law are more limited. Though they can be used in combination and in sequence, each case can also be used on its own.

In this case study, using role-play, students explore the use of biospecimens to serve biomedical research by drawing on the historical case of the establishment of the HeLa cell line and by looking to the future construction of contemporary biobanks, such as the US Precision Medicine Initiative and the UK National Biobank. This [case study approach](#) to teaching and learning presents a fictionalized story that is based on real

world events. The activity promotes the development of higher order thinking skills associated with the later stages of the [7E model of learning](#) proposed by Arthur Eisenkraft (Engage, Elicit, Explore, Explain, Elaborate, Evaluate, Extrapolate) and helps students develop empathy and tolerance for multiple points of view. Additionally, the case study provides scaffolding to move students through [Perry's Theory of Ethical Development](#) by focusing on the integration of affective and cognitive learning.

By adopting the role of a stakeholder attending a symposium, students learn the biological, ethical, legal, and social dimensions of using human tissues, cells, and DNA to simultaneously support clinical diagnosis/treatment and scientific/therapeutic research. The learning resources invite students to consider advantages and disadvantages associated with various models of biospecimen acquisition and informed consent practices designed to provide researchers with the necessary biological resources and information to support public health.

Because each student adopts the role of an attendee at a real world conference, students acquire depth by *exploring* a specific person's view, disciplinary approach, values, and rationale, as well as breadth through engagement with peers who have adopted different roles and provide multiple perspectives. By engaging in dialogue, students construct knowledge together. By *explaining* and *elaborating* on their character's position, they are better able to *evaluate* the range of policies and practices in the private and public sector regarding biospecimen provision involving blood, tissues, cells, and/or DNA.

The choice to use real-world characters, organizations, and the conference setting reflects the desire to impart a level of authenticity to this performative assessment designed to judge a student's ability to use specific content knowledge and skills within a real-world context. The hyperlinks to real-world post-doctoral fellowships, undergraduate journals, and college programs are included to broaden students' knowledge of existing venues for interdisciplinary activities and to help them consider publishing the work they create for this assignment.

This capstone activity asks students to grapple with the benefits, risks, and trade-offs of any given policy regarding biological resource procurement using public funding. Through their personal policy proposals students must identify potential areas of compromise and articulate specific practices and policies they are not willing to accept and provide the rationale for doing so. This approach is in line with [Perry's Model of Ethical Development](#) intended to move students from dualistic thinking to relativistic thinking, and ultimately to arrive at a committed stance.

Portions of this case have been implemented by me at Eugene Lang College of Liberal Arts at The New School in an intermediate level cell biology course, a non-majors stem cell seminar course, and in university wide courses, such as the summer bridge course in the Equal Opportunity Program, and a University Lecture course ( lecture and recitation format) for liberal arts and design students. It has also been adapted by other instructors at multiple institutions for a junior level bioethics course and first-year general education courses taught at San Francisco State University, that latter of which satisfies the life sciences, multicultural, and social justice competencies. Some colleges and universities that have adopted Rebecca Skloot's book *The Immortal Life of Henrietta Lacks* have adapted the case for courses across the curriculum, while high school teachers have done the same within the [Facing History and Ourselves](#) educational project designed to promote tolerance and democracy and combat racism and prejudice. Depending on how the case is delivered it will span one to four class sessions of ninety minutes each. Students are asked to complete readings, conduct research, view multimedia and works of art, and engage in discussions during class, and ultimately craft a policy proposal that addresses the biological, ethical, legal, and social dimensions of different approaches used to construct biobanks using the historical case of the provenance of the HeLa cell line as a reference point.

Instructors of cell biology courses will easily connect the notion of cell cycle control to this case study, while instructors focused on cancer or infectious diseases could use the case as a springboard for conversations about HPV, genomic instability (TERC duplications), telomerase, and molecular biology techniques that address the cancer and immortality phenotypes. For students with limited biology background these topics can be explored using the accompanying [slide sets for this Module](#) with more emphasis placed on the social context of the investigations.

### STUDENT LEARNING OUTCOMES:

- Describe the unique biological characteristics of cells grown in tissue culture
- Explain how viral infection can allow cells to defy the Hayflick limit, confer immortality, and contribute to the development of cancer
- Explain why cell and DNA repositories and banks are important for life science research, and why the size and diversity of the samples can influence the direction of research.
- Demonstrate how biospecimen acquisition, property law, and compensation schemes relate to procedural and distributive justice.
- Compare the regulations and oversight of private versus publicly funded research.
- Describe how advances in computing and genomics technology relate to issues of privacy for biospecimen donors.
- List risks to mental/physical health associated with different models of biospecimen acquisition.
- Critically analyze arguments for specific policies shaped by competing positions for, or against, public funding for national or community biobanks, and map these to specific stakeholders.
- Gain awareness of the diverse points of view *within* stakeholder groups regarding compensation, acknowledgement, and rights to controlling how and when biospecimens can be used in research.
- Construct evidence-based policies that recognize trade-offs regarding benefit and risk to individuals, communities, and society, and mitigate the drawbacks of any particular model, being careful to consider who benefits and who carries burden.
- Recognize the influence that advances in basic science, health law, business, human rights, and medicine can have on one another.

Instructors can set the stage for the case study role-play activity using [Activity 1](#) and [2](#) in this module or using the materials associated with Activity 3.

### Setting the Stage Using Learning Activity 1 and 2

Prior to using this case based role-play activity, instructors may choose to utilize other learning activities associated with this *HeLa Cells & HPV Genes: Immortality & Cancer* Module to address the earlier steps in the [7E model of learning](#) (Engage, Elicit, Explore, Explain, Elaborate, Evaluate, Extrapolate). [Learning Activity 1](#) introduces students to the case study presented in Activity 3 by *eliciting* prior knowledge and *engaging* students in a progressive disclosure activity designed to provide a cursory review of the history of the HeLa cell line, tissue culture contamination, and genomic biobanking. [Learning Activity 2](#) provides students with an opportunity to *explore* secondary literature, infographics, and videos, and *explain* what they have learned about the biological, ethical, legal, and social dimensions of human subjects research, informed consent, compensation for biolabor, and biobanking using individual cases and those that affect entire communities such as the Native American Havasupai diabetes study, the creation of national biobanks, and the establishment of national registries for embryonic stem cell lines.

**Essential Resources** associated with this [module](#) and the [Video Resource Guides](#) provide a range of references spanning the arts or humanities and include shorter news pieces for courses short on time, or interested in using multimedia to set the stage. Under the Artwork section, the educational video [“HeLa Cells & Tissue](#)

[Culture.](#)” provides a brief counter narrative for the story that unfolds in Rebecca Skloot’s book *The Immortal Life of Henrietta Lacks*, providing a historical context of oppression through a first person narrative in the play *They Called Me HeLa* and photomontage. Alternatively the film [The Way of All Flesh](#) by Adam Curtis could be viewed in or outside of class, or video excerpts can be used to provide the historical context for tissue research. The short *New York Times* article by Amy Harmon titled “[Where’d You Go with My DNA](#)” provides a brief address of the past and future challenges associated with biospecimen research and the brief post “[The Story of Henrietta Lacks: A Lesson in Biology and Ethics](#)” by ErinC on 23and Me’s *Spittoon Blog* explains how biomarkers can trace a donor, and how this led to the racial framing of cell line contamination by HeLa. For a quick overview of both the HeLa cell line and future biobanking challenges, instructors could use health law scholar Radhika Rao’s 12-minute presentation at “The Challenge of Informed Consent in Times of Controversy Symposium” held on November 11, 2015 at the UC Irvine School of Law which is available at this [video link](#) along with panel sessions with a range of social justice and biomedical ethics scholars.

### **Setting the Stage Using the Materials in Activity 3**

The Trajectory of Events provides a timeline and list of regarding the history of cancer research, tissue culture techniques, cell line derivations, and biobank construction, as well as public policies regarding the use of human subjects and bodily tissues in biomedical research and therapy. This list is intentionally designed to be broad and encompassing to afford instructors flexibility in their approach to setting the stage. Within the list are links to a few short videos that serve this purpose quickly and within the classroom. For instance, the dissemination of the genomic sequence of the HeLa cell line and the subsequent development of the HeLa Genomic Data Access Working Group can be reviewed in a five-minute Newsy video excerpt titled “[Informed Consent: Genomics](#)” The Newsy reporter reviews the scientific community’s and the Lacks family’s concerns in genomic sequence sharing, exploring issues related to privacy and property. In the list of resources for this video, the second entry also from Newsy “[Henrietta Lacks’ Family Finally Gets Say in Genome Research](#)” explores this further in a more contemporary context of biobanking and policies to coordinate trust between research subjects, patients and the scientific community.

**Stakeholders’ Connections, Biographies, and References** present students with a chart of 21 characters, their area of expertise, their affiliation, and relationship to the case study. This chart is followed by a list of biographies coupled with a customized list of references for further character development.

**Questions to Consider** overlaps with **Discussion Questions** provided with this module, but are intended to be more focused and customized based on the goals of the case study learning outcomes. Instructors should review the questions and choose those that are appropriate for the time frame and goals for their course. Students will find it useful to review these questions early on as they prepare their character statements, as they offer an opportunity to *explore* the content deeply and *elaborate* on their character’s views.

**The Grading Rubrics** provide a detailed and structured overview of criteria essential to the role-play activity and the personal policy position paper. These should be customized for the course and shared with students early on.

[The Primer](#) associated with this module can be assigned in courses for which cell culture, cancer, human subjects research, informed consent, and social justice, are not already embedded. The primer is a rich resource replete with hyperlinks to infographics, slide shows, and video. Depending on the goals of the course and the background of the instructor and students, specific sections of the primer may be more appropriate for

groups with background knowledge in some areas and not others. The table of contents can direct individuals to these sections.

**The Case Study** is a fictionalized story presented in three parts to provide a real-world view and context to the assignment (all organizations, characters, and events are real). The three parts utilize a constructivist approach to learning and are designed to move students from the familiar and reflexive binary responses to more critical and evidence-based responses that demonstrate tolerance and understanding of multiple points of views ([Perry's Model for Ethical Development](#)). The case draws on research from cognitive science that suggests learning is retained when narrative is used to move students from situational interest (the case study and role-play presented by the instructor) to personal interest (identification with a specific character in the role-play) and the incorporation of personal values (the policy position paper). The sections in italics present directives to students.

#### Part I: Written Character Statement, Questions and Counter Argument

Part I asks students to adopt the role of a specific character who may have a stake in this policy. They *explore* the case material on their own and *explain* what they have learned to their peers about their character's position by posting a 500-word character statement that details their expertise and position, provides a 300-word counter argument to opposing views, and poses two questions to other characters. This statement is posted online prior to the convening of the symposium. The **Stakeholders' Connections, Biographies, and References** and **Questions to Consider** documents prepare students for this task. Students can be required to review these statements and questions ahead of time prior to the simulated symposium, but instructors would need to build in an online venue for this review and interaction being mindful to provide adequate time. It may also be easier for students with limited time for this assignment to have the questions directed to them pooled into a single document by the instructor.

#### Part II: Oral Role-play & Dialogue

In Part II students engage in an in-class simulated symposium "Informed Consent and Biobanks: Who, What, How, and When?" hosted by the [Revolutionizing Informed Consent Regional Conference](#) in which they maintain the role of their character throughout. The conference in 2015 was a real event, though the stakeholders presented here in this case study were not all present. Through facilitation by the instructor, who acts as the Facilitator of the symposium, students defend their character's position using evidence but remain open to other people's views. Since each student represents a stakeholder with different views, discussion leads to requests for clarification. Through this discussion students will *elaborate* on their characters' positions and understand that commitment for a position evolves through ongoing activities that often require revisiting new evidence and hearing multiple viewpoints. The deliberate distinction between debate and dialogue emphasizes the need to hear those views that might diverge from an assigned character's views. Though debate can ask students to use evidence to craft a position, students can become so vested in "winning" the debate, that they are no longer listening, nor willing to amend their position. Thus, the symposium is intentionally framed as a dialogue to allow students to grapple with the full complexity of this case and provide students with an opportunity to experience shades of grey and bring more inquiry to a discussion aimed at identifying points of connection and shared values. To see the difference in using debate, discussion or dialogue, with special attention to issues of identity, status, and power, see this [chart](#) compiled and adapted from Rahmesh Nagda, Patricia Gurin, Jaclyn Rodriguez, and Kelly Maxwell's work on Intergroup Dialogue (IDG), Diana Karda and Todd Sevig's work on IGRC, and Sally Berman's paper on this topic from the Dialogue Group of the Boston Chapter of Educators for Social Responsibility (ESR). Additionally, reviewing this [book review](#) or [summary](#) of Daniel Yankelovich (Magic of Dialogue) and [Mark Hicks' explanation](#) of how dialogue can contribute to Multicultural Communications Competencies may also prove helpful for instructors and students. In the case itself, students are provided

with a link to a brief and easy to read [comparison chart of deliberative dialogue, discussion, and debate](#), created by the American Library Association.

### Part III: Written Personal Position Policy Proposal

Part III asks students to shed their character role and to step back into the role of a student and write a position paper that addresses policy that is informed by the historical and contemporary aspects of the establishment and use of the HeLa cell line. Here they are asked to *evaluate* the various models for biospecimen acquisition and compensation in order to take a position on the use of public funds for the establishment of a national database/biobank designed to support biomedical research. Students must decide whether this use of public money is warranted, or whether other models prove to be more ethically and scientifically relevant. The range of stakeholders involved with the symposium allows students to *extrapolate* from the singular historical case of Henrietta Lacks and the HeLa cell line to the collection and use of human biospecimens in cancer and biomedical research in shaping their policy stance. Here, again, the **Stakeholders' Connections, Biographies, and References** and **Questions to Consider** documents prepare students for the task. Additionally a **Grading Rubric** can be shared with students and used to evaluate their performance.

This approach to teaching and learning is constructivist because the position papers reveal what is most important to students and can then serve as reasoning tools in discussing policies for regulating biospecimen resources. As students construct their knowledge they become more self-aware of their own learning, reflect on social values, and grapple with how their personal values mesh or clash with social policy. With respect to [Blooms Taxonomy of Cognition](#), students acquire and remember content knowledge, connect specifics to broader concepts, and synthesize mental models, in an effort to evaluate various proposals.

### **FORMAT and CLASSROOM MANAGEMENT:**

#### *Timing*

The case study has been used in first year seminars and general science education and bioethics courses (Eugene Lang College, Loras College, and SFSU).. Depending on the level of course the case may span three weeks or one. Instructors should be mindful of what they assign, and organize time both inside and outside of class to execute the case properly. The nuances that emerge during a seminar-based course where time can be spent exploring resources associated with this Learning Activity will most likely be glossed over or missed entirely in a lecture course if time is not allocated properly. In the bare minimum, students should have at least one week to prepare their character statements and another week to complete readings, engage in an in-class dialogue, and submit a position paper. If they are being asked to review each other's character statements then more time may be needed. One class session should be dedicated to the dialogue and another to the debriefing of the dialogue. Additionally, as this is an unconventional assignment, students will need directive and instructors may want to spend 20 minutes reviewing the components of the case, the resources available, and due dates before the case commences.

#### *Assigning Resources and Readings*

The resources listed in the **Stakeholders' Connections, Biographies, and References** include primary and secondary resources specific for each character and total between 20-30 pages of reading for each character. However, if an instructor intends for students to have a common set of readings in addition to these, they may choose from the following options:

1. Use only one article to give students a common background

- a. To teach the historical case study of the provenance of the HeLa cell line and the future construction of biobanks, use the article by Javitt (2010) as it provides a comprehensive and humanistic perspective in examining the shortcomings of property and privacy law as applied to biospecimen research. She reviews the Lacks case including the views of geneticist Christian Lengauer, and three significant legal cases (John Moore, Greenberg/ Canavan Health Advocates, and Catalonia/Prostate Cancer patients). Javitt also presents ethnographic data on participants' desires to be involved in decision-making as it relates to future research directions and reporting of findings. She also includes the not often heard views of the dissenting opinion in the Moore case by Judge Mosk. Though this article is a bit dated, it can easily be updated with the events listed in the **Trajectory of Events**.
  - b. To teach the historical case study of the provenance of the HeLa cell line and point to DNA traceability issues use the article by del Caprio (2013) which provides background to the family perspective, the cell contamination, the immortality phenotype due to viral infection, present uses of the cell line, and the establishment of the HeLa Genome Access Working Group.
2. Use one article from each category of the [Essential Resources](#) that accompany this module.
  3. Use the twelve references listed below.
  4. Assign the [Primer](#) associated with this module. Though this approach is less constructivist, the complexity of the case study may require introductory students to have a resource that provides foundational knowledge before exploring on their own.
  5. For introductory courses, assigning the Garrison article works well for those students who may go on to seek medical degrees or conduct life science research. Because Garrison carries out ethnographic research using interviews with researchers, and IRB chairs and members, students can get an insider view on the challenges associated with a revamping of the human subjects protocols in light of new biobanking procedures and a desire to create more ethnically diverse banks. If the Garrison article is not available from your campus library the open access piece by Lehrman ([Link](#)) published by the SACNAS organization can be substituted.

Reference	Key themes
Landecker, H. 1999. Between beneficence and chattel: The human biological in law and science. <i>Science in Context</i> . 12 (1):203-225. <a href="#">Link</a>	<b>Racial and class perspectives on provenance of cell lines; cell line definition; continuity or discontinuity of cell and donor; anthropological analysis of biotechnological objects within the context of power and privilege; racial discrimination; commercialization of the biological</b>
Weasel, L. 2004. Feminist intersections in science: Race, gender and sexuality through the microscope. <i>Hypatia</i> . 19(1) Winter:183-193. <a href="#">Link</a>	<b>Intersectional and scientific perspective of the provenance of the HeLa cell line; race, class and gender.</b>
Winickoff, D. 2007. Partnership in U.K. Biobank: A third way for genomic property. <i>Journal of Law, Medicine, and Ethics</i> . 35 (3):440-56. <a href="#">Link</a>	<b>Charitable Biotrust Biobank model; biomedical commodity; Iceland DeCode</b>
Lucey, B., et al. 2009. Henrietta lacks, HeLa cells, and cell culture contamination. <i>Archives of Pathology &amp; Laboratory Medicine</i> . 133(9): 1463-1467. <a href="#">Link</a>	<b>Scientific perspective of the provenance of the HeLa cell line and scale up for vaccine production; HPV18; immortality; cell culture contamination; includes contributors (Kubicek, Gey, Gartler); enzymatic biomarkers for cell typing; race; questioning of renaming the cell line <i>Helacyton gartleri</i></b>

Javitt G. 2010. Why not take all of me? Reflections on The immortal life of Henrietta Lacks and the status of participants in research using human specimens. <i>Minnesota Journal of Law, Science &amp; Technology</i> . 11(2):713-55. <a href="#">Link</a> (text itself is only about 20 pages)	<b>Humanistic and legal perspective on biospecimen research (Lacks, Moore, Greenberg, Catalona); property and privacy law; social justice; ethnographic data; informed consent; acknowledgement</b>
Knoppers, B., & Isasi, R. 2010. Stem cell banking: Between traceability and identifiability. <i>Genome Medicine</i> . 2(10):73. (7 pages) <a href="#">Link</a>	<b>Bioeconomy; biobank definition; informed consent; harmonization of transnational regulations; tracing donor; return of results</b>
VanderWalde, A., & Kurzban, S. 2011. Paying human subjects in research: Where are we, how did we get here, and now what? <i>Journal of Law, Medicine &amp; Ethics</i> . 39(3):543-558. <a href="#">Link</a>	<b>Paying human research subjects; human dignity (Jonas); wage payment model; health risks and harms of participation.</b>
Callaway, E. Aug 2013. Deal done over HeLa cell line. <i>Nature</i> . 500:132-133. <a href="#">Link</a>	<b>Donor control over research directions; HeLa Genome Access Working Group; compensation</b>
Garrison, N. March 2013. Genomic justice for Native Americans: Impact of the Havasupai case on genetic research. <i>Science, Technology, &amp; Human Values</i> . 38(2):201-223. <a href="#">Link</a>	<b>Native American Perspective; traceability; donor control; community investment</b>
del Carpio, A. Spring 2014. The good, the bad and the HeLa. <i>Berkeley Science Review</i> . <a href="#">Link</a>	<b>Scientific and Lacks family perspective of the provenance of the HeLa cell line; HPV18; immortality; cell culture contamination; HeLa Genome Access Working Group</b>
Reardon, S. July 21, 2015. US tailored-medicine project aims for ethnic balance. <i>Nature</i> . <a href="#">Link</a>	<b>US Precision Medicine Initiative; ethnic diversity; community trust; Trust and Privacy Principles</b>
Hudson, K. and Collins, F. Oct 28, 2015. Bringing the common rule into the 21 <sup>st</sup> century. <i>NEJM</i> . <a href="#">Link</a>	<b>Human Subjects and Biospecimen Regulations; advanced notice of proposed changes</b>
Arias, J., et al. 2015. Trust, vulnerable populations, and genetic data sharing. <i>Journal of Law and Biosciences</i> : 1-7. <a href="#">Link</a>	<b>Challenges specific to trust and stigma for vulnerable individuals and groups in genetic data sharing</b>

### Assigning Characters in Part I

Five teaching challenges emerge:

Character Assignments: Some characters in the role-play are quite popular, and students can feel slighted if they do not get their first choice. One can avoid this by assigning the roles randomly to students, but this goes against the idea of moving students towards their personal interests. Another approach is to ask students who did not get their first choice to specifically comment on the depiction of the desired character by their peer during the debrief period. I have used up to 16 characters at one time, and in larger classes I assign two students to each character. In this latter scenario one student performs in character during the

symposium and the other submits observer notes critiquing the performance and pointing out where they may have done things differently had they been performing. This latter scenario works well in classes with shy students, students with learning disabilities, or where English is a second language.

### Researching Character Roles:

To aid students in delving beyond surface level research, I have included a list of character biographies each of which is followed by a bibliography of resources. Instructors need to be mindful about character assignments and equity in workload with regards to research. Though some characters may have up to ten resources, many of the readings are short on the order of 1-2 pages, with one or two longer in length. Most characters have about 20-30 pages or reading. Students can be encouraged to do more research or view the resources of their potential opponents and allies. Instructors should note that some characters may appear to have larger reading loads or more resources than others. Instructors need to be mindful about character assignments having some equity in workload. For instance, the student assigned Bob Ehrlich is asked to read *portions* of a very long article authored by Gallant detailing the relationship of Johns Hopkins Hospital with the Baltimore community. Specifically asking this student to focus on the sections that address financial investment in biomedical research at a time of heightened class inequity balances out their load. Other students, such as those playing David Lacks, may appear to have less reading, however the instructor should point out that this character is assigned interactive web pages that require viewing multiple video clips, podcasts, and navigating multiple pages for information.

Some instructors choose to provide students with both the detailed biographies and a list of references that appear in the **Stakeholder's Connections, Biographies, and References** document, while those teaching more advanced students may choose omit the biography. In this latter case, it is strongly recommended that students be provided with the curated list of references for their character as they were chosen to bring forth a range of diverse views to the overall role-play dialogue. If students are left to conduct research on their own, they may only identify the dominant narrative for their character and the dialogue will be short changed as a result. Jimmy Sarkett (#7) is a good example, in that surface level research will pull up little on this character, most of which suggests he supports the "gift" approach and considers his role in the development of the Salk polio vaccine a service for the public good. However, the reference link I have included reveals that as a disabled retiree struggling to cover the cost of a new set of crutches, Sarkett was the beneficiary of a gift in kind some 50 years later by the very institution that used his body as a source of biological material to develop the vaccine. One might interpret the gift as a form of reparations or damage control. That this character can provide perspective on both the biomedical and social models to health is important, as it brings in the complexity of inequity and the ways in which "compensation" and "gift" take on different meaning in different times.

### Choosing Characters:

Whatever the choice, instructors should strive for a diverse representation of expertise, values, and lived experiences in character assignments. One point instructors may want to highlight is the racial and gender diversity among the list of characters; 11 of the 21 possible characters identify as female and 11 of the 21 characters identify as being from under-represented minorities spanning Latino, Asian, Native American, and African American communities, and one individual who is disabled. There are characters that address issues of under-represented minorities and affiliate with organizations that advocate for these groups and these include the Lacks, Palmer, Chung, Peters/Garrison/Echo-Hawk, Mitchell, Nix/Yeampierre, and Benjamin. Instructors should explain that diversity with respect to race is not coincidental and, rather, representation can reflect the distribution of power in terms of who guides and directs research agendas and health policy. In choosing characters, it is best to select a group of characters that address the issues of under-represented minorities, support compensation/reparations/ access to goods (Andrews, Saxby,

Palmer, Mitchell, Benjamin), argue against compensation (Ehrlich, Salk, Brin) and present caveats to compensation (Holder, Willibanks, Javitt,). Additionally, if the conversation is to encompass biological understanding of biobanking in a contemporary context, some characters that provide alternative models for bioresource acquisition using a biotrust model should be included (Nix/Yeampierre, Collins, Winickoff, Arias et al.). Similarly, if instructors intend to connect this case study more directly to issues of commercialization and patenting, characters should be included to address gene and cell line patents (Nix, Saxby, Chung, King).

If all characters are not assigned, some resources can be redistributed to other characters. Some characters will read the same material, while others will read slightly different perspectives on the same topic. An example of the overlap and range in views, can be seen in the eight common readings shared by the Lacks family members, and the two additional articles that are specific to each character, allowing there to be some representation of the diversity of family views about how the HeLa cell line is used and recognized in biomedical research. If only one member of the Lacks family is included instructors should choose David Lacks Jr. or Jeri Lacks, both of which preside on the Henrietta Lacks Genome Working Group and are vocal about issues of privacy and recognition. Likewise, social scientists Lisa Weasel, Ruha Benjamin, and Hannah Landecker share some readings, but bring different levels of scale to the discussion, using race, class, and gender perspectives. While Landecker and Weasel analyze specific historical cases, Benjamin addresses systemic change at the level of government investment in social goods. Given that some characters use a more theoretical approach while others are more practice oriented, instructors should be mindful to have a good mix of characters representing theory and practice. Lastly, if characters are eliminated, instructors should be mindful of the important contextual difference in the US Precision Medicine Initiative and the UK National Biobank. The US project will amass existing data and secure new tissue and DNA donations to construct a large database of lifestyle and genetic information for biomedical research against the backdrop of a limited national healthcare policy (The Affordable Care Act), while the UK project has reached 500, 000 altruistic novel donations from those that benefit from a national healthcare system. As many of the characters are assigned readings regarding the US initiative it is important to remind students of this difference in national health care policies.

Moreover, students should be made aware of the changing landscape regarding biospecimen collection and access more generally. The European Union, which had taken a similar approach to the US in proposing more restrictive guidelines requiring consent for secondary research questions, reversed its position at the end of 2015. The new draft legislation would grant researchers access to data for which patients or research subjects provided broad consent ([Feldwisch-Drentrup, 2015](#)). The Advanced Notice Proposal for Rulemaking and the EU legislative processes regarding human subjects research allow for public input. In some cases activism and lobbying are influencing the process with large effect. In the E.U. the European Data in Health Research Alliance, which includes the Wellcome Trust, pushed hard for the reversal of the proposed legislation using the URL "[Datasaveslives.com](#)," a concept reviewed in the [blog](#) by Gent advocating for self sharing. In the US, the National Institutes of Health funded a project to collect public opinion through [surveys](#) informed by a meta analysis of patient and research subjects' views via the eMERGE consortium working group ([Garrison et al., 2015](#)). With the changes to the Common Rule, additional readings could be added that are quite short , yet highlight the nuances associated with biobanking in a contemporary context.

1. Berskow, L. 2016. Lessons from HeLa cells: The ethics and policy of biospecimens. *Annual Review of Genomics and Human Genetics*. 17:395-417. [Link](#) (regarding proposed changes to Common Rule for de-identified specimens/ Gail Javitt and Jill Peters characters)

2. Lynch, H. and Joffe, S. April 2, 2017. A Lesson From the Henrietta Lacks Story: Science Needs Your Cells. *New York Times*: A27. [Link](#) (A call for universal health care if there is to be universal donation/ Yeampierre character)
3. Chen, A. Mar 13, 2017. Apple's ResearchKit generates reliable health data- at least for asthma patients. *The Verge*. [Link](#) (positive outcomes of public data de-identified/ Willibanks character)

There are 21 roles provided, but if the class is smaller, the following "short list" can work for a class of 10 students: #2 (Lacks Family Member on Working Group), #3 (Systemic Disparity in Baltimore), #5 (Reparations for Minorities), #7 (biomedicine for the public good), #8 (compensation and commercialization), #10 (against patents in science) #11 (Native American communities), #12 (compensation for diversity), #14 (pay to participate), #20 (public biotrust). This selection will work if the #11 Native Americans and #5 Reparations are asked to read papers or videos created by #19 Benjamin and #18 Rao as they broaden the vulnerable risk groups and provide more systemic and proactive address. In fact, the Rao article published in 2007 titled [Genes and Spleens](#) provides the only mention of the [PXE case](#), in which patient advocates took control over their own biospecimen database through the use of contract law based on ownership of property and, thus, a share in any profits made downstream. Additionally, the short list does not have a diverse representation of participants from under-represented minorities, thus, one could switch out #3 with #16 and depending on whether Nix or Yeampierre is chosen, issues regarding patents that exclude access to diagnostics for high risk populations and community participation could be highlighted. Lastly, it should be noted that many characters reference other characters or specific issues of contention. Examples include Palmer and Winickoff, both of whom are referenced in resources associated with other characters. The polio vaccine is raised as a public good model in a number of characters' resources (Spector article for #10 King or Loring), suggesting altruism and gifting on the part of Jonas Salk. However, a counter narrative emerges as students learn that the project was funded through the March of Dimes via altruistic donation allowing some to claim it is a public good not subject to patenting (Palmer article #7 Sarkett). Likewise, the controversy over patents in life science research is raised in the work of Sergey Brin (#14) and initiatives to identify new products, with Pharmastem which sued commercial blood banks for patent infringement as seen in the Kurtzberg reading assigned for Mitchell (#12), and with the work of Chung (#9) and King (#10) with respect to the Myriad patent on BRCA1/2 and Loring who fought the Wicell patents on embryonic stem cell lines (#10). This last issue presents grey areas as seen in the character Lengauer (#4) who is a supporter of patient's rights and serves as Chief Scientific Officer for the company Blueprint Medicines. The characters with resources on the Bayh-Doyle Act which allowed federally funded research to serve in profit making, include Jeanne Loring and Sergey Brin (#10 and #14).

Though many role-play exercises place students in stakeholder groups (industry, scientists, patients, social justice activists), this case study deliberately includes a range of characters from these generalized groups, but does so in a manner that highlights the diversity of opinion *within* these groups. It is crucial that students do not walk away from the experience believing that all the members of a particular group share the same position or use the same evidence or arguments. Though it may seem that those affiliated with a specific stakeholder group, say "scientists" or "feminists," share values and goals, it is imperative that character assignments represent the diversity of opinion within stakeholders' groups. For smaller classes this may prove challenging if the instructor wants to have class, race, and various biobank models raised in the dialogue. So sometimes breadth will need to be sacrificed to ensure that diversity of approaches within stakeholders' groups shine through. Alternatively, the instructor can provide some class sessions prior to the role-play to present these challenges. Instructors should provide ample opportunity to showcase the fact that those who may seem to share the same end goal do not do so for the same reasons, and that those that support particular initiatives may not seek the same end goals. For

instance, though many agree that donors should have some control over what happens to their bodies and their tissues, they are not in agreement about how consent should be secured, using different kinds of arguments that include upholding choice and autonomy, reducing risks to donors, avoiding commodification of the body, ensuring “just participant” selection, and addressing access to downstream products and profits associated with cell research.

Lastly, some instructors have chosen to use a cast of characters more closely centered on the Lacks case, using a combination of living and dead characters. For some students this incongruence proves challenging while for others imagination serves them well. In these instance, characters no longer living such as Howard Jones, George Gey, and David Golde (Moore case) interact with present day characters such as the living members of the Lacks family, Judge Mosk (Moore case), Christoph Lengauer, Darrell Salk, Kara Saxby (Moore case), Judge Sweet (Myriad BRCA patent) and Sergey Brin. If instructors choose this approach they should assign the Lucey article ([Link](#)) as it presents the scientific viewpoint of Gey, Kubicek, and Jones, the Skloot article, “Taking the Least of You” ([Link](#)) and the Landecker article “Between Beneficence and Chattel” ([Link](#)) to provide the Moore and Hela cases in full social context. Rebecca Skloot author of the book *The Immortal Life of Henrietta Lacks* has a [character guide](#) on her website for educational purposes that also provides some backdrop for the characters presented in her story. Whatever the choice, instructors should be clear about expectations as students struggle to know what they should know and bring to the table. For instance, can a character who has passed away communicate with a character who is alive today, and if so, in what context; would the historical figure be privy to the contemporary laws, policies, and practices? In addition, historical figures can allow students to assume conjecture; in one classroom situation, students made assumptions about the reason for Dr. Golde’s suicide and attributed this to a guilty conscious placing the student who played Dr. Golde in an odd position of defense. One way to address this challenge in courses with more room for exploration, is to ask students to participate in two role-play exercises, one set in the past with historical figures, and one set in the present with contemporary figures.

Stakeholders Connections: The chart depicting possible common ground or oppositions among characters in the **Stakeholders Connections’, Biographies, and References** is provided, but instructors should use discretion in implementing it in their classrooms. In upper level or seminar-based courses it might be appropriate for students to complete the last two columns on their own (Allies/Opponents; Buzzwords for Resources). In more introductory level courses, the chart was provided with these columns filled in, as students did not have the time to conduct open-ended research. However, instructors should explain that though some individuals may share some values, it does not imply that these individuals would share *all* values. Students should inform their performance by what they have learned about their character and how they imagine this person to respond to the policy proposals at hand. It is useful to remind students that most policy decisions involve compromise and, therefore, they should feel comfortable shifting their position in response to good ideas that might be in line with their character’s overall philosophical beliefs.

As an example of the complexity in the case, Willibanks, Handelsman, Lengauer, and Brin all aim to construct large databases of information to serve biomedical research, yet Ruha Benjamin and those individuals representing underserved communities would most likely be critical of these proposals despite the claim to produce products and information for the public good. Benjamin and others would argue that the public national database or patient database model does not adequately address existing and pervasive economic inequity in society. Another example would be Eric Holder, Saka Mitchell, and Winickoff. All three appear to be interested in biobanking, however, Holder supports altruistic donation to public banks, Mitchell supports incentivizing donation to public banks for those most in need by

addressing economic inequity and racial diversity, and Winickoff supports the construction of a biotrust to ensure a sustainable model and access to goods and knowledge.

To successfully achieve robust dialogue, the instructor may need to do some individual prompting or provide directives to students regarding their character's views, arguments, and rebuttals. Providing feedback along these lines after reviewing the character statements and questions, will help students recognize areas in need of more exploration or challenge, allowing them to fully develop their responses and positions in advance of the symposium.

Adopting a Character Role: Students will often be very nervous adopting the role of a real person. This is true even for those students who are comfortable with seminar discussions. Because they may be nervous the instructor should repeatedly throughout the activity remind them that this is a learning environment and that any mistakes or misrepresentations can be useful for “teachable moments.” Precisely because they will be nervous, during the session when roles are assigned, instructors should remind students that there will be plenty of opportunity for debriefing where they can explain their discomfort, excitement, confusion, and their choices.

If instructors would like to modify and prefer a document in Pages or MS Word, they can contact me at [chamanyk@newschool.edu](mailto:chamanyk@newschool.edu) and I can send these assignment in that format for ease of editing.

### *Role-play and Dialogue*

Depending on how many characters are assigned, the role-play can take 50 minutes (8-10 roles) or 90 minutes (11-15 roles). For non-forced discussion to take place, the instructor should facilitate the conversation and draw on each character to address the questions posed in the case to ensure a balanced discussion. For instance, the symposium could be organized around themes based on the character statements or questions posted; e.g. who would like to speak about compensation? Reading over the short biographies prepares the instructor to call upon specific characters to respond to a particular question, and direct the conversation to allow for all voices to be heard. This type of facilitation works much better than asking each student address each question in succession or to do formal introductions, as the facilitated discussion allows for a more natural flow of conversation. The instructor should only intervene as facilitator to ensure that students do not slip into debate, hold the floor for too long, or remain stalled on a singular issue for too long. This may require the instructor, as facilitator, to summarize and pose questions to participants to shift discussion accordingly and help make sense of the arc of the conversation. It is also important to note that given the time constraints most students will not be able to ask their two questions. Hence, the written statement and questions serve a place for the instructor to assess all students regardless if they have a chance to vocalize their views during the discussion.

As students will feel some pressure, they may revert to casual language, and the facilitator may need to remind students to refrain from language that makes assumptions that are not agreed upon by all in attendance. For instance, instructors may ask students to refrain from using the term “cripple,” “handicapped”, or “suffering” when discussing disease and disability. Instructors can host discussion to determine if the terms are being reclaimed as they are in “crip studies” or whether students are using these terms in ways that could be interpreted as derogatory or deficient. As alternatives, instructors could remind students that with advances in social and biomedical models to health, many individuals now manage, or live with, disease and disability, and that to assume that they are suffering is an assumption we cannot always make. Lastly, the area that may prove most challenging is when students begin to discuss economic inequity. Because so many students are grappling with economic hardship, instructors will need to monitor language regarding poverty very carefully

and take into account the context in which it is raised. For some students using the word “poor” is offensive and they would prefer an address of the systemic factors leading to poverty and thus, prefer the terms “impoverished” or “under-resourced.” For others “being poor” may be an important part of their identity.

Eight classroom management and teaching challenges emerge during Part II:

Opening Script: A script to set the stage is provided in the **HeLa Learning Activity 3 Case Study Assignment**. This can be modified, but should involve framing the discussion, reminding students to maintain their character role and to refrain from slipping into discussion from their own personal view, and emphasizing the nature and goals of dialogue versus debate.

Prepping for Authentic Engagement: Students often are reluctant and nervous to jump right in. One approach to minimize a slow start is to have a “coffee break” of 10-15 minutes where like-minded characters can assemble and discuss their stance together and recognize that there might be strange bedfellows in that they may agree about outcomes but their rationale may be quite different. In this way, students recognize their allies’ positions and the subtle nuances in stances that exist within these groups.

Emergency Intervention: The dialogue may omit a crucial element or perspective. In this situation, an intervention can be introduced in the form of a “late attendee” joining the dialogue. The dialogue may omit a crucial element or perspective. In this situation, an intervention can be introduced in the form of a “late attendee” joining the dialogue. This person could be the instructor assuming a role of a scholar, or activist, who brings this omitted view into clear focus, or a student or teaching/learning assistant, who assumes the role of a student representative from the home institution at which the case study is taking place etc.

Equitable Student Participation and Student Input on Success: Because the role-play moves quickly it can be difficult to monitor the degree and quality of the participation of each student. The “Characters’ List For Instructors” allows instructors to see at a glance the positions and allies that should emerge. To equalize speaking time among all students, it is useful for the instructor to turn the conversation to allies and opponents of the character being represented by a student that happens to be speaking often and at length. By drawing out other characters the conversation develops more complexity and the frequent speaker must pause and reflect before speaking again. “**The Role Play Rubric**” is designed to facilitate assessment, however, asking each student to reflect on who performed most convincingly during the role-play is a helpful way to debrief and also to gather a more accurate and thorough account of what transpired. This can be done as a quick oral Round Robbin style (one minute per student, and captured with written notes or audio recording) in a reflective statement post role-play, but will require 15-20 minutes depending on class size.

Debriefing: For this component, a thirty-minute debriefing session at minimum is essential as strong opinions are brought to bear and conflict emerges. This can be done immediately after the role-play if the class session allows, but it can also be conducted in the next class session. Because students may be assigned a character for which they have no lived experience, it is not uncommon for students to present stereotypes as they craft their role. The stereotypical representation does not necessarily negate the role-play, but it does need to be addressed fully by the instructor and the class in the debriefing. For example, a student may be assigned a character that holds a different position from them with respect to socioeconomics, race, ability, or gender, and may inadvertently offend peers with their depiction of the character. It is best to allow students five minutes to write down some immediate responses to the role-play experience, collect, and review these anonymous submissions while they jot questions down for their peers, and then commence the debrief. This way, if there is a student who does not feel comfortable

voicing concern or discontent, the instructor can present that view being careful not to reveal the identity of the student.

### Race

For a discussion on the racial perspectives associated with this case study, please see the teaching notes for [Activity 1](#) in this Module (page 5). Instructors should be aware that many of the references assigned to students address racial inequity and that some may appear in unexpected places, such as the role of Bob Ehrlich, former Governor of Maryland. Here the Zakaria et al. reference presents John Hopkins University as a leader in medical school education reform that addresses racial and class inequities in light of the death of Freddie Gray and national protests against police brutality. However, the Gallant piece provides a deeper history regarding the university's practices of land grabbing and urban upheaval in Baltimore. These oppositional stances are deliberately included to showcase the evolution of an institution as societal values shift and its response to public activism. Other roles are more obviously connected to issues of inequity and this framing is important for instructors to facilitate without deepening prejudices.

Social Justice History: As part of the debriefing, social justice should be specifically addressed. During the role play activity, students gradually realize that even if they thought they knew something about Henrietta Lacks, or HeLa cells, there are many things they do not know, and that their peers hold differing views on the history of this case. For example, in biology courses, some students may refer to the cells as Helen Lane's, in ethics courses some may challenge the use of the word "donate" in reference to the cervical biopsy, and in classes with students familiar with issues of intersectionality (ability, race, class, and gender) and past race-based abuses of the Public Health Service (namely the recent investigation of the STD study in Guatemala, Mississippi Appendectomies, La Operacion in Puerto Rico, and the Tuskegee Syphilis Trial). If time allows, instructors may want to include a screening of a video recording of the World Stem Cell Summit Plenary Session titled "The Immortal Life of Henrietta Lacks: Lessons for Stem Cell Researchers and Patients." The clip is accessible from the *Stem Cells Across the Curriculum Media and Infographics* in the **Videos** section and is titled "[Human Subjects and Biomedical Research](#)." This lengthy video provides an overview of research involving human subjects, followed by a creative spin on cell culture as represented by Chris Hempel (time stamp 51:30 min), the mother of children with Neimann Pick disease. She, her husband, and her children have "donated" their cells to develop induced pluripotent stem cells and also to generate mice that carry their autosomal genetic variants in an effort to produce mice that would represent their children who carry two copies of the gene variant conferring Neimann Pick disease (homozygous). The ways in which she describes these cells and model organisms is through very humanistic language. The upshot is that people want to "donate" or gift their cells as long as there is complete transparency and attention to justice. In the same plenary session theologian Laurie Zoloth argues that there is a duty for altruism to support biomedical research and goes so far as to say that if Henrietta Lacks knew that her cells prevented her children and countless others from contracting polio she would "not want a cent." She also uses the example of Jimmy Salk's body in the development of the polio vaccine and emphasizes the need for altruistic donation for this to occur at a time when profit was not the focus (time stamp 34min; HeLa at 43min; quote at 48:50-51min). Instructors will need to be mindful of these alternative histories and counter narratives regarding the provenance of the HeLa cell line and the use of humans in biomedical research. Instructors may also want to connect social justice to stem cell research and review the article authored by Regenberg and Matthews titled "[Promoting Justice in Stem Cell Intellectual Property](#)" published in the 2010 World Stem Cell Report. If this course expands in this area of biology and social justice, the book [Achieving Justice in Genomic Translation: Re-Thinking the Pathway to Benefit](#) might prove useful. The authors of this book evoke a responsive justice framework to question the normative approach to biomedical research and call on researchers to take on increased responsibility to protect subjects and communities, and more specifically to address redistribution and

recognition with respect to under-served communities (page 3-20 in Google Books). Other books that address health inequities in biomedical research include Alondra Nelson's book *Body and Soul: The Black Panther Party and the Fight Against Medical Discrimination*; Harriet Washington's book *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans from Colonial Times to the Present*; and Miguel Melendez's Chapter "The Hijack" in his book *We Took the Streets: Fighting for Latino Rights* with the community activist group The Young Lords, which describes the movement to expand access to TB screening to Latinos living in East Harlem.

Ethics: Instructors can refer to the **Timeline** of events and remind students that protections for human subjects research were not in place at the time that these cells were removed from Henrietta Lacks' cervical cancer biopsy. To bring forth counter narratives, it may be useful for instructors to confront unethical practices in biomedical research openly and illustrate the ways in which current regulation comes up short. This can be illustrated by highlighting the investigative report of practices conducted on human subjects during the Guatemalan STD study conducted by the US Public Health Service in the 1940s. The report "[Moral Science: Protecting Participants in Human Subjects Research](#)" was released in December 2011 at the request of President Obama. The letter exchange between the President and the Presidential Commission for the Study of Bioethical Issues appears on pages 7-8 and is instructive for students to see. Moreover, recommendation #7 calls for education at the undergraduate and graduate level on human subjects research and bioethics. The Executive Summary is in the first 28 pages. In July 2012, an editorial in *The New England Journal Medicine* titled "[Justice for Injured Research Subjects](#)" references this report and speaks to proposals to bring the United States policies and practices surrounding research with human subjects in line with those of other developed countries. In addition, a podcast [Ethically Sound](#), provides a first-hand account from one of the members of the commission as they detail the realization of the crimes through interviews with those living in Guatemala today. Though this is somewhat tangential to the case at hand and the context is vastly different, it is not uncommon for students to slip into discourse that conflates these cases. Though Henrietta Lacks, John Moore, and others were not in the strict sense research subjects harmed by their clinical diagnosis and treatment, their bodily tissues were used in research. As biospecimen acquisition continues to be obtained during clinical diagnosis or treatment the risk of therapeutic misconception will remain high. When patients in these circumstances are asked to donate cells from their clinical biopsies and blood draws for research they do not always realize that downstream products to treat patients will serve those in the future, but can do little for those currently living with disease and disability. These important aspects are well reviewed in the [Arias et al. paper](#) discussing trust and vulnerable populations. Additionally, a perspective not often raised is the cost of conducting biomedical research and the impact this has on marginalized populations. The [blog post I authored](#) highlights how the proposed rules regarding human subjects could have harmed the very populations in dire need of being included in biomedical research studies. The proposed guidelines would not have allowed de-identified samples collected using broad consent to be used for other studies without obtaining consent for each study. Had the change been adopted, it could have undermined procedural justice by placing undue burden on researchers and non-profits that do not have the funding to carry out the administrative tasks associated with dynamic consent (consent for all secondary research questions using biospecimens collected for a primary research question). This notion of economic inequity in biomedical research can also be addressed using the distributive justice perspective by emphasizing the views of those characters who address the patenting of genes and cell lines.

### *Personal Policy Position Paper*

This part of the case study asks students to revisit their personal stance on the case after having completed the role-play and address the *evaluate* and *extend* steps of the 7E learning cycle. The goal is to craft an informed essay that recognizes multiple points of view, and explains each perspective using objective reasons

supported by evidence to arrive at a **decision concerning public funding for biobanks and revisions to regulations o guiding research conducted on biospecimens and/or DNA**. Instructors can edit the list of **Questions to Consider** to align the prompts to their course more directly. For instance, a focus specifically on the Lacks family, or more contemporary issues surrounding biomedical research involving human subjects, or both.

Students must consider the benefits, risk, and trade-offs and the implications of such a decision for related controversies moving forward. The Grading Rubric is adapted from the curriculum “Issues, Evidence, and You” from the Science Education for Public Understanding of Project (SEPIP) at the Lawrence Hall of Science ([Wilson & Sloane 2000](#)). This particular curriculum is designed to develop an understanding of scientific content and scientific problem solving approaches related to social issues without promoting an advocacy position. In this adaptation there is a strong focus on personal commitment, as research has shown that having students check in on their personal values results in greater long-term learning retention. In using this approach, I have found that students are able to grapple with moral reasoning more directly.

I have also asked students to consider evidence on three levels: social, legal, and scientific. In other words, students cannot take a stance on public funding and regulation without addressing the consequences of their approach in these three areas. They must provide evidence that would support, or argue against, public funding and updated regulations from each vantage point.

Providing the rubric to students in advance results in much more sophisticated arguments because it supplies them with a set of criteria with which to evaluate different arguments and proposals. Because the rubric is organized at these different levels, students cannot take a stance without addressing the consequences of their position, or proposal, as they relate to social, legal, and scientific practice.

Five teaching challenges emerge in Part III

Explaining the Rubric: Some of the categorization in the rubric may be unfamiliar to students and require explanation. For instance, in the area on “stance” there are a number of subcategories, one of which is “compensation.” In the context of a biospecimen donor, compensation can be viewed as a benefit or exchange for biolabor, but some might argue that the National Organ Transplant Act prohibits commodification of the human body and its parts. The counterargument could be the case of Flynn v Holder, which has made it possible to provide compensation for bone marrow stem cells of a specific haplotype to achieve immunocompatibility for those with rare genotypes. The issue of compensation is often nestled in arguments regarding the commercialization and privatization of biomedical research. Students should mention the Bayh-Dole Act which led to a shift from government funded research being a public good, to the creation of a profit making industry based on licensing fees for patented materials. In this context students must clarify whose lives are being protected by this model, and whose lives might be burdened or harmed. The characters with resources on the Bayh-Doyle include Jeanne Loring and Sergey Brin. Some who live with disability may believe that investing in biospecimen-based research rather than social models (e.g. physical structures, information access, social support, assisted technologies, etc.) to support health is not promoting the lives in their community. Others that live with disability or disease may see investment in biobanking as supporting lives in this community through the biomedical model of health (e.g. cell based therapies, drugs, etc.). For the issue of privacy, students should recognize that gamete donation results in cells that are not identical to the donor because only half the genetic information of the donor is contained in the eggs or sperm, however, biospecimens of any other cell type would be traceable to the donor. Given the complexity and the dependency on role assignments and the role-play some attention to the rubric should be provided when it is distributed.

Single Perspective: Less advanced students struggle with the complexity in this assignment as they are not accustomed to addressing both sides of an issue and taking a stance. Most have experience with opinion but struggle to craft an argumentative essay that uses quality evidence. Instructors may want to include a reference to the [Online Paradigm Writing Assistant](#) that has a tab and tutorials for writing argumentative essays under the menu link “Convince.” Additionally, the grading rubric can be less complex and be customized to prevent the introductory student from feeling overwhelmed or intimidated.

Not Taking a Stance: Because the goal of this case study is to move students away from debate and dualistic thinking, instructors may want to be lenient in this regard on a case-by-case basis regarding the position papers. Papers can be rich in their analysis, yet struggle to come to a “one answer fits all” solution and, instead, provide solutions that are dependent on the context of the type of research, the community research site, and other variables. If the essay is well evidenced but does not take a stance it may still qualify for a high mark. As is detailed in [Perry’s Model of Ethical Development](#) to move students from dualistic thinking to multiplicity, or relativistic thinking, and to move them from decisions made based on emotion to those based on evidence, is an accomplishment for introductory level students. If students are more advanced they may arrive at a committed stance, and this would be a sign of successful ethical reasoning.

Being Clear About the Number of Issues: Instructors may want to adapt the case such that different questions are addressed in the position paper (either compensation/damages, privacy, or consent). If instructors provide the **Questions to Consider** they should be clear about what they expect students to address and provide sufficient time for research, writing, and potentially if using all areas, expand the length of the essay. Without this clarification, student papers will represent a wide range of responses with some students addressing only one aspect of the case, and others addressing several. That said, it is common for students to feel overwhelmed by the number of questions in the **Questions to Consider** document and the detail in the rubric, so another approach may be to provide a streamlined sequenced set of open-ended questions that provide much less directive and a simplified rubric. A more truncated list may work for more advanced students who would understand that a discussion of public and private funding models and their associated regulations should be included, but introductory students may be better served with questions that provide more specific directives. An example of the open-ended type of short list questions is provided below:

1. Should biobanks be constructed and why?
2. What are the strengths and problems associated with biobanking and research using biospecimens?
3. If we do not continue to invest in biobanking, what alternatives would you propose and what are the strengths and weaknesses of these alternatives?
4. If biobanking should continue, what policies do you propose to mitigate the drawbacks?
5. If biobanking should continue, should biospecimen providers be compensated, have control over some aspects of research, or obtain access to knowledge and products derived from research?
6. If so, how? If not, how would research continue?
7. Who argues for and against policies similar to the ones you propose?
8. Where have similar policies been attempted and what were their effects?

Incorporating Biology: Because the case is so heavily focused on the ethical dimensions students often neglect to include any scientific reasoning for biospecimen-based life science research. If the rubric is adapted and biology learning outcomes are desired, the rubric should clearly direct students to use

biological evidence to support their position and clarify the characteristics specific to immortality, cancer, tissue culture, diversity, immunological matching, etc. They should address what could be lost if this avenue is not pursued and who would suffer (scientists, patients, under represented minorities, etc. For instructors, the **Media and Infographics** portion of the [Stem Cells Across the Curriculum](#) site containing [PPT slide sets](#), [Timelines](#) and [Infographics](#) tracing the trajectory of technologies may be most helpful in quickly reviewing the biology and technology of biomedical research involving human subjects.

**FURTHER LEARNING:** Instructors and students would benefit from reviewing the [Primer](#) associated with this module, and fore grounding this case study with [Learning Activities 1 and 2](#). A collection of [Discussion Questions](#), [Timelines](#), [PPT slide sets](#), [Essential Resources](#), [Videos](#), and [Infographics](#) tracing the trajectory of technologies and policies.

**NOTE of IMPORTANCE REGARDING INTERSECTIONAL ANALYSIS**

As many will be unfamiliar with intersectional analysis and the alternative narratives of Henrietta Lacks, instructors are strongly encouraged to review the [Pedagogies and Philosophies](#) document on the *Stem Cells Across the Curriculum* website and an article published in [Studies in Social Justice](#) and the [Primer](#) associated with this module. The [Primer](#) provides a comprehensive view of many of the topics that will emerge during discussion with learners from diverse backgrounds.

**ASSESSMENT:**

Instructors can choose which portions of the case study to assess based on course goals. For the written and presentation facets, rubrics are provided here in a separate document.

**Part I: Character Position Statement + Counter Argument + Two Questions Rubric**

Possible	Earned	Item
10		<b>Statement:</b> Clear statement of who character is and what specific expertise or experience they bring.
10		<b>Statement:</b> Identifies a point of controversy that is pertinent to the character and provides clear and direct presentation of perspective and position on public funding being used for biospecimen-based research.
10		<b>Statement:</b> Narrows in on one or more core themes (nature of informed consent/broad/narrow/controlled access; maleficence/health risks/privacy/ community discrimination; beneficence/compensation/access to goods; autonomy/choice/opt-in; public good/volunteer/opt-out, commodification/private funding)
10		<b>Statement:</b> Use of factual evidence with concrete examples (historical or contemporary) that serve as precedent or relevant comparison.
15		<b>Two Questions:</b> Questions are posed to potential allies / opponents. Questions are appropriate, insightful, and demonstrate comprehension of material.
10		<b>Counterargument:</b> Identifies a point of controversy that is pertinent to the character and most likely to be argued by someone with very different values or lived experience.
10		<b>Counterargument</b> Demonstrates foresight with respect to the factual evidence that might be used by opponents to argue against character’s position and speaks directly to that.

10		<b>Counterargument:</b> Narrows in on one or more core themes ((nature of informed consent/broad/narrow/controlled access; maleficence/health risks/privacy/ community discrimination; beneficence/compensation/access to goods; autonomy/choice/opt-in; public good/ volunteer/opt-out, commodification/private funding)
10		<b>Rebuttal:</b> Comprehensible, demonstrates logical reasoning, and does not simply reiterate statement section
5		<b>Citations:</b> Reference section is complete, demonstrates the use of at least five class resources sources, and is appropriately formatted.
100		

## Part II: Role-Play and Dialogue

For the role-play dialogue, instructors might be challenged by the speed by which conversation turns and find it difficult to take notes and stay engaged as the facilitator. For this reason instructors may choose:

1. To have someone else take notes or serve as facilitator
2. Refrain from formal assessment and instead summarize and debrief orally with the students; this may be particularly important in large classes where it may not be possible for every student to speak.

For note taking purposes a chart with the following headings may prove useful, and information for the Stakeholders Possible Connections Chart can be placed in the first three columns. The remaining columns would be completed based on student performance

Character & Student	Perspectives & Position	Allies & Opponents	Clarity of position	Stays True to Character	Provides Evidence	Pertinent Q&A	Counterargument (Engages in Dialogue)
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## Role Play Rubric

Score	Meaning
90-100	Clearly articulated their position; provided evidence of their experience; provided insight on the perspective they bring to the discussion; gave ample accurate supporting facts and precedent, connected the facts to the case in a concrete manner, and responded directly to the comments and statements made by other stakeholders, and addressed opposition with questions and counterarguments

80-89	Clear position, mostly accurate facts/precedent, some possibly irrelevant or inaccurate; Responded directly to comments and statements made by other stakeholders, using evidence and examples; addressed some of opposition with questions and counterarguments
70-79	Weak response; few facts & relevant evidence cited, illogical engagement with other stakeholders
60-69	Weak response; inaccurate and irrelevant facts, poor detail & logic, no engagement with other members.
< 59	Did not participate

### **Part III: Position Paper Grading Rubric (see separate document)**

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