The Immortal Life of Henrietta Lacks (HBO Movie)
Genomics Salon - May 3rd, 2017

References/resources:

"A Lesson From the Henrietta Lacks Story: Science Needs Your Cells"
Holly Lynch & Steven Joffe. April 21, 2017, *The New York Times*
"Rather than demanding consent and payment, we should promote biospecimen research, shore up privacy protections and push for universal health care to ensure that the benefits of the research are available to all."

"Your Cells. Their Research. Your Permission?"
Rebecca Skloot (Author of *The Immortal Life of Henrietta Lacks*) Dec. 30, 2015 *The New York Times*
"They believe tissue research is important, but they wish they'd been asked permission from the start, to avoid difficulties that followed: the shock of learning they were part of research, debates over who controlled samples, questions over profits."

"Henrietta Lacks' Story is a Powerful Lesson that Patients Deserve Full Control of Their Genetic Data"
Ken Deutsch April 26, 2017 ACLU Blog
"With the support of the ACLU, I have joined with others to make sure that patients can get the full results of their genetic tests in a format we can share with researchers. Patients should have the same rights to our genetic information as we do to other types of health information, so that we can make decisions about our own care as well as contribute our data to research if we so choose."

"HeLa publication brews bioethical storm"
Ewen Callaway. March 27, 2013 *Nature*
"Genome of controversial cell line no longer public, but another sequence is in the works."

"Radiolab Extra: Henrietta Lacks"
This Radiolab podcast episode features interviews with Rebecca Skloot and members of the Lacks family.
http://www.radiolab.org/story/radiolab-extra-henrietta-lacks/

"Lessons from HeLa Cells: The Ethics and Policy of Biospecimens."
Laura Beskow. *Annu Rev Genomics Hum Genet. 2016 Aug 31;17:395-417*
This review paper includes helpful context on recent national discussions about human biomedical research regulations, including the possibility of requiring informed consent for all research involving biospecimens (including "deidentified" biospecimens).

Discussion Questions:

While undergoing treatment for cervical cancer at Johns Hopkins Hospital in 1951, Henrietta Lacks' clinical tissue samples were passed on to a researcher without her or her family's knowledge or permission. However disturbing this seems to us now, this was common practice at the time (Beskow, 2016). The HeLa cell lines went on to undergird significant scientific discoveries of vast public health significance.

- How does the HeLa story affect how we think about the tradeoffs between individual autonomy and public benefit of scientific research?
- How would the HeLa story have played out differently if the identity of the donor cells had remain anonymized?

What are the pros and cons of requiring that patients receive full control of their genetic data? What guidelines would be sufficient for informed consent of patient specimen donations? How could these requirements affect biomedical research?

In 2013, scientists published the full genome sequence of HeLa cells. The sequence was quickly removed from a public archive after bioethics concerns were raised. After seeing the film, how do you respond to this incident?

- Given that one person's genetic information gives significant information about their family members, should consent rules change so that family members also need to give consent for the sharing of genetic information?

In September 2015, the federal government published a plan for updating the Common Rule, the regulatory framework for human subjects research first established in 1974. Under existing laws, research involving de-identified biospecimens generally does not require informed consent from the original donor. The 2015 proposed updates would have changed this, requiring informed consent for research uses of all bio specimens. The regulation, passed in January 2017, ultimately did not include this change.

- Do you think it would have been preferable if this change had been passed in the updated Common Rule? What costs and benefits would it have imposed on researchers? On patients and research participants?

In a recent interview (*The New York Times,* April 19,2017) Skloot talks about the awkwardness of inserting herself into the story of the Lacks family while still trying to adhere to journalistic ethical standards (e.g. the prohibition on paying money to story subjects). Do you feel that Skloot maintained an appropriate amount of distance from her subjects? How does the blurring of lines between subject and journalist affect the story?