

Contemporary Ethics and Qualitative Oversight

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Part A: Contemporary Ethics

Christoph Lengauer's comparison between human cells and oil is a provocative way of describing biological value. Oil can lie beneath private land, possess enormous economic importance, and become the subject of ownership, licensing, extraction, sale, and profit. Cells can also acquire value beyond the body from which they came. Researchers may culture them, distribute them, modify them, patent inventions developed through them, and use them to create diagnostics, medicines, vaccines, and commercial products. The analogy therefore draws attention to a difficult fact: material originating from one person can become the foundation of benefits and wealth controlled by others.

I agree that the analogy reveals how institutions can treat biological material as a valuable resource, but I disagree with using it as a complete moral model. Human tissue is connected with identity, bodily integrity, privacy, family history, ancestry, and health information. A person is not a deposit from which useful material may be extracted merely because researchers can create social value from it. Oil has no autonomy, dignity, relationships, or capacity to be harmed by deception. Ethical research must therefore treat cells not only as laboratory material but also as material obtained from a human being whose rights and interests deserve respect.

What the Oil Analogy Clarifies

The analogy helps explain why ownership questions emerge after tissue leaves the body. Once oil is removed, different parties may claim rights through land ownership, contracts, licenses, labor, processing, or investment. Biological samples likewise pass through several stages. A hospital collects tissue, a laboratory isolates cells, researchers establish a cell line, another institution stores it, and companies may use discoveries developed from it. Value is produced through both the original biological contribution and later scientific work.

This comparison prevents the discussion from becoming sentimental in only one direction. Researchers do contribute expertise, equipment, funding, quality control, and years of work. A cell removed from the body does not automatically become a successful research tool. The establishment and maintenance of a cell line require labor and scientific innovation. Ethical analysis should recognize those contributions without erasing the person from whom the material originated.

Where the Analogy Fails

The analogy becomes morally dangerous when it suggests that the person's role ends once the material is extracted. Oil does not reveal hereditary disease, ancestry, reproductive information, or family relationships. A human biospecimen can generate information affecting relatives who never entered the clinic or signed a form. Genomic analysis can expose risks, identity, and connections that were not understood when a sample was first collected.

Oil can be bought and sold without asking whether it feels exploited. Human beings can experience betrayal when tissue is used for purposes they did not anticipate, particularly when institutions profit while the family lacks information, healthcare, or recognition. The moral injury may involve loss of control and disrespect even if the physical sample was discarded during treatment and its later use causes no new bodily injury.

Henrietta Lacks and HeLa Cells

Henrietta Lacks was a Black woman treated for cervical cancer at Johns Hopkins Hospital in 1951. During treatment, cells from her tumor were obtained and provided to researcher George Gey without her knowledge or consent. The cells became the first widely successful immortal human cell line and were named HeLa from letters in her name. They multiplied rapidly and could be shared among laboratories, creating an extraordinary research resource.

HeLa cells contributed to studies involving polio, cancer, viruses, radiation, genetics, drug testing, vaccines, and cell biology. Their importance is unquestionable, but scientific importance does not erase the conditions under which they were obtained. At the time, taking discarded or removed tissue for research without specific consent was common and generally lawful. Ethical judgment, however, is not limited to asking whether the practice violated the rules then in force. It must also ask whether the patient was respected as a person.

Whose Consent Was Missing?

The original discussion focuses on the fact that the Lacks family did not consent. The first and most important consent failure concerned Henrietta herself. She was the patient whose tissue was taken while she was alive, and she was not told that her cells would be used in research. Her family later became important because researchers contacted relatives, collected blood, published information, and discussed the family's genetics without providing clear communication that they understood.

It is therefore more accurate to say that the case involved several layers of failed respect: Henrietta's lack of informed consent, poor communication with her family, exposure of private information, racial and class inequality, and commercialization without meaningful recognition or benefit sharing. Family permission is not automatically a legal requirement for every use of a deceased person's deidentified

tissue, but ethical obligations can extend beyond the minimum legal rule.

Informed Consent

Informed consent requires understandable disclosure, voluntariness, capacity, and an opportunity to agree or refuse. A signature alone is not sufficient. The person should know the nature of the research, important risks, privacy protections, expected use, alternatives, and whether commercial products may result when those details are relevant to the decision.

Contemporary research rules distinguish identifiable and nonidentifiable biospecimens. Identifiable specimens generally trigger stronger consent and review requirements, while research using deidentified or properly coded material may fall outside certain federal human-subject definitions. Institutional review boards can sometimes waive consent when legal criteria are met. These rules are more protective than the environment of 1951, but they do not solve every moral question. (Tracy, 2010)

Broad Consent and Future Use

Researchers often cannot predict every future study at the moment a sample is collected. Broad consent can authorize storage and secondary research within described boundaries. It should explain the types of research, duration, sharing, privacy, commercial potential, and whether participants will receive individual results. People should be able to decline without losing ordinary clinical care.

Broad consent must not become a blank check written in technical language. The participant needs a meaningful understanding of the categories involved. Institutions should also honor promises made in earlier forms rather than reinterpret them whenever a new commercial opportunity appears.

Ownership and Property Rights

My initial moral reaction is that a person should retain strong authority over cells originating from the body. The legal position is more complicated. Courts have often declined to recognize an unlimited continuing property right in removed tissue, particularly after it has been transformed into a distinct research product. Researchers and companies may obtain intellectual-property rights in inventions created through biological material even when the donor receives no ownership share.

The absence of a complete property right does not mean the donor has no ethical interests. Consent, privacy, confidentiality, nondiscrimination, recognition, and governance remain important. The law may define who owns a patented process, while ethics asks whether the distribution of benefit and control is fair.

Commercialization

Human cells and derived technologies can in fact participate in commercial markets. Cell lines may be sold by repositories, and companies may profit from products developed through tissue. The statement that cells “cannot be sold” is therefore descriptively inaccurate. The moral question is whether commercialization is transparent, regulated, and just.

Research participants should not be promised personal profits from every discovery, because most samples never generate a product and scientific value is created collectively. Nevertheless, institutions should disclose foreseeable commercial use and consider benefit-sharing models, especially when a community provides a rare resource or bears disproportionate risk. Benefits can include healthcare access, community investment, affordable products, recognition, research partnerships, or financial arrangements.

Race, Power, and Historical Context

The HeLa story cannot be separated from the history of medical racism. Black patients in the United States have experienced experimentation, segregated care, undertreatment, exclusion from research benefits, and violation of reproductive and bodily autonomy. Henrietta received treatment in a period when hospitals were segregated and Black patients had limited options.

Not every scientist using HeLa cells acted from racist intent, and the cell line has benefited people worldwide. Structural injustice can exist even when later users are unaware of the origin. The pattern is visible in who supplied the material, who controlled the knowledge, who received recognition, and who could afford the resulting healthcare.

Privacy and Genomic Information

Cell lines contain DNA. Modern genomic analysis can generate information far beyond what was possible in 1951. Publication of a genome may reveal information about biological relatives, making deidentification difficult. The Lacks family’s later involvement in governance of access to HeLa genomic information represents an effort to recognize these family interests.

Researchers should use controlled access, data minimization, security, and clear plans for sharing. Participants should be informed that complete anonymity cannot always be guaranteed when genomic information is combined with public databases. Privacy protections should be updated as technology changes.

Return of Results

Research may produce findings with possible health significance. Whether results should be returned depends on validity, clinical importance, consent, laboratory standards, and the availability of useful action. Returning uncertain information can create anxiety, while withholding a serious actionable finding can also cause harm.

A consent process should explain the policy before analysis. Researchers should not contact families unexpectedly with speculative interpretations. Genetic counseling may be necessary when information has implications for relatives. (U.S. Department of Health and Human Services, 2026)

Contemporary Ethical Position

My position is that cells should not be treated as ownerless material merely because they have left the body. Researchers may acquire legitimate rights in the work they perform, but those rights should operate within consent, privacy, review, transparency, and justice. The greater the identifiability, sensitivity, or commercial value of the material, the stronger the case for participant involvement and governance.

The Lacks family should have been informed honestly and respectfully once the importance of HeLa became clear. Recognition should not have required decades of public pressure. Scientific institutions benefit when communities trust them, and trust cannot be demanded while information and benefits flow in only one direction.

Part B: Qualitative Oversight

John D. Lantos's "Thirteen Ways of Looking at Henrietta Lacks" presents multiple perspectives rather than reducing the case to one moral slogan. This qualitative approach is useful because HeLa can be described at the same time as a scientific breakthrough, a story of exploitation, a problem of consent, a family history, a racial-justice case, and a lesson about the changing rules of research. The perspectives do not cancel one another. They reveal why the case remains ethically unsettled. (National Commission, 1979)

First Point: Scientific Dependence on HeLa

The claim that medical science would have been delayed by decades without Henrietta's cells emphasizes the scale of the contribution. It is difficult to prove a precise counterfactual number such as thirty years because another cell line or method might have emerged. The statement should therefore be read as an argument about exceptional influence rather than a measurable historical fact.

I agree with its larger meaning. HeLa cells gave laboratories a reproducible human cell system when such systems were extremely difficult to maintain. They could be transported, frozen, divided, exposed to pathogens, and used repeatedly. This accelerated experimentation and standardization. Scientific progress was not created by the cells alone, but many researchers built work upon their unusual properties.

Why Scientific Benefit Does Not Erase Wrongdoing

A common ethical mistake is to argue that a beneficial result retroactively justifies the way material was obtained. Consequences matter, but respect for persons also matters. A discovery that saves lives can still originate in a process that denied consent. Acknowledging the wrong does not require destroying the scientific knowledge or claiming that every later experiment was immoral.

The appropriate response is to preserve beneficial knowledge while learning from the injustice. Institutions can recognize Henrietta, communicate with the family, strengthen consent, improve privacy, and create fair governance. Ethical accountability is not hostility toward science; it is part of responsible science.

Second Point: Exploitation and the Research Economy

The second point that interests me is the transformation of a patient's cells into a research economy from which the patient and family initially received neither information nor control. The original response refers to a pharmaceutical "black market," but the central issue is broader than an illegal market. Universities, hospitals, repositories, government laboratories, nonprofit researchers, and commercial companies all participated in distributing and using HeLa cells.

Exploitation occurs when one party bears the burden or provides a valuable resource while another controls the benefit under conditions of unequal power. Henrietta did not volunteer for the role later assigned to her body. Her family struggled to obtain healthcare while hearing that her cells were invaluable. This contrast creates a powerful sense of injustice even when no one can calculate a simple royalty owed for every experiment.

Qualitative Oversight

Qualitative oversight means listening to narratives, relationships, context, and lived experience rather than reviewing only technical compliance. An institutional review board may verify that a consent form contains required elements, but a family can still feel confused or disrespected. Interviews, community advisory boards, participant feedback, and culturally informed communication can reveal problems that checklists miss.

Oversight should ask how participants understand the research, whether they trust the institution,

whether language is accessible, and whether communities share in decisions. It should also examine who is absent from governance. The people most affected by research should not be consulted only after controversy.

Legal Compliance and Ethical Excellence

Legal compliance sets a minimum. In 1951, tissue research practices were different and specific consent was not routinely obtained. Saying that the practice was lawful at the time explains the environment but does not prove that it was respectful. Ethical standards often develop because people recognize harms that law had ignored.

Current institutions should avoid defending a decision solely by saying that a waiver or deidentification rule permits it. They should ask whether the use is consistent with participant expectations and institutional promises. Transparency may be ethically appropriate even when not strictly required.

Community Engagement

Research involving communities with histories of exploitation requires sustained engagement. A one-time public meeting is insufficient. Communities can help define research questions, consent language, recruitment methods, data sharing, and benefit plans. Their participation should be compensated and influential.

Engagement does not mean that one family or community has veto power over every scientific question involving a widely distributed cell line. It means that governance recognizes affected interests rather than treating them as obstacles. Legitimate science depends on both expertise and public trust.

Benefit Sharing

Benefit sharing does not have one required form. Direct payment may be appropriate in some commercial partnerships, while other projects may provide healthcare, technology transfer, training, infrastructure, access to discoveries, or support for community priorities. The arrangement should be discussed before value is created whenever possible.

Benefit sharing should not become an inducement that pressures economically vulnerable people into risky research. The objective is fair reciprocity, not purchase of consent. Basic healthcare should not depend on surrendering biological material.

Recognition

Naming Henrietta Lacks and teaching the history of HeLa are forms of recognition. Recognition matters because scientific narratives often celebrate institutions while erasing patients, technicians, families, and marginalized contributors. It restores personhood to a story once told mainly through a cell line.

Recognition should remain accurate. Henrietta should not be portrayed only as a victim or as someone who consciously donated her cells. She was a woman, mother, patient, and member of a family whose life cannot be reduced to laboratory immortality. (American Anthropological Association, 2012)

Language and Respect

Strong emotional language can communicate moral outrage, but academic analysis is more persuasive when it identifies the specific wrong. Instead of saying only that the situation was disgusting, I would describe it as a violation of respect, a failure of informed consent, an example of unequal power, and a breach of trust. Precise language allows institutions to design precise reforms.

Researchers should also avoid describing people as sources, samples, cases, or populations without remembering that these categories refer to lives. Technical language is necessary, but it can create moral distance.

My Final Reflection

The HeLa case has changed my understanding of research ethics. Scientific benefit and ethical wrongdoing can coexist. It is possible to value the discoveries made through HeLa while condemning the lack of consent and communication. The lesson is not that tissue research should stop. It is that progress should not depend on invisibility of the people who make it possible.

I also understand the oil analogy more clearly. It exposes how value can be separated from origin, but it fails when it treats human tissue as an ordinary commodity. Cells participate in markets, yet they remain connected with human dignity and information. Ethical oversight must preserve that connection through consent, privacy, justice, recognition, and accountability.

Conclusion

Henrietta Lacks's cells transformed biomedical research after they were taken during cancer treatment in 1951 without her knowledge or consent. The resulting HeLa cell line contributed to extraordinary scientific progress, but the family's later confusion, exposure, and exclusion reveal

failures of communication, privacy, racial justice, and respect.

Modern rules involving institutional review, informed consent, broad consent, waivers, and identifiable biospecimens provide stronger protection than existed in 1951. They remain incomplete because deidentified specimens can be used without specific consent in some circumstances and because commercial value, family interests, and genomic privacy exceed simple legal categories.

Cells are not ethically equivalent to oil. Researchers can create legitimate value through scientific work, but human biological material should be governed as part of a relationship with persons and communities. The enduring contribution of the HeLa story is therefore both scientific and ethical: it shows what research can achieve and what it must never again ignore.

References

Gold, M. (1986). *A conspiracy of cells: One woman's immortal legacy and the medical scandal it caused*. State University of New York Press.

Lantos, J. D. (2016). Thirteen ways of looking at Henrietta Lacks. *Perspectives in Biology and Medicine*, 59(2), 228–233.

U.S. Department of Health and Human Services. (2018). *Federal Policy for the Protection of Human Subjects: The Common Rule*.

U.S. Department of Health and Human Services, Office for Human Research Protections. (2026). *Research involving coded private information or biological specimens*.