



# The Intersection of Bioethics, Black Women, and Healthcare

## Community Conversation

*The following piece captures a panel discussion held online on February 28; it has been edited for length and clarity. Moderator's prompts have been summarized.*

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*The conversation was sponsored by the Alumnae Board Diversity, Equity, and Inclusion Committee.*

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*A full video of the conversation can be found online at [www.visi.org/alumnae/dei](http://www.visi.org/alumnae/dei).*



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# What is Bioethics?



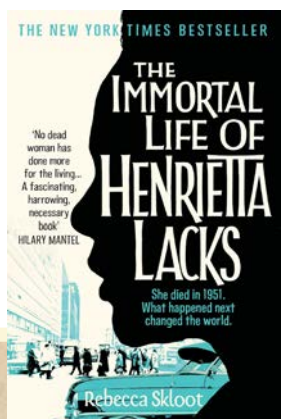
**BIZ •** Bioethics is the study of life issues—the beginning of, during, and after life. It includes human experimentation and technological advancement; it is the study of “What should I do?” Ethics means character and character development. With my students, we ask ourselves these questions: If I do this science, what kind of human am I becoming? Or, what kind of nation are we becoming if we do this?

[Reading] *The Immortal Life of Henrietta Lacks* [in class] has allowed us to enter into discussions that may have intimidated students in the past. The book tells the story of Henrietta Lacks, an African American woman who died of a horrific case of cervical cancer; it is the story of her cancer cells, which had the ability to grow outside her body. It is a book about Henrietta Lacks; it amplifies her voice and gives us a better understanding of her life...and her legacy. It is the story of her family and her children, most importantly her daughter Deborah, who desperately wants to know about her mother's life and purpose on earth, but also about the legacy she left behind in her cells. It's a story about the enduring legacy of medical racism and its pervasiveness in the United States.

It's a story of medical advancement. And it's the story of her extraordinary cells and the life they have provided people. It allows students to enter into difficult conversations and connects them to structural racism through one woman's story. For example, we spend a lot of time looking at women's health care and White women's health care vs. Black women's health care during Henrietta's life—which was in the 50s in Baltimore. We also talk about pain management and what was provided to her and what might have been provided to a White woman. We talk about being able to choose your medical care and how White women could choose their care but Henrietta had to go to Johns Hopkins, because it was the only place that would treat her. The chapter on where she grew up—Clover—opens the door to talk about segregation and the impact Jim Crow laws had. It's a story about consent. We spend a lot of time talking about autonomy. Students become indignant—How could this have happened in the U.S.—[they ask], “Is this still going on? What other stories are there?”

Students have explored other forms of medical racism through other experiments. Students can name the Tuskegee syphilis experiment and the Nazi experiments but they don't know much about others. We try to end on a more positive note: interviews with her great grandchildren at NIH, [learning] how they want to continue with the use of her cells, but they want researchers to find a way to do that in a way that is respectful of the family. We try to end the unit with [a focus on what we hope for] the future—we can use the cells, but we need to honor the family.

We try to relate what we're reading to what's going on in the world. In the last few years, that has been Covid and talking about communities that have been impacted by Covid in much different and larger ways than the White community. We talk about vaccine research and access to vaccines. We try to keep it relevant to what's happening in the lives of our students.



# How does the story of Henrietta Lacks relate to the work each of you do today?

Growing up as a Black woman, the daughter of immigrants, I thought, “How could this happen in America?”

SARAH



**SARAH** • I first became aware of the story in high school. Growing up as a Black woman, the daughter of immigrants, I thought, “How could this happen in America?” I certainly wanted to know how it tied into racism. In terms of how it relates to the work I do with hospitals, I work with hospitals to develop strategies on how they can improve care, especially for Black women. When I think about strategies and models to decrease maternal care disparities, what immediately comes to mind is value-based care, which incentivizes providers to focus on the quality of care instead of seeing patients as quickly as possible.

I’m sure Henrietta was seen by her provider probably pretty quickly, with a focus on collecting cells. With value-based care rather than fee-for-service basis—which incentivizes them to see as many patients as possible—[providers] are rewarded for promoting patient health outcomes or reducing chronic disease burden or engaging in patient-centric care.



**MIRIAM** • My first memory of Henrietta Lacks was in college; I was working as a teaching assistant for a summer class (I was a chemistry major); I was talking to my students about her and that her cells were “immortal” and they wanted to know how and why. Henrietta’s cells were taken from her without her consent. [As a researcher, I’m] thinking about how do we get the consent of people who ID as people of color (POC), primarily Black women and men, to participate in clinical studies. I want POC to know what is available and open to them so that they are fully aware of the clinical studies that they can participate in and maybe even get treatment from; that they know how their data is being used.



**AYANNA** • The book came out right after I finished undergrad and was doing a post-bac program at Johns Hopkins. It was very timely as I was working in the Baltimore community and still seeing all of the health disparities that were described in the book, which we still see now, twelve years later. For me, it has always been a guidepost in my public health career. In my office, I have a picture of Henrietta Lacks with a short bio of who she is, what she means, because to me, the work I do, we have to think about people every day. Particularly what I do now, working in maternal and child health. She really grounds me.

We should never have someone come to get care and not receive the best possible care that we know and

have in America. Everything we do in terms of policy and public health programs needs to be infused with what we know about health disparities and equity and making sure we don’t give disparate treatment. For me and my work, it is important that when I’m at the table, I bring my perspective as a Black woman and those of my friends and family. I think about that story—we never want to have a case in America where we have research being conducted on someone that they haven’t consented to. [We need to ensure that] the people who need to benefit from the research actually do. We need to make sure that regardless of whether you can pay or have the right health insurance, that you can get the right health care.



**ASHLEY** • I read the book in between grad school and applying to medical school. I keep thinking about a quote I have seen recently online: “I am my ancestors’ wildest dream.” And that is how it impacts me. Representation is so important. Being a Black woman and giving care to Black patients as well as patients of diverse backgrounds, it means so much to have that representation. It means so much for me to work in the space and advance diversity, equity, and inclusion (DEI) initiatives amongst other clinicians and physicians like myself who may not be familiar with this work in encouraging equal treatment among people of color.



## Let's look a little more at maternal health; could you share some stats on maternal health in the U.S.?



**ASHLEY** • I recently completed a project on Black maternal health. Black women are impacted disproportionately in terms of morbidity and mortality as it relates to childbirth. For instance, in the U.S., there has been a rise in pregnancy-related deaths in the last two decades. If you compare us to other countries in the same economic demographic, theirs have been trending down, while ours is going up. [Between 2014–2017, there were 13.4 maternal deaths per 100,000 live births for non-Hispanic White women, but 41.7 maternal deaths per 100,000 live births for non-Hispanic Black women.<sup>1</sup>] What is so shocking, so disheartening about this statistic is that it remained unchanged in 2019. So, Black women are twice as likely to die in childbirth from preventable occurrences than White women. To put this in true perspective, even with all of my education and training as a physician, when I walk into a hospital, I have the same risk of dying from childbirth as another Black woman who may not have even graduated from high school. This removes factors like education and economic status—it is purely based on the color of your skin.

Other things that statistically have been shown are that Black women are less likely to receive certain treatments. So, for instance, let's say you're going through delivery and you're having a hard time with the baby coming out. An

episiotomy can be performed in order to help with childbirth. Black women are less likely to receive an episiotomy. Black women are more likely to suffer from premature delivery, but we are less likely to receive treatments like progesterone that can prevent that. This really highlights the differences in care. When you remove the other factors that might lead to these things like comorbid conditions, such as diabetes, hypertension, obesity, those confounding factors don't change the statistics.



**AYANNA** • Last week, the Centers for Disease Control (CDC) came out with updated data from 2020; Black maternal mortality actually went up—the only race that the rate went up. We're now talking about Black women being three times more likely to die during childbirth in the first year of their child's life. You don't see this in White women. You don't see it in Hispanic women. It's serious. Then if you look at DC, we have twice the national rate of maternal mortality despite improvements in the care we're providing in DC.

I think about the birth stories of Serena Williams and Beyoncé. We're talking about famous women who have access to all kinds of health care; they're wealthy Black women. They *still* were in a situation where they had to advocate for themselves consistently while giving birth in order to receive the care they needed. We're talking about pain, we're talking about high blood pressure, we're talking about bleeding. Even women who know what to look for are still facing the same issues. We have to figure out what's really happening in the health care system and we need to figure out what's happening before you get to the doctor's office, what's happening in your community, what resources do you have.

There are inequities in the system that lead to these effects. We hear the statistics, but what are some inequities that are rooted in racism and sexism that are happening earlier in the process?



**MIRIAM** • Often scientists will find participants for studies and the studies are predominantly White men, so if people of color have a particular disease, say cystic fibrosis, they would not get the care they need because the type of treatment that is given was based on results from a small group of people that was not representative of the U.S. population. On the other side, there's a huge gap in how we conduct science and how we go out in the community and tell them about our science. We don't have the participation of physicians or case managers. We don't take into consideration the opinions or values of those participating in these studies. There's a breakdown in communication across the board.



<sup>1</sup> "Pregnancy Mortality Surveillance System," Centers for Disease Control and Prevention, November 25, 2020, [www.cdc.gov](http://www.cdc.gov).

## Can you tell me more about the failures when it comes to training medical professionals and physicians in this regard?

## There are mitigation strategies that we can work on. Can you tell us about where change can happen at the hospital level?

... Racism, not race, causes the social determinants of health or how folks experience their lives.

SARAH



**ASHLEY** • These differences in care are not just limited to this sector. It has been well-documented that Black individuals do not get pain medications; Black individuals are less likely to be offered certain procedures than an age-matched White counterpart. We talk about having to figure out the reason for all of this, but the root cause is simply structural racism. I'm talking about things, both historical and contemporary examples that still permeate the very lived experiences of the individuals that I'm currently treating—Black people in the United States.

In terms of training, I can say from my experience, I have been fortunate to be in a supportive environment. While I've been the target of microaggressions, I'm in a place where I'm supported, but that's not the same across the board. My program specifically has a program dedicated to DEI, to make sure we understand how diverse our population is; that's not something you see in all programs or all specialties. You have to start with training the individuals who are going to be treating this large population, with making sure they have the tools and resources they need to take care of these individuals. I couldn't imagine sitting in Ms. Wittschen's class in 2005 talking about racial and ethnic health disparities. I'm honestly just floored that this is going on at Visitation and that's where it starts. Those girls are going to grow up and be doctors and lawyers and health policy advocates and with that training, they can be the ones to make a difference.



**SARAH** • We're working at the hospital level to retrain physicians. For physicians, one of the hardest parts is the idea of race-tailored care. A lot of times, students learn to associate race with disease, when really race is a construct.\* Race is not biology. A lot of times when we try to create curriculums and retrain physicians, oftentimes, physicians ask, "What is race?" It really resides not in nature, but in politics and social institutions and how wealth is disproportionately distributed. So when we talk about race-tailored care, it really does drive medical errors and increases health inequities.

A lot of times medical students endorse these false beliefs that Black patients have longer nerve endings or thicker skin and feel less pain and that then promotes a lot of the inequities that Ashley was talking about. But it's also infused in how Black patients are diagnosed. There are things like the glomerular filtration rate, where Black patients are assumed to have higher body mass and so that is over-indexed. It can actually impact your care. We have to change how medicine is constructed.

The first thing we do in retraining physicians is talk about the fact that race has no biological basis; racism, not race, causes the social determinants of health or how folks experience their lives. The use of race as a risk factor for a predictor of health outcomes is misleading, leads to bias, and can be really harmful for patients. And that is a lot of why we're experiencing this maternal health crisis, especially for Black women. A lot of these misleading practices were put into place back in the Jim Crow era, back when Henrietta Lacks was being treated and just were never reexamined. That's a huge problem.

At the hospital level, there's a need to increase the number of



For more on  
Visi students learning  
about this, see our  
Lesson Plan on  
page 18.


physicians of color, but also diversify the number of types of physicians. A lot of times people of color would like doulas and other types of medical providers, so that diversification is needed. Also, training physicians of color is very important. We need to standardize practices. Often, what people think of as racism is just the active form of racism. But really, it is implicit biases that lead to off-the-cuff decisions that can lead to somebody losing their life. So, how do you standardize protocols and procedures. We talked earlier about the social determinants of health and that's

really rooted in how and where people live. But it is important to understand what are the root causes of what we're seeing, like why are Black women experiencing these disparities?

It's rooted in racism, classism, gender expression, and sexism. These factors were around when Henrietta Lacks was being treated and still exist in our society today. As Black women, we experience the double whammy of racism and sexism in care. It's really hard to receive care that is culturally competent. There were many years when our bodies were abused, which

created medical mistrust. There's going to have to be a long road ahead of building back that trust with care providers that is not going to be easy. That connection is going to have to be re-established. When you hear folks say, "I don't want to go in for a procedure, I don't trust my medical provider," you have to validate that person; you can't just look over that person. It comes from a very real place. We see that in the story of Henrietta Lacks. So, strategies to rebuild that broken trust are very important.

## What are policy changes that are needed?



We've seen major shifts in the public discourse, calling out structural racism.

AYANNA



**AYANNA** • We are in a really interesting time when we look at policy, perhaps because of the pandemic and the Black Lives Matter movement. We've seen major shifts in the public discourse, calling out structural racism. There were over 100 public health entities that wrote public health proclamations that called out racism as a public health issue or crisis. So, that put in words that racism is impacting the way we're able to deliver care, the way people are able to live their lives, how they get access to the things that they need to live a healthy, safe, happy life. We have never really seen that before.

That has really started to shift the discourse because now you have some sort of accountability at the federal, state, and local level. Even President Biden put out two executive orders: one on Black maternal health—the White House actually acknowledged Black maternal health week, acknowledged the work by the Black Mamas Matter alliance—and one directing the federal government to instill DEI in the programs we're talking about. To make major changes, we need policy that aligns with that; you need the federal government, you need the department of transportation to provide vouchers so women can get to their appointments. You need housing to be talking to Medicare and CMS so that if you know that someone is receiving food stamps or nutrition supplement or housing benefits, then they should also be connected to some of the other resources that we know people need. We need to make sure all of these things are connected.

In my office, our training grants are looking at how do we diversify the maternal and child health workforce and partner with minority-serving institutes. You need to create connections between training at all levels—starting in middle school all the way up through post-docs. We're also looking at faculty; what can we do as a government to provide additional support to universities to make sure you have tenure track lines for faculty of color and that the training that we receive is based on equity and what we know works. Congress has drafted the "Mamnbibus Act"—it has about seven or eight different bills that are related to maternal health; a majority of them are directly impacting Black women.

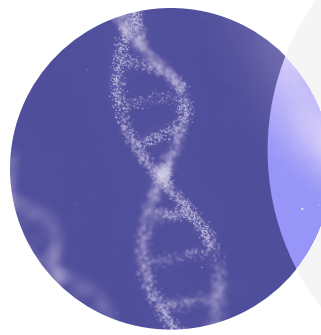
# Can you each tell us about the DEI work you're doing in your field?



**ASHLEY** • My work with DEI started at Visitation as a member of the Black Women's Society (BWS); I was President. I continued those things through college. Going to Predominantly White Institutions (PWIs), you are forever reminded of your minority status. So you gravitate toward these types of issues. Now, as a physician, a physician of color, a mother, I'm even more impassioned around these issues. I'm a physician mentor to medical students; we talk about this idea of representation. I think it is very important for minority medical students to see that this is achievable, this is attainable.

At the residency level, I serve on our diversity & inclusion committee; we do things like making sure our office is a comfortable place for our patients, making sure our language and signage is [accessible and equitable regardless of] race, gender, or sexuality—that our patients feel comfortable. We also work at the system level to make sure all our patients are getting equitable care.

At the policy level...another issue is distrust. While we have lack of access, we have lack of representation, we have health care literacy issues, there's also an extreme distrust for good reason among Black people and that is where I think we need to start. We can have all the policies to get these initiative and these health care bundles, but if patients are still showing up at delivery, at 38 weeks, for their babies with no prenatal care, because they didn't trust anyone to take care of them and their baby, we're going to still continue to have these outcomes.



## Electrophoresis

is a laboratory technique used to separate DNA, RNA, or protein molecules based on their size and electrical charge. It's used in everything from forensics to mapping the human genome.<sup>2</sup>

# Can you talk about what education programs have worked to bridge the gap between patients and the health care industry?



**MIRIAM** • I think we have a good example with the Covid pandemic—looking and seeing how people of color have not wanted to get the vaccine for good reason. We've had a history of Black people being used as test subjects without their knowledge, without their consent, so it is natural, it is not surprising that they would not want to get a vaccine injected into them when it seems like the process has been rushed. From my own experience, [there was great value in] just going out and talking and explaining what's actually happening as a scientist. There were a lot of people in my circle who I had to sell to get them to get the vaccine; these were highly educated people.

Language matters. When we talk about the flu shot, it is actually a vaccine. A lot of people don't understand that vaccines are not meant to cure a disease. That is also a failure of our school system in not teaching what a vaccine is meant to do. And when you get symptoms from having a vaccine, people think, "Oh! The vaccine made me sick," instead of, "This is my immune system doing what it is supposed to do because I've injected it with a non-active part of a virus."

The things that work are: getting people interested in and excited about science. As a grad student, I actually did a lot of "fun with science" days and I would talk to students about DNA and **electrophoresis**. •

I did a "whodunnit"—asking who stole my dog? And how do you figure out who is the person that took my dog? [We] compared "eyewitness" testimony and a photo of the "crime scene," and then I showed them what DNA electrophoresis can do.

So, doing things like that, talking to people in an interesting way. A lot of it has to do with how we communicate to the people around us and I say that as a Black person because the people who I like to communicate science to are primarily Black people. I want them to know and be excited about science and to understand what's happening. Science education is not only supposed to happen in school. It's supposed to happen outside in the real world as well.

<sup>2</sup> <https://www.genome.gov/genetics-glossary/Electrophoresis#:~:text=Electrophoresis%20is%20a%20laboratory%20technique,move%20faster%20than%20larger%20molecules.>



# Can you speak to any successes hospitals have had in moving the needle on this?



**SARAH** • Messaging is really important. Speaking as myself, one of the most important things is reframing the issue clearly. So [with the pandemic], in the Black community, it is reframing the issue as not anti-vax, but anti-scientist due to endemic racism in medical communities and structural inequalities in health care. So there has been a big push especially in public health spaces to reframe the issue, to not depict Black communities as resistant to the vaccine, but as anti-scientist. In hospitals, the bigger messaging is “who is going to get the vaccine first?” and helping Black communities understand that they are going to get the vaccine and that they are going to be prioritized.

A lot of the mistrust has been around, “are we going to be prioritized?” Covid-19 has impacted Black communities at some points two times higher than other communities, especially White communities. So, how do we message the fact that they are going to be prioritized, they are going to be important in the distribution of the vaccine. So, one thing is reframing the Black community as not anti-vax and then making Black communities feel that they were going to be prioritized, especially since their care was not prioritized. You can see that the impact of Covid-19 in the Black community was disproportionate; they had a higher burden of Covid-19. So the real win for many hospitals was showing that once they had the vaccine they were going to prioritize this population. We also need to go into Black communities’ spaces instead of asking them to come into our spaces and hopefully reestablish trust there.



**AYANNA** • I think you raise something interesting because good public health is not just relying on your doctor, your nurse, the hospital system to tell people what’s happening; good public health means relying on the community organizations, the non-profits, the church, your family and friends—that network that people have, that you normally get your information from, your trusted sources.

In the Covid-19 case, we really were so hamstrung by trying to make sure that we didn’t have mass deaths, that we missed opportunities. All of our focus was on what’s happening: who’s getting sick, how are they getting sick, how can we prevent the spread. We didn’t do a good job about explaining the importance of wearing your mask, we didn’t do a good job explaining about the vaccine and how, while it may seem new, it’s built on 30 years of research. It was built by a Black woman and her partners at NIH. We didn’t do a good job explaining what was happening and that is why we had a lot of vaccine hesitancy and not just in the Black community. We saw this in the Hispanic community, in the White community, and among folks who don’t normally get vaccines.

When we did start using public health messaging, it was a little bit down the road, which is why in America, we saw such a late uptake of the vaccine compared to other countries. But we also saw when we did distribute the vaccine, people who were not getting prioritized in the beginning would jump the queue because they didn’t understand the reasoning behind our vaccine rollout strategies. As a whole, our country has to do a better job in talking about science, using our community organizations to be the change agents we already know they are. The work I do is making sure we are empowering non-profits and teachers and parents to be able to talk in an informed way. That’s key—we don’t want people to spew information that’s incorrect. We want to make sure we have informed advocates talking about the work that we have put into the science, put into the vaccine. This is a case study for what can happen in the future—we have to learn everything we can now to better prepare.

... Our country has to do a better job in talking about science, using our community organizations to be the change agents we already know they are.

AYANNA



# What can we do?



**ASHLEY** • Sarah and Ayanna brought up good points that public health is not just the onus of the physician, but that it is a community endeavor. Part of the issue that we saw with Covid was that it goes to different spheres, like people in communications, and it shows why we need representation so that people understand the hesitancy or the distrust within the population. It is important that we have people in positions that are able to advocate—outside of the medical space and who can understand the ideas and the cultural perspective of this community that we're trying to serve.



**SARAH** • Oftentimes people think that to be racist you have to be doing something that is active, to be doing something that really hurts somebody, maybe saying a racial slur. That is simply not true. To not be racist, you need to be actively antiracist. You need to be actively fighting racism in order to not be racist. There's no such thing as being passively antiracist.

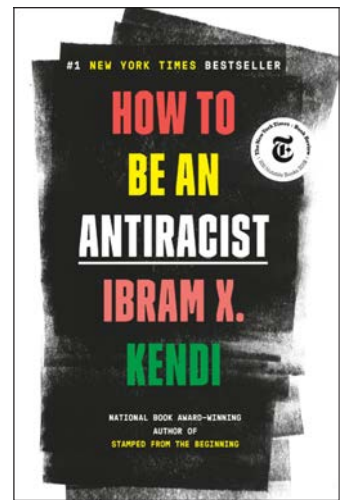
The best advice I can give to anybody in order to understand "What can I do as an individual?" is to be actively antiracist: to callout any type of active racism that you see as an individual, to understand what your privilege is as an individual, what your power is as an individual, and to always self-assess. If you don't know what power or privilege is, you should educate yourself on those things. And then to make changes. To understand what implicit bias is, what your implicit biases may be towards people of color, towards Black women and then to try to support people of color. The best quote I ever heard was, "Don't ask the oppressed to do the work."



**AYANNA** • Call it out in your workplaces and with your friends and family. I know these are awkward conversations, but this is the time. We're in a new environment. We can't continue to let people slide for creating injustices or being passively racist or turning a blind eye. We have to make some noise. You don't have to be an expert in order to engage in conversations around race, around bias. Go read the book *How to Be an Antiracist* by Ibram X. Kendi.



**MIRIAM** • As we're seeing these changes happening at the federal level, it is also about being good citizens and being active citizens, being informed of the things that are happening in our laws, the policies that are currently being shaped. That means looking up and seeing what some of these House committees are doing. You can go to any House committee meeting that is open! You are allowed as a citizen to attend. [Go and make] sure that your representatives in the House and the Senate are actually clued in to the things that are of interest to you. //



*Thank you to our moderator and panelists for joining us for this illuminating and empowering community conversation.*

You need to be actively fighting racism in order to not be racist. There's no such thing as being passively antiracist.

SARAH

