

STAT

Color Code

“Medicine lost the trust of many Black Americans — how can we mend that?”

Transcript Key:

In this written version of the episode, all words, including speakers, ambient sound, effects, and music, will appear in size 11 black type. **SPEAKER NAMES** are in bold and all caps. Music and other sound descriptions are indicated by [brackets] in regular font.

Speakers:

- **NICHOLAS ST. FLEUR (“NICK”)**: Our narrator Nick is a science reporter for STAT, where he often covers the intersection of race and medicine. Based in Long Island, NY, he is in his early 30s.
- **ARNETHEA SUTTON**: A postdoctoral fellow in her mid-30s, Arnethea was born and raised in Richmond, Virginia. Not far from where she grew up, she earned her bachelor’s, master’s, and doctorate degrees at Virginia Commonwealth University. There, she conducts cancer research and studies health disparities.
- **NICOLE BOWDEN**: Nicole served in the army, starting at the age of 17, from 1999 to 2005. Now, based in the Chicago area, she is training to be a Peer Support Specialist through the Depression and Bipolar Support Alliance.
- **REED TUCKSON**: Hailing from Washington, D.C. Reed is a physician and healthcare executive in his early 70s. A co-founder of the Black Coalition Against Covid, he has held numerous leadership roles at the National Institutes of Health, National Academy of Medicine, academic boards, and more.
- **TERRI LAWS**: Terri is a professor in bioethics and African and African American Studies at the University of Michigan. In her research, she has paid special attention to the interplay between religion and healthcare.

Transcript:

NICK (setting up his microphone)

Hello? Okay, I have it recording. I will start the script.

[A tambourine is shaken in a slow, steady rhythm, like a heartbeat.]

NICK

The [first story](#) I wrote for STAT was about the presidents of Dillard University and Xavier University of Louisiana, two historically Black colleges in New Orleans. It was the fall of 2020, and the presidents had decided to enroll in a clinical trial for Covid vaccines. To them, it was a small act of civil service: “Just two Black men rolling up their sleeves.” After they received their shots, the presidents wrote a

letter to their communities. They suggested that maybe *everyone* should join the trial and get a shot as well.

But almost immediately, they were flooded with angry reactions on social media. They got letters and comments from people saying things like, “Our children are not lab rats for drug companies”; “How dare an HBCU do this to our people?”; and “Tuskegee, Tuskegee. Me and mine won’t be first in line.”

For me, it was an eye-opening moment to see this real-time microcosm of medical mistrust among the Black community.

[Sounds from an electric keyboard enter. A musical phrase glides back and forth across 5 notes. It’s the THEME MUSIC for Color Code.]

My name is Nicholas St. Fleur. I’m a science reporter at STAT, where I focus on the intersection of race, medicine, and the life sciences. This is Color Code, a podcast where, over 8 episodes, we’ll highlight the history and the current reality of antiblack racism in health care. We’ll be releasing episodes every other week this spring.

We made this podcast to add to the national conversation on health equity. It’s a conversation that the pandemic and our country’s racial reckoning has thrust into center-stage. Through these episodes, we’ll hear from patients as well as from clinicians and researchers who are trying to get *and* give good care in a deeply flawed system. This podcast is for anyone interested in helping close racial health gaps in medicine.

[THEME MUSIC rises and fades out.]

NICK

From the unethical Tuskegee syphilis trials to today, Black folks have every reason to feel mistrust. The trepidation that we saw on those HBCU campuses toward the vaccine clinical trials – that was just one example. Sometimes, mistrust is borne out of an individual’s interactions with the medical system. Even one traumatic experience can stick with someone for a lifetime.

NICOLE BOWDEN

I view it as changing into a monster. These blisters start popping up on my skin. They itch. It’s very uncomfortable. My ears, the bottom of my feet, my hands – you know, you can hardly bend your hands. I can’t wash dishes for two weeks. These are things that interfere with my daily lively activities. If you can see this mark right here, these are from...

[Nicole shows her hand.]

NICK

Nicole Bowden served in the army in the late 90s and early aughts, enlisting when she was 17. One day, years after her service ended, she went to the VA for a birth control shot. She'd been getting the shots every few months for a while. But this time, she said something felt different.

NICOLE BOWDEN

The next day, I woke up. My throat was closing. I had an allergic reaction. They took a biopsy of the blister and said that it was my immune system – it attacked my immune system. They said I had “erythema multiforme,” which I had never had a day in my life. I had never had a blister like this. And when I tell you! It's like, “Oh, well, maybe you had this already?”

Well, maybe I didn't because I've been taking depo birth control shots since I was 17 years old. I was 29, 30 years old and just now had an allergic reaction to a depo-provera shot that I've been taking for years.

10 years later, if life becomes too overwhelming for me, – or I don't know how to release my stress, and I internalize it, – it comes out in blisters. That made me mistrust them.

NICK

Nicole – she didn't know what was going on! She said she felt dismissed by doctors, and, in some cases, judged by them. They weren't answering her questions; they were trying to blame her; and she often felt gaslit. She felt she never got the answers to some of the questions she was looking for. It's a feeling that many Black patients, especially Black women like Nicole, have experienced. Black clinicians and researchers have witnessed it, as well. Sometimes, they see it from their own colleagues.

REED TUCKSON

The thing that most struck me in my training was the way in which patients with sickle cell disease were treated.

NICK

That's Dr. Reed Tuckson.

REED TUCKSON

I remember so vividly that a sickle cell patient would be in the emergency room of a major American teaching hospital in a major American city, and the nurse in the E.R. would pull these “soundproof curtains” that separate one treatment bay from another and then declare fairly loudly to the other people, “I think they're just here to get drugs.”

Well, you know, a person with sickle cell disease usually has a chart about the size of a Manhattan telephone book if we still had, you know, telephone books. It was so clear that this person has had a long history of pain, misery and suffering, and that really was one of the most important moments in my professional career because I then knew I had to take steps to reorient that hospital, and how they took care and treated my brothers and sisters.

NICK

Reed works to repair the relationship between Black folk and the medical establishment. He's the co-founder of the Black Coalition Against Covid, an advocacy group designed to bring trustworthy, fact-based information about the pandemic *to* Black communities, *from* Black experts. So, that's meant hosting town halls with Black doctors and researchers in order to combat misinformation, especially around vaccines. He built the Coalition on the foundation of his more than 40 years in medicine.

REED TUCKSON

Unfortunately, because of the historical and contemporary experience that Black Americans have with our society, there is a built in level of distrust of elites, of institutions of our society, and, of course, of our medical community.

When tens of thousands of people are compelled to take to the city streets to scream out that their lives matter, that their dignity has to be respected, that is not – and we knew – that was not just a criminal justice issue. When we deal with voter disenfranchisement efforts across the nation, we knew that that is not just a political issue. All of these also roll up into affecting how people interact with institutions such as our health institutions.

NICK is talking to REED.

So you had mentioned the Tuskegee experiment and such and how that has been, you know, really burned into the psyche of Black Americans in this country, in terms of, you know, the medical mistrust and such. Through numerous people I've spoken to and doctors as well, they say not only is that an issue, but the current experiences of Black people when it comes to their interactions with the medical community or doctors is also an issue. Sometimes they might go to see a doctor and feel like they're not being listened to, or they're not heard. And how does that play into this overall problem of mistrust in the Black community of the medical establishment?

REED TUCKSON

There is no question that these are legitimate and real issues, and that the medical community is not different from the criminal justice or the political or other parts of America's social fabric. It is sad. I, as a physician, have observed it

personally and witnessed it and fought against it. I have worked in major white hospital institutions, and I have been dismayed by the way in which my colleagues have treated Black patients, and I have endeavored to call that behavior out and to try to rectify it.

[Notes from a synth fall like droplets of water into a rippling puddle. Soon after, Nick returns.]

NICK

Physicians like Reed have long been fighting for just treatment of Black patients in hospitals. While injustice is spread across the country, communities within a state, a city, or even a neighborhood may often have specific historical memories and present-day experiences of mistreatment.

NICK starts an interview.

Well, hello there, Arnethea Sutton. How are you doing? Tell me a little bit about who you are and how your day has been going, kind of as an intro here.

ARNETHEA SUTTON

Hi, I'm Arnethea Sutton. And thank you for pronouncing my name correctly. And I am in Richmond, Virginia...

NICK returns as narrator.

Arnethea is a postdoctoral fellow at Virginia Commonwealth University. She's been in the community for over two decades, having studied and worked at VCU, where she earned her bachelor's, her master's, *and* her PHD. Most of her work focuses on racial disparities in breast cancer. But she also studies medical mistrust.

ARNETHEA SUTTON

I feel like some people just consider it this kind of loosey-goosey concept. Medical mistrust impacts outcomes, period. You know, people will not engage in the medical system because of their lack of trust in the medical system. And that's not that individual's problem – as healthcare providers, that's our problem.

NICK

For many people who live around the VCU medical system, that distrust – it runs deep.

ARNETHEA SUTTON

We had, at one point, segregated hospitals, and there were vast differences in the actual facilities and the actual care that people received. And this wasn't that long ago. So people that I know very well remember being treated at this

hospital, and remember being told, “Don’t walk past VCU after a certain hour or someone will snatch you for medical experimentation,” etc.

NICK

In 1994, a ghastly discovery gave historical fuel to that fear. During construction for a medical school building at VCU, workers uncovered the remains of about 50 people, mostly of African descent and most likely enslaved people. These Black bodies were stolen from their graves and used as cadavers for medical students in the mid-1800s. When the students were done eviscerating the bodies, the remains were thrown into nearby wells.

We listen in on NICK interviewing ARNETHEA.

Tell me a bit about knowing that history, because as you said, you had to go and learn that history. Now knowing that history, how does that change or inform the way that you do your outreach now?

ARNETHEA SUTTON

Well one, it’s great because it’s not a shock factor anymore. So at first, where I would engage individuals in different studies or even in some education, I would go to some churches and educate. And they would bring up some things that occurred in Richmond or with VCU, and I would sit there and be in shock. And yet I’m wearing a VCU shirt. You know, that’s unacceptable.

NICK continues with the interview.

Obviously, VCU isn’t alone in this. There is, you know, a history of institutions who have mistreated Black folk, especially in this country. Has VCU taken steps towards acknowledging these faults in their paths? Have they either done enough, or what would that look like? What would atonement look like?

ARNETHEA SUTTON

So the first thing you said was “acknowledge,” which, I have to say, you know, VCU has definitely acknowledged what they’ve done. And, you know, there are lots of institutions now who can’t even get that close. Like, they know it, and they skirt around it, but it’s like, no: Just explicitly state this is what we did, and this was wrong, and this is what happened.

NICK reprises his role as narrator.

The university set up a small [exhibit](#) to tell the story of the East Marshall Street Well. Four panels hang on a wall inside the building where the discovery was made. Each panel details a period in the history of the bodies, from the 1840s to present day. In the text, the school acknowledged their past mistakes, their insensitivity during the discovery, and their plans to rebury the bodies. These are small steps towards repairing the institution’s relationship with the Black community.

ARNETHEA SUTTON

VCU has done a lot over the last, I guess, almost 30 years now, working with the community to figure out, like, “How do we address this?” But, you know, that’s just one story...

NICK

That history – it stays with people and affects how they interact with the institution today. It’s hard to forget that. The bones in the wells, or “limb pits” as they were called, gave credence to many Black folk in the community that their mistrust in VCU was *not* misplaced. But you don’t always have to go back into history to find incidents that make people feel cautious or unsafe in hospitals. As a Black woman, Arnethea has her own personal experiences with healthcare that leave her wary.

ARNETHEA SUTTON

I mean, I have a mistrust of the medical establishment, and I’m a researcher. And part of mine is just how I’ve seen providers treat my family members. My mother called me crying one day in the emergency room. “Something’s wrong. They’re not listening to me. The doctor has not been, and every time he comes in, he just leaves out.”

And so I had to drive two hours away to go to my mother’s bedside. And I say – you know, I use the term, “Try to flex.” Like, okay, hey.

And then my mom was like, “My daughter’s a doctor,” and I’m thinking, “Oh God, don’t start.” But it’s sad that we have to do things like that to try to get quality care. And that’s why I said: So I think there’s still a lot more for us to try to understand with regard to where mistrust comes from in certain communities, and trying to understand it in the present-day context to help us with regards to trying to eliminate it.

NICK

It’s hard to overstate the impact that centuries of unequal care and abuse can have on a community.

ARNETHEA SUTTON

A young lady I worked with when I worked for the health system – her mother worked up the street, and she had a medical emergency, and she got a phone call. And I just remember her mother saying, “Make sure they don’t bring me there.” Now, mind you, she’s literally a couple of blocks away from the health system, and yet she wanted to go somewhere that was probably about 15 to 20 minutes away because her mother had said, “Don’t go there.”

And so these are very palpable real stories that you're hearing from people. People's perceptions of things – you got to remember people's perceptions of the reality. And that's the way it's going to play out because that's what's been going through their family and their communities, then that's their lived experience.

NICK is talking to **ARNETHEA**.

So as someone who's been in the community for 20 years, as you said, do you feel that you are kind of like a – the term we hear a lot is “trusted messengers,” people who have the trust of their community. Do you feel that's where you are right now?

ARNETHEA SUTTON

I do. I like to think so. I like to think so. That's an interesting question to ask somebody, like, “Yeah, of course I am.” No, yeah, I really do.

For the last 10 years or so I've been very intentional about sharing messages about health in general. And so, you know, I do attend a very nice-sized church within the city. And so I definitely do work there. And then through my church, I've had opportunities to do things with other churches. Anything from, yeah, blood donation to sickle cell disease to just talking about cancer and prevention and health disparities. And so, you know, I've had opportunities. People reach out to me to ask me questions – what I think about this. You know, I have to constantly remind people that I'm not a physician, so I can't diagnose you, even though I guess I've become trusted for that, even though I shouldn't be.

[A synth zooms into earshot. It passes like a train.]

NICK

Trusted messengers can be key figures in rebuilding trust. They often acknowledge that there are valid reasons that people would NOT trust medical systems. For many, the Church is *the* essential trusted messenger.

TERRI LAWS

People don't walk around, you know, sort of saying, “Oh, I don't want to be healthy.” Nobody does that, right? But what they *do* do is say, “I want to be healthy, but I want to be healthy on my own terms,” or “I want to be healthy because I believe you care about me.”

NICK

That's Dr. Terri Laws, an assistant professor of African and African American Studies at the University of Michigan. Part of her research stands at the intersection of religion and health care, which was not an intersection I was used to hearing about.

TERRI LAWS

I actually went to seminary, and when I went to seminary, we were reading a passage that I saw as essentially exchanges in the Bible itself that were really about health care and access to health care. And of course, some of my colleagues were like, "You're reading into the Bible," and I didn't feel that way. I just felt like, no, what we're missing is how even in ancient wisdom, there is a need to serve others. And that includes health care.

NICK

To Terri and many others, it's long been an important part of a pastor's role to talk about health.

TERRI LAWS

The history of Black pastors in America is that they don't just serve in the pulpit. They serve the community as translators. They were often some of the most educated persons in the community. This is from slave time and reconstruction.

NICK talks to **TERRI**.

What do you say to people who may not, you know, look like the community they serve, especially, like, white doctors, but who want to be trusted messengers? What do they need to know? What do they need to learn?

[A familiar broken chord – the music of falling water droplets – returns. We heard this song before Nick started his interview with Arnethea Sutton.]

TERRI LAWS

I always say, please do understand when I'm talking about cultural competence, and this is across racial ethnic groups — understand the role of elders. Understand the role of the community. Community messengers – they are trusted, but they are serving multiple roles. Never think of a physician, only as a physician.

Whatever the question is, justice always has to be the answer. And justice being: How do we distribute the social goods that impact all of us? And excellent health is a social good, but it is not created by the individual alone.

NICK

For Nicole, her experience in the army plays a big role in her mistrust towards medicine.

NICOLE BOWDEN

Okay, so then, I'm 17, and I go to the military, and I'm being shot up, which is everything. You walk through a line, and you're just hoping you and your arm, like... what are you giving me? You know, "Face forward. Eyes straight." And, I think that was my first sense of mistrust, because I'm asking you, "What are you

putting inside of me?" And you can't tell me. You tell me to look forward and keep my eyes straight ahead.

NICK

As an adult, she sought mental healthcare from the Veterans Affairs (VA). But that experience was similarly troubling for her.

NICOLE BOWDEN

You know, I developed PTSD. And then, going back to the VA for mental help – so it was physical at first, [and] now, on the mental side. Now you're just trying to give me pills.

"Take this. Try this."

Well, I can't really function. These have me, you know, so groggy and so down. I'm waking up, like I'm having a hangover.

"Oh, just keep taking it. It'll get better."

Well, no, what is this doing to my body? Hold on. Hold on.

I shied away from the VA for a long time. I went, I served, and this is what's free to me. And I can't afford a better insurance, so it's either public aid or the VA.

NICK

Today, Nicole is seeking therapy outside of the VA. When she's meeting a potential new therapist, she's hoping for a shared understanding of race, gender, and other life experiences or past trauma.

NICOLE BOWDEN

First of all is... you looking at the person, and they look like you. First and foremost. But not only look like you: They've experienced some of those things that you've experienced. They can relate.

NICK

You know, in some cases, a therapist can be a trusted messenger. There's an intimate connection between counselor and client.

NICOLE BOWDEN

I connected to her experience, you know? She could relate to me. She'd been through an experience – not maybe mine, but she's been through something that can connect. So she's been through it, right? She's been through it, so she can go back and tell somebody about it. That was – that's the difference right there.

NICK opens up to **NICOLE**.

Personally, I feel like you and I kind of connect over that in that: I'm early in my search looking for a therapist as well or someone who could kind of relate to me on those levels. So actually last week, I kind of had a consultation or an interview with a gentleman who is, you know, a Black therapist as well as a professional kind of executive coach as well. And through that talk, I kind of felt like that was something that I was interested in or looking for, because one, as you said, like, you know, he looked like me, but he also kind of runs a service aimed towards Black men, especially Black men in the professional world. And that's something that I didn't realize connected so well with me. I had seen a therapist once in college, and it was just an experience where I only saw him once, maybe twice, and it just kind of turned me off from the whole thing.

And, you know, for myself, now that I'm at that point where I kind of finally feel like, "Okay, maybe I should, you know, seek out someone to just talk to." I'm definitely in a similar position where I'm seeking out someone who does look like me, who could relate to some of those things where, you know, I don't have to explain what a microaggression is or something – someone who understands that.

[Reflective music with a sparkly synth plays in the background.]

NICOLE BOWDEN

Right, and you know, I want to take it back to why I connect so much, and maybe her training is maybe a little different also. Because, you know, she's a trauma-informed therapist. You know, she's dealt with people that's dealt with traumatic experiences. And maybe she's even been through some traumatic experiences.

NICK continues speaking with **NICOLE**.

How would you describe yourself right now in terms of your relationship with, you know, doctors and the medical institution?

NICOLE BOWDEN

Yeah, I used to say powerless, but now I know that there's a strong word called "advocacy," right? There's a strong word called "advocacy." And we have voices, right? So, getting with organizations that amplify the peer voice – just being out there, being educated, being a voice, getting out there, and being in spaces to be heard, okay? That's how a change is going to come.

NICK

Trusted messengers can create more trusted messengers. Through the Depression and Bipolar Support Alliance, Nicole is training to be a peer support specialist. As she continues to fight for herself within the medical system, she

wants to serve as a trusted messenger to people like her. By using her own lived experiences as a touchstone, she's helping people who are dealing with similar mental health issues.

NICOLE BOWDEN

To me, I see them like, as that helper, you know. They would be that person that, "Hey, I've been through this before. I can relate to you. I want to help you in reaching your goals, whether that be advocating with you for medical access to your provider, whether that be getting transportation to your appointments, whether that be helping you get set up with the therapist – helping you reach those goals that's going to keep you living that self-directed life because everybody's journey is different.

You know, this thing called "recovery" is not linear. It's not a one-line thing. Everybody is going at it at their own pace in their own way.

NICK

The upsetting or even traumatic experiences Black people often face within medical systems can create distrust. But people who share in those experiences have an intimate knowledge of how others are feeling. And they can help them find the care they need. For *Reed*, he was able to utilize his experiences as a trusted messenger and lean on other trusted messengers to help get Black communities vaccinated.

REED TUCKSON

And so we had to work very hard to get doses into the Black community itself. And having trusted institutions, like Black churches, Black community organizations, partnering with medical administrators to be able to hold these vaccine clinics and getting people vaccinated in the community itself. That was a very important learning, a very important initiative, and a very important opportunity to get more Black folks vaccinated.

NICK

Reed and other trusted messengers face many challenges in trying to restore trust. But an all-too important mission compels them to keep moving forward.

REED TUCKSON

I am given hope because I have an undying love for Black people. And through that undying love for Black people and undying love for all people – I remember the great civil rights warrior named Ella Baker down South during the civil rights era, and she fought so hard for Black civil rights. And Ella Baker is one of the great heroes of the movement, and I remember her saying one day, so clearly, "I ain't no ways tired." And I'll tell you what: There's too much at stake, too much at stake, too many lives at stake, too much pain and misery at stake.

I'm inspired by love, an undying love, and I will never stop.

NICK

That love is a shared, unshakeable sentiment that drives each trusted messenger to try their best to mend what really seems unmendable.

[Full, uplifting music, complete with a keyboard, drums, and more, rises. THEME MUSIC closes the episode and takes us to the credits.]

Thank you so much for listening and for being part of our Color Code community.

Our team here at STAT is Alissa Ambrose, Hyacinth Empinado, Theresa Gaffney, Crystal Milner, and me, Nick St. Fleur. Kevin Seaman is our engineer, and Tino Delamerced is our intern. Our theme music is by Bryan Joel.

Special thanks to Nicole Bowden, Dr. Reed Tuckson, Dr. Arnethea Sutton, and Dr. Terri Laws.

Thanks to the Commonwealth Fund for supporting this podcast.

After every episode, we'll have a bunch of photos and some more reading related to the episode's topic at [STATnews.com](https://statnews.com), so please: go check it out! We'll have a new episode in two weeks.

If you like the podcast, please leave a review and subscribe! And if you have any thoughts for us, you can reach us at ColorCode@statnews.com.

[THEME MUSIC ends on a final note.]