

Charles Ryan:

Good evening everybody. Welcome to our PCF Webinar for February 21st, 2023. I'm Chuck Ryan, I'm the CEO of the Prostate Cancer Foundation and will be your host for the next hour for the very stimulating conversation that we're going to have. Thank you all so much for joining us.

This is another webinar brought to you by the Prostate Cancer Foundation, where our mission is to reduce the death and suffering from prostate cancer, to support transformational research, to accelerate progress towards our goal, and as we'll talk about a little bit tonight, to fund teams of scientists across multiple disciplines, multiple institutions working against that goal and grow the field of prostate cancer researchers by supporting the brightest and best young investigators. I encourage you all to maybe at your leisure go to [pcf.org](http://pcf.org) to look for updates, sign up for our guides, our webinars, you can see past webinars that are streamed there and register for the next webinar, which is coming up on March 14th, or join an online support group through our large and growing Facebook community, and as you can see, many other publications there as well.

We have been focusing now, this is our second webinar of the month that is focusing on the challenge of the worsening situation for prostate cancer in African American men in this country. If you tuned in two weeks ago to our webinar, I showed this slide, which was published in European urology in December, which shows the increasing incidents of prostate cancer of patients presenting at a distant stage. So in other words, less likely to be cured with surgery or radiation or local therapy. Just take a moment to let this slide sink in because what you see at the bottom here is every other race, Asians, whites, Pacific Islanders, Hispanics, all have an increased risk, but then you see the Black men's risk going up so substantially higher that it's its own separate curve.

Now what's interesting also is that we have seen a slow and steady progressive decline in the rate of individuals dying of prostate cancer. So this is testament, I think, to the fact that we are making a lot of progress on the therapeutics front. We have multiple new drugs that are available for this therapy and we're beginning to be able to tailor therapies for patients based on genetics, genomics, et cetera, et cetera. So while we are encouraged that there is a plateauing of the death rates across all races, we still see a substantially higher rate of Black men dying of prostate cancer than other races where it is now two times that of other races.

So I'm thrilled to focus this month for the Prostate Cancer Foundation on prostate cancer disparities because it is a very significant part of our mission, it is a very significant part of the past work that we have funded, and we are redoubling our efforts and recommitting to this very, very important problem.

So we have done a number of things that are available on our website. Most notably we have awareness kits that one can download on [pcf.org](http://pcf.org). You could watch our public service announcement with Steve Harvey. You could take our screening quiz. You should also know that we are convening the first ever expert panel to develop guidelines specifically for the screening, diagnosis, and the treatment of prostate cancer in Black men. So we are taking this very, very seriously.

So with that in mind, I'm really thrilled to welcome two profoundly qualified guests tonight to talk about this issue. They have devoted their careers to it and have active research and clinical programs looking at this very significant issue.

The first introduction is for Dr. John Carpten. Professor Carpten is a professor and chair of translational genomics at the University of Southern California, where his research interest include the development and application of genomic technologies and bioinformatics analysis with a major focus on prostate cancer genetics, and he seeks to understand the role of biology in disparate cancer incidents and mortality among underrepresented populations. So highly qualified to talk about these issues that I've introduced.

Notably, he is an investigator of the RESPOND study, and I would encourage you all to go to the [respondstudy.org](https://respondstudy.org) website. You can even do it while we're on this call and register for this study. This is a registry that seeks to gather 10,000 African American men with prostate cancer over the next five years to study clinical outcomes, genomics, et cetera.

My next guest is Dr. Stanley Frencher, who is the chief of urology and the medical director of surgical outcomes and quality at Martin Luther King, Jr. Community Hospital. He is also an assistant professor at the David Geffen School of Medicine at UCLA, where his focus is on strategy, delivery, and growth of surgical specialties at Martin Luther King Hospital, as well as an improvement on focus on surgical quality, access to specialty care for vulnerable population, and minority men's health. He has directed prostate health research through a partnership with the Black Barbershop Health Outreach program, a national initiative aimed at improving the health of African American men through barbershops and a network of community resources.

So welcome to both of you. Thank you for joining us. We're going to be together for the next 50 minutes or so talking about this very important issue. I'm going to first start with you, Dr. Frencher. We can put our cameras on and there you are, good to see you. I see that you both have your university logoed clothing on, USC, UCLA, here in Southern California, so we could play off that a little bit, I guess too.

Stanley Frencher:

One of the places where we all can work together.

Charles Ryan:

Exactly, common ground. Right. Right.

So let me just ask you, Dr. Frencher, your response to these data that I just showed. You've had some time for them to be digested after having been published a little bit. Are you surprised, are you not surprised? What are you seeing out there in the real world relative to these data?

Stanley Frencher:

Yeah, I think fundamentally to give it some context, I mean I think it first requires to think a little bit about the challenges that Black men have in the first place even accessing care. I think that it's not surprising that when we had significant confusion years ago regarding prostate cancer screening and various guidelines around PSA testing as a modality for us to use to identify men early in the disease process that Black men were probably be affected most significantly by that confusion because we already suffered disproportionately from a variety of illnesses. We already struggle to access care for a variety of reasons, not the least of which may be low income, disproportionately lacking insurance, and years and generations of mistrust of the healthcare system leading to lack of seeking care in the first place. So you layer all of that on top of the prevailing confusion that some of the disparate guidelines may have created, I'm not surprised that Black men would disproportionately be suffering at higher rates of the disease and potentially be suffering from dying from that disease at higher rates.

I think the other thing to think about is other prevailing data that suggests that when we're out there taking care of men, they're not getting the same care that men who are of different races are. We see that in studies of men who belong to clinical trials. We see that in studies of men who have access to care through the VA system. So when you take away the challenge of accessing care, some of those disparities and inequities disappear. I think that seeing that and seeing the data you just showed it reinforces the fact that we need to both raise awareness about the need for Black men to gain access to care generally and certainly to gain access to screening and treatment for prostate cancer specifically.

So those are my reactions I see on a daily basis taking care of Black men here in South Los Angeles.

Charles Ryan:

A multifaceted problem, no doubt. You've identified the patient population, if you will, as having mistrust of the medical system, with PSA screening in particular, the medical system has not been on one page for the past two decades, and so the medical system has failed, and then there may be other biological issues that may or may not exist behind all of the back of this.

So for that, I'll go to you Dr. Carpten. We are seeing an increased number of Black men diagnosed with advanced prostate cancer, is this a detection bias, is this a biological phenomenon? What's your thought?

John Carpten:

My thought. My opinion. Oh boy.

I think without a doubt we can harken back to the days when there was very active PSA screening, whether it was during checkups, but also just community-based screening efforts when we look particularly among Black men. I'm sure Stanley was privy to a lot of the AUA meetings where there was a lot of controversy and debate around the effectiveness of screening and in weighing the treatment of cancers that may or may not be indolent or aggressive and weighing that against the possibility of saving men's lives if the cancer did turn out to be more aggressive.

I think a number of groups, and I don't want to name too many names, but we can look at some of the screening recommendations that significantly changed that course, and lo and behold, we're starting to see a significant increase in the rates of aggressive and advanced prostate cancers. There are some in the field who would say, and I'm one of them, who would say we saw it coming.

That all being said, I think there is also mounting evidence that would suggest that Black men are not just at higher risk of developing prostate cancer, but might be at a higher risk of developing cancers that might have a more aggressive behavior, and if not kept in check early, can turn out to cause a lot of problems. We all know that once the cancers become more and more aggressive they become harder and harder to treat.

So I think it's probably a bit of both, Chuck. I think we're dealing with issues of screening and higher rates of detection for these advanced cancers, but we also might be dealing with an issue where the cancers may actually be inherently more aggressive. We're starting to, I think, generate data that would suggest that that is the case. So we have to keep our eye on it and I agree wholeheartedly with everything that Stanley said, that the foundation of many disparities is essentially just lack of access.

I've always also approached it from the standpoint that we want to make sure everybody gets access to care, but wouldn't it be great if we gave them access to the right care? The most precise care. The care that's going to be tailored more towards each individual. Thus, I think it's important to study the biology of these cancers when we look at cancers that are derived from men from different racial and ethnic groups to begin to really understand what's driving these different cancers and how can we best approach management for each man's disease. So there's a lot of work underway in that space to understand the biological differences that may be present when we look at tumors derived from men from different groups.

Charles Ryan:

So I think I'm going to come back to that issue that you brought up so nicely of access to care is not an access to good care. I want to come back to that after we've tackled the issue of diagnosis.

John Carpten:

Sure.

Charles Ryan:

Because I want to dive into a couple of questions. So it's likely that Black men, they develop prostate cancer at an earlier age and thus potentially may miss a screening window. Is there evidence for that that has been suggested that one of the biological disparities is age of onset? Do you see that in your research, either one of you?

Stanley Frencher:

Yeah, I think certainly we believe and see that African American men are often diagnosed at earlier ages and often with more aggressive forms of the disease. That's led many of us to at least believe that when you have certain risk factors, like African-American descent, having a family history, meaning having a first degree relative, as we may call it, a father or uncle or brother who had prostate cancer, and based on when they may have been diagnosed with prostate cancer, if they demonstrated having the disease early in life, there may be a benefit to getting screened earlier than the general guidelines of between 55 and 70 for most men.

So in my clinic, practically speaking, I start having that conversation with men in their early forties such that they do not miss that screening window. Because oftentimes the first conversation doesn't lead to a blood test, right? Sometimes it takes several conversations and sometimes even a conversation with one of their family members, namely being their spouse or partner to encourage them to proceed with a screening test.

I was just in the hospital today rounding, and one of my colleagues who happened to be African American ran into me and he was like, "Yes, Dan, every time I run into you it reminds me I need to go get that PSA test that you keep talking about." All right? So I think that it highlights that even amongst us as healthcare professionals we often may miss that window largely because we're not thinking about getting it done.

John Carpten:

Yeah, and early onset, just to tag on, is the hallmark of inherited cancers, whether it be prostate, breast, colorectal, or any other heritable cancer. There's this concept of heritability, meaning how likely is something inherited, and when you look across all cancer types, prostate cancer has among the highest heritability factors, which means that some relatively large subset of cancers likely are rooted at least in part in genetic predisposition.

That can vary. For instance, we've all heard of the BRCA genes that we know increase risk for breast and ovarian cancer. But germline or inherited variants in mutations and those genes also increase the risk of prostate cancer. So we've learned a lot about the heritability of prostate cancer and then a number of studies that focus specifically on Black men. So Stanley's absolutely right, we can see those trends of earlier diagnosis among Black men and familial cancer among Black men and we've begun to identify genetic variants that are strongly associated with both.

Charles Ryan:

Are there specific genes that are relatively unique to Black men with prostate cancer or much more commonly mutated or associated than it would be in a white or a non-Black population?

John Carpten:

Yeah, I think we think about it in two ways. One is the actual genes themselves, and typically those are genes that are known to be what we say highly penetrant, meaning if you have the mutation, you have a very, very high likelihood of getting the disease. The other are these common variants that are very common in the general population and essentially it increase risk moderately, but it can be an accumulation of loss of those variants that the additive effect increases risk.

So what we do know is that there are specific genetic variants, and this has been validated by many, many groups, that are associated with prostate cancer risk. I mean, very associated. Some of these variants are highly enriched in sub-Saharan African populations. So going back to men in Africa, we can see that some of these genetic variants are very enriched among those populations compared to, for instance, European or Asian or Indian populations. So those evidence lend to our belief that there is a strong genetic component that increases the risk of Black men developing prostate cancer.

Charles Ryan:

However, for somebody who's out there listening and they're hearing this and they're wondering, boy, should I go out and get tested tomorrow for one of these genes, are these genes, they're not commonly tested for in a standard primary care setting or in 23andMe or something like that, right?

John Carpten:

No, it's going to take a little bit more research. So there are other types of tests that doctors actually can prescribe or order as part of a man's workup, but we're still trying to validate. I don't want to go too deep down this rabbit hole, but one of the things we also know is when we look at genetic research, probably 90 to 95% of the individuals who participate in those studies are white. So it's a numbers game, right? So we're really working hard with some of the large funding agencies, PCF, NCI, ACS, and others to really increase the number of African American men in biomedical research to allow us to generate the data that we need so that we can validate these findings and hopefully create clinical tools that can help the physicians make the most informed decisions for their patients.

Charles Ryan:

I mean, there are some areas where we just can't speak with a generality about the population because we don't have enough data to say with statistical validity that this is something that is true in an African-American population versus not true.

I would say that you talk about the tests need to be validated, of course they do, but I look at this from two sides of the coin. One is we can certainly hope to identify individuals who are at greater risk so we can increase the screening, increase the outreach, start screening earlier, but on the other side is we might be able to find populations who are protected and have a lower risk. That would be something akin to a person who has a colonoscopy and they don't have any colon polyps. Well, their next colonoscopy is a long time later compared to the person who has polyps, and so it's this idea of risk adapted screening that one would hope for and perhaps the genetics would roll into that.

John Carpten:

Exactly.

Charles Ryan:

So let me go back to you, Dr. Frencher. You have, in addition to a practice in urology at Martin Luther King Hospital, you've got NIH funding to study the phenomenon at an academic level. Tell us a little bit about your work that you're doing.

Stanley Frencher:

Much of our work is focused on two sides of the prostate cancer spectrum. I think on the front end it's really raising awareness and trying to understand how to build and promulgate tools to better educate men about prostate cancer. So that work has been really focused around how do we create culturally tailored tools, instruments, educational tools to provide the awareness about, for example, prostate cancer screening, like early detection, diagnosis and treatment?

Where should that be done? I think traditionally we've tended to wait for patients to reach us in our clinics and within the four walls of our hospitals, and so what settings and what places can we go out to meet men where they feel comfortable, where they are willing to receive that information openly, and willing to question it, frankly. A lot of that works for the activity that we were doing in the barbershops.

So studying the impact of leveraging videos and tools that were developed specifically with Black men in mind and comparing those to tools that were not, and we found that ultimately the uptake and their decision quality when they would make a decision about whether to undergo screening was enhanced, was better when leveraging culturally tailored tools in these settings that were more comfortable, like a barbershop, like a church, perhaps maybe a bodega. So thinking about more creative ways to reach out to the community to ultimately engage Black men where they are was the beginning of a lot of the work that we did.

On the opposite end of the spectrum, one of the challenges for men is what is my experience going to be like when I ultimately have prostate cancer and choose to undergo treatment? So recruiting men who've had that experience of undergoing treatment at various stages, either advanced cancer or even local cancer treatment, to be able to document and understand how to communicate their symptoms, their quality of life to other men so that they for themselves can understand the progression of their quality of life as they reset the way that they see the world, both from their sexual function, from their urinary function, and from their overall experience having undergone treatment.

So those are two critical areas where we focus a lot of our research because I think the decision around whether to undergo treatment depends first on knowing about the disease and being aware, and secondly, making a decision that's rooted in understanding what my life is going to be like if I decide to go down this path of getting diagnosed and treated for prostate cancer. Those two things I think prevent men from ultimately coming to see us as urologists and undergoing treatment or even getting diagnosed and so we've focused a lot of our attention on those two areas with the work that we do at UCLA.

Charles Ryan:

You also put prostate cancer in the context of overall health and other health issues. We've put the link to the Man Up program, which is MLK Community Healthcare's website, which is designed to help launch these community-based campaigns around men's health.

You used a really interesting term, you talked about the cultural environment, and then you talk about decision quality is better in those environments. Let me pull on that thread a little bit. So what you're saying is that a barbershop environment, for example, is a place where men will make healthcare decisions. Is that what I'm hearing?

Stanley Frencher:

Yeah, I mean that's where they're getting the information and ultimately feeling comfortable in receiving it.

Charles Ryan:

Yeah.

Stanley Frencher:

So someone in my office, they're deer in the headlights. They're staring at the white coat, at Dr. Carpten wearing, and they're asking-

Charles Ryan:

At least it says USC, right?

Stanley Frencher:

I think that in that environment, they're deferent. They're saying, "Well, whatever you think Dr. Frencher. If you think I should do this, great." But when I meet men in the barbershop and I walk in just wearing shorts and a T-shirt like everybody else and we're having a conversation that is rooted in fact and is rooted in many of the tools that we provide in the barbershop so that they understand the disease, the questions are richer, their thought process comes from a more comfortable and secure place, and they have the benefit of others in the room asking the question that they may not be willing to ask perhaps about am I going to have erectile dysfunction if I undergo treatment?

Charles Ryan:

Right.

Stanley Frencher:

Or am I going to leak urine and have to wear a diaper? But not really be willing to engage in that discussion when it's in the clinic. So when we say that their decision quality is better, they are making a decision that's more consistent with their preferences, not that of the clinician that's sitting in front of them.

Charles Ryan:

We did a webinar a few months ago on treatment regret, which is a big problem in prostate cancer, and I just wonder hearing you talk that I would assume hypothesize that treatment regret rates are lower when people have made a decision in that culturally competent and comfortable environment. I'm not sure if that's something you're measuring or not, but it certainly is implied in the work.

Also, you identify two related but somewhat different issues. One is the place, not the doctor's office with the white coat and the sterile environment, but a place where men go when they're healthy at other times. But then there's also making the decision with a group, with being in a community, and I think the overarching sort of theme you talk about is building a community and that decision making in a community is probably more well thought out and probably going to lead to lower rates of treatment regret. So I applaud you for that. Look forward to reading results as your work continues. It's a very interesting thing.

So in addition to barbershops, what would be other areas that might have that same set of opportunities? Churches, you mentioned, I think.

Stanley Frencher:

Yeah, traditionally churches, community centers. Oftentimes we will combine efforts with sporting events and sports teams. The whole goal is to help to go to where men are already. Because the idea that we're going to wait for them to come to us, given that many men in our community do not have a primary care physician, their usual source of care, depending on their income, may be the emergency room or urgent care, and so ultimately engaging them in these conversations about help generally require us to be more proactive and go out into the community where they are.

Yes, your point is definitely well taken. I mean, I think that from what we've noticed and from our perspective is that when you do that then men are more likely to engage in our traditional healthcare system more and so then they're going to seek out a relationship with a physician after they're being armed with that information.

Charles Ryan:

So are men literally coming to the barbershop with their sensitive health information and sitting in a group and sharing it and saying, "Can you help me make a decision about what I should do?" Or is it not quite that personal?

Stanley Frencher:

Yeah, so it's interesting, it's organic. So the way we structure these events at the barbershop is that we will have a variety of health conditions that men will be able to ask questions about, not just prostate cancer. It may be diabetes, it may be high blood pressure. We even have screenings for those diseases at the barbershop. We'll have physicians at the barbershop as well for them to ask questions.

But the key also is that we engage one of the community leaders who is the barber themselves. So many times the barber themselves ends up being the biggest advocate for these kind of things and ultimately educating them allows them to be someone who is a trusted advisor to their colleagues. So they become some of our biggest advocates and educators and I think that peer to peer teaching, that's seen in a variety of other environments.

But I think in particular, to your point, it's an organic conversation that's happening anyway. What we've done is we've tried to inform that conversation such that guys aren't getting misinformation.

Charles Ryan:

Well, a lot of what you're saying sounds a lot like a support group. However, it's not. It's different in many ways. What are your thoughts and experience and data on participation by Black men and support groups versus something like this?

Stanley Frencher:

Yeah, I think support groups are important. I think programs, I participate in a variety of advocacy groups, Zero Cancer and others, or they have a mentor program, and I think that those groups are super important, particularly for those men who've been diagnosed with cancer, who undergo treatment, and need that support. The challenge that we are talking about to some extent in the work that we're doing out in the barbershops is we're trying to identify healthy men. We're trying to identify those men who do not have the disease. They do not need support in the sense that we're thinking of it for those who



have the diagnosis of cancer and are undergoing treatment. What they need is they need community awareness, outreach, and we need to build a community around each of us such that we feel that we can support one another.

Black men, not to overgeneralize, and there's a lot of heterogeneity within our community, but in general we can be somewhat loners. I think that for women who have breast cancer awareness groups, support groups like large community efforts, for Black men, that doesn't exist the same level. We simply do not engage in those kind of activities in the same way, particularly before we get the disease. So I think that by creating these opportunities for us to come together to talk about a variety of our challenges, both health and otherwise, I think that we open up an opportunity for men to then engage in some of these other things that we want them to do in terms of screening for prostate cancer.

John Carpten:

I think that was probably another issue that happened when we lost the screening. When we used to have the community based screening events, a lot of men would come and just get educated and just learn, and like Stanley is saying, they are much more open. It's a much more organic environment for men to engage with the healthcare professionals and it was just a level of comfort.

On top of that, you get screened, right? So it was just such an amazing opportunity and set of activities and I'm hoping we can begin to rethink some of these things and hopefully we'll see a reversal in the current trajectory with this increase in advanced cancers.

But I applaud Dr. Frencher for all the work that he does in the community. It's amazing.

Charles Ryan:

Yeah, absolutely. I'll ask a question then of you, John, which is we talked about genetics, we talked about diverse genetics may be at play across different populations, is there any reason to think there could be other things happening environmentally or other that could be leading to this increased incidence? Diet, toxins, stress, all have been brought up as contributing factors. What are your thoughts on the data now?

John Carpten:

Sure, all of the above. I think there are a number of studies that at some point I think we're going to talk about RESPOND as one framework to begin to help understand this multifactorial model of why the disease manifests more aggressively in Black men.

But there are other things. So there's mounting data on vitamin D that many Black men, Black people, people of sub-Saharan African descent, are vitamin D deficient and that there can be an increased risk of prostate cancer associated with that deficiency.

Chanita Hughes-Halbert and others at I know Medical University of South Carolina had done some really amazing work, Chanita is currently here at USC, showing that the biology of the cancers are different as well. So vitamin D and the processing of vitamin D might play a role in the biology of how these cancers grow in Black men.

So that's one of those sort of dietary slash environmental factors that we're starting to understand a little bit more about. I think there is more and more research in that area and right now it looks really promising, such that ensuring vitamin D levels are sufficient as we grow, as we age, could reduce the risk of prostate cancer.

Charles Ryan:

You're saying that a prostate cancer that develops in a vitamin D deficient environment is different from prostate cancer that develop in a vitamin D replete environment?

John Carpten:

Yes. It could also help the actual cancer manifest in the first place. So the risk of getting the disease in the first place. Which might have to do with, for instance, the immune microenvironment of the normal prostate.

Charles Ryan:

Right.

John Carpten:

Right? And setting an environment for a cancer cell to grow and thrive.

Charles Ryan:

Yeah, I'm certainly no expert on vitamin D, but my whole career people have been talking about vitamin D and its relationship to the onset of prostate cancer. I remember learn learning that vitamin D deficiency was more common in white men from northern climates and that it was more of a specific sort of the Scandinavian prostate cancer. I don't think that actually-

John Carpten:

They have a lot of cancer in Scandinavia too. Prostate cancer in Scandinavia as well.

Charles Ryan:

Yeah. But I don't know that vitamin D, it's always been at the scene of the crime, but it's never been really proven to be the cause. The other myth about vitamin D is that it's not really a vitamin, it's almost like a hormone in a way. It's got a receptor.

John Carpten:

Exactly.

Charles Ryan:

[inaudible 00:35:20] is very similar to the androgen receptor. So there's probably some interplay there that we don't really quite fully understand, but it's a very interesting area for research.

John Carpten:

Yeah, a lot of in and interesting work ongoing in that area.

Charles Ryan:

We had a conversation a couple of weeks ago about social determinants of health and the comment was made that poverty, stress, some of these other things that could be frankly on the rise might also contribute to earlier onset or more aggressive prostate cancer. What are your thoughts about psychological or environmental non-toxic stimuli?

John Carpten:

Again, there's a lot of work in that area and we're hopefully going to get into some of that with our RESPOND study where all of the men will get detailed questionnaires about social stressors, environment. So yeah, you can begin to postulate that social stressors can increase or can impact physiology and physiological conditions, like we call allostatic load, ER stress, things like chronic inflammation, that these physiological conditions can lead to the increased risk of a cancer manifesting and having the ability to grow. Because one has to believe that cancers occur in our bodies and in many cases our bodies fight them off before they can take hold and manifest, but certain physiological conditions could possibly provide a cancer cell the ability to take hold and grow.

Charles Ryan:

I talk about this phenomenon a lot, which is the difference between an initiation of cancer and promotion of a cancer.

John Carpten:

Exactly.

Charles Ryan:

Testosterone, for example, is a promoter, not an initiator. That might be something where other hormones play a role in that as well. I think diet is probably a promoter. I get asked about diet and prostate cancer every day and my response is that I believe there are some prostate cancers that are clearly related to diet, certainly not all, but I believe that having a healthy diet doesn't hurt anybody.

John Carpten:

It doesn't hurt anybody.

Charles Ryan:

It may alter the trajectory of cancers in some, and so I encourage everybody to do it, but I certainly don't want to blame people for their cancer being more aggressive because they can't stick to a vegan diet or things like that. So it gets a little sensitive.

John Carpten:

Right. There are other physiological conditions like the consequences of obesity, right?

Charles Ryan:

Yeah.

John Carpten:

Again, mitogens that begin to circulate in our body because of those physiological conditions. I use that word a lot now outside of biology, our physiology. So I do think it's important that you try your best to stay away from those dietary factors that can increase obesity.

Charles Ryan:

Certainly. Well, let's transition and talk a little bit about the RESPOND study, which we've mentioned a couple of times. I encourage people to go to [respondstudy.org](http://respondstudy.org) to register and read about it. Tell us how it's going and what the goals are and how one can be involved.

John Carpten:

Yeah. So we think it's an incredible study. It's funded by the National Institute of Health and National Institute for Minority Health and Health Disparities, as well as, I think, PCF is also playing a role in some components. RESPOND, it's a large national, and it's a population-based study, which is very different from a lot of studies that we do in prostate cancer that are what we call hospital based. All the men are patients in a hospital. But we're using the registry system to identify men, which makes it more of a population-based study.

It's a huge study from the standpoint of scale because the goal is to enroll 10,000 African-American men and we are really close to those goals. It's been an amazing study just ramping up, setting up the sites across the country, Detroit, New York, Florida, Georgia, Louisiana, Texas, California, so it's a national registry based study.

Again, all of the men will get detailed questionnaires to collect information on demographics, on social stressors, environment, aspects relative to access to care, poverty, all of this demographic information on each man. For a relatively large proportion of these men we'll also collect biospecimens. So that includes saliva where we can collect DNA samples to look for genetic risk factors that can help us better identify those genetic risk factors that are associated with risk of advanced aggressive prostate cancer.

We're also collecting tumor tissue from a large proportion of these men, which will allow us to look at the tumor cells themselves and begin to ask questions about what's similar or different in tumor cells derived from these particular men compared to, for instance, a cohort of tumors derived from white men.

We're also going to look at the immunological features of the cancers. We're going to look for signs of inflammation, signs of different types of immune responses in the tumors themselves.

So it's one of the largest and most comprehensive studies ever for any cancer type, and so it's amazing that we're able to bring these types of resources to bear specifically for prostate cancer in Black men.

Charles Ryan:

So it's a really important area to underscore because we want to do prospective clinical trials of almost everything we can think of as being beneficial, but there just aren't enough resources, there's not enough money, there's not enough time to do all the prospective experiments that we want to do to prove exactly everything precisely. So these registries that are so richly curated, such as the RESPOND study, allow us to make investigations into areas that we can come pretty close to understanding without the prospective study, so it's really important.

I'm sitting here doing the math in my head and thinking there's 230,000 men diagnosed with prostate cancer every year, probably 35 to 40,000, maybe a little bit more, Black men diagnosed with prostate cancer every year. You want to do this over five years, so that's 50,000 times five years, that's 250,000. A quarter million Black men will be diagnosed with prostate cancer during the course of your study. So you're really trying to capture, what is that 2% of them? Something like that?

John Carpten:

Yeah, yeah, yeah.

Charles Ryan:

It's both a small number and a huge number at the same time and can-

John Carpten:

Yeah, I agree. You think in those terms, yeah, it's a small study, but it's one of the largest imagined and most comprehensive. Again, you can sometimes see large studies, but they really only focus in on one component. But this study is allowing us to focus in on all of these epidemiological risk factors, the demographics, the geocoding, where people live, stress factors, poverty levels. All of the social determinants of health are being captured on all of these men, and then we're also layering all of the biological studies on top of that. So it's an incredibly comprehensive study and we're already starting to learn things from it.

Charles Ryan:

There are already hints that you can overlay a map of poverty with a map of prostate cancer, a map of diabetes, and they all travel together.

So Dr. Frencher, I'm going to come back to you. I want you to be aspirational and I want you to think about the ideal world, and you're a young doctor, and think about when you retire someday from the practice of urology, hopefully many, many years from now, how do you want things to be different for Black men or all men related to prostate cancer detection and outcome?

Stanley Frencher:

Yeah, I think fundamentally I'd love to see a world where we are no longer viewing the treatment and diagnosis of prostate cancer through a lens where disparity exists. So fundamentally, we need to study subgroups and subpopulations in order to understand the disease better.

That said, I want to see a world where the discoveries that folks like John are making are applied to all populations of men who have prostate cancer, such that the rates of disease and mortality plummet because of what we learn from the important work that John is doing by studying Black men.

I think, secondly, I want to see the access gap disappear. When we start thinking about some of the challenges that I spoke to earlier in terms of men accessing care, it's not just on the front end, getting screened and getting treated, it's also amongst those with advanced prostate cancer who ultimately go bankrupt or for whom financial toxicity is a death sentence because they're not getting access to the advanced treatments that we've been able to develop. So I think that ultimately eliminating that access gap for Black men is also going to be a win for everyone. Because if Black men can afford advanced treatments, if Black men can have access to the best treatments around, presumably everybody does.

So aspirationally, that's the world that I want to see by the time I retire, such that we're not talking about health equity as a goal, we're talking about things that John had mentioned, precision medicine, and ultimately getting the right care individually for every individual in the country, not just those who belong to one group or another.

Charles Ryan:

We've already seen some results, for example, in the Veterans Administration system, where if you look at individuals, Black, white, all races, all getting care most likely according to the same protocols in the same system that some of these racial disparities and outcome go away. That leads me to wonder as we're having this conversation, so much of what we're talking about is let's just say uniquely American. We're an incredibly diverse country and we have a healthcare system that is different from many other

healthcare systems around the world, let's just put it that way. So I don't know if either of you have insight into this, but in other racially diverse populations, does this disparity exist to the same degree, or is it just nothing compares to the US?

John Carpten:

Yeah. Well, I mean, I think some of these disparities do exist, maybe not to the same level. I mean, if you look at the UK or you look at Canada, some of the trends are similar, but just maybe not to the same extent.

I think Stanley is right and I think we all know that disparities and inequalities in healthcare play a huge role. If you can get men screened, all men, and detect the cancers earlier and intervene appropriately we can see a leveling off of all of these disparities.

When we look at the trends, the downward trend in prostate cancer rates has been significant for Black men. I mean, strikingly significant, right? But the gap persists. There's still a gap. The gap remains. So I think that we can do better. I'm like Stanley, I actually believe that we can get there to this world that we would all like to live in, but there are important considerations that are related to policy and things of that nature. I could sit in the lab and do all the work in the world, but if policies don't change, things don't get implemented appropriately, and here we're still in the same place 20 years from now.

But just circling back to your question, I think the differences do persist, they just aren't as significant. Interestingly, the rates are high as well in sub-Saharan West African and South Africa, I mentioned that as well.

Charles Ryan:

And the Caribbean.

John Carpten:

Look at Black men, they have very high rates of prostate cancer. So we do believe that there is some biological genetic component, but we're not saying it's the whole deal. We're not saying that it's all genetic, it's all biology. By no means. But if we can understand those things, if we can get to equal care, perhaps it can be tailored appropriately to everyone and everyone does better.

Charles Ryan:

You used another phrase, which I wrote down here, intervene appropriately. We've been talking about screening as if it's all the same and that the interventions that follow out from screening are all the same, but of course they're not. Of course, one of the big challenges with regards to the screening debate, if you will, was that there has been an assumption that we were overtreating men with low risk disease and thus the morbidities of treatment outweighed the potential benefits of eradicating a low-grade cancer. I wonder if both of you could comment on that briefly and then we'll end on a positive note.

Stanley Frencher:

I think where I land on that question is that ultimately you maybe asked the question too simplistically. It's screening or no screening. It's population based screening or nothing at all. In fact, I think that we need to be deliberate and intentional about whom we're targeting with our early detection tools, knowing their pros and cons, their benefits and risks, and applying them intentionally and strategically to ensure that we're diagnosing cancers in a way that then we can have also an intentional and

deliberate discussion about their treatment, or which also can include active surveillance, which can include treating the cancer locally, which may include treating advanced cancers with emerging tools.

So I think that is complicated because we have a variety of ways to ultimately treat the disease and those treatment options need to be tailored to the individual patients sitting in front of them. So we are combining what is a population health tool, the form of screening, with the conversation about individualized treatment, and not understanding the difference in that conversation. So I think that we as healthcare professionals have to take a step back and make sure we have population experts at the table, community members, and physicians such that we can come to consensus around how are we going to do targeted early detection, and then when we have the answers to those diagnostic modalities for that individual, how to have that discussion in a way that patients arrive at a decision that is good for them.

So I think we need tools on both ends to continue to be developed, but we need to be better about communicating those messages. So I think that from my perspective, that's where I land on that question about early detection versus the variety of treatments we may have to ultimately address prostate cancer.

Charles Ryan:

A big challenge, because as you just stated, it's a very, very complicated issue for all the reasons you just identified that we as physicians are challenged to put into a simple message, and that's the difficult part.

Last few minutes here. I'm going to go to you, John. Your parting words, thoughts on what Black men should be thinking right now about what they can do to decrease their risk. If they're worried about prostate cancer. Who should they be talking to and what should they think about doing?

John Carpten:

Yeah, I think it's pretty fundamental. I mean, you have to think about, Stanley said, age 40, right? 40, you should be thinking about a PSA minimally. We have to, he used the terms, deliberate and intentional as individuals and to be tested on a yearly basis. I think with that we are in a position to be more informed along that trajectory of our healthcare, such that if something changes, it can be tracked.

It sounds really simple, but for some reason it still continues to get lost, that message. I think we do better though. I constantly look at that trajectory, the trend of prostate cancer rates from 1980 to 2016 or so, and we have to say something happened right along the way. But here we are, we're at this place where we're starting to see an uptick in the bad cancers. I think we learned from that and we can go back and say perhaps we need to rethink the screening policies and the screening recommendations. But bottom line, we have to be intentional as individuals to seek out a physician once a year and minimally get a PSA and track that number over time. I think just with that information we put ourselves in a much better situation.

Charles Ryan:

I would add to that seeing a physician once a year has many benefits beyond getting a PSA.

John Carpten:

Sure, sure, sure, sure, sure. Yeah, sure, sure. For sure.

Charles Ryan:

First of all, everything you said is exactly right on. We've shown that we can do it, we've shown that we can take the curve down, but now we have a question of implementation, why aren't we doing it?

Then the other piece that I put in there is I think that the PSA test, or I should say a discussion about prostate cancer screening and prostate cancer screening when taken in the context of global primary care for an individual man can lead to reductions in all kinds of problems. Early detection of diabetes, early detection of hypertension, et cetera, et cetera.

So Stanley Frencher, your parting words here in the last couple of minutes. You get an opportunity to speak to existing patients, all of whom may have, or many of whom may have, male relatives that might be concerned, et cetera. What are your parting words for Black men about what they should do, their risk for the disease, and how it should be approached?

Stanley Frencher:

Yeah. I mean, I said earlier that it's complicated. I'm going to keep it quite simple. Get a physician, a primary care physician. If you don't have one or don't want one, urologist can be your primary care physician for your health needs as a man. Get a urologist, get tested if you fall into the risk categories we talked about, you're African, you have a family history.

More importantly, get educated. You need to talk to one another, talk to your family, talk to your sons, talk to your brothers, talk to your uncles about your experience. If you've had prostate cancer, if you're worried about prostate cancer, if you just need information about other healthy habits that you have questions about, we need to begin a dialogue that emphasizes prevention and us talking about our health.

So I'll keep it simple, we to get a doctor, we need to get educated, and we need to get together about this problem.

Charles Ryan:

Have the doctor, have the conversation, and get educated. I think it's very, very well put and can save a lot of lives, just those simple messages.

I want to highlight before we close, I want, first of all, to thank John Carpten from USC and Stan Frencher from Martin Luther King Hospital and UCLA for your time today, your insights, and most of all for your devoting your careers to this challenging issue of prostate cancer in Black men in the United States.

I want to also turn everybody's attention to the webinar chat where there's an opportunity for female partners to participate through some survey connections that we have through the New York NYU Langone Health. Dr. Stacy Loeb and colleagues, if you're the female partner of a patient with prostate cancer, would like to learn more about it. There is connection there, nataliya.byrne@nyulangone.org. It's in the chat.

For those of you who have joined us tonight live, thank you so much for joining us, and for those who of you who are watching on the stream recording, thank you for joining us as well. Goodnight everybody and take care.