### Speaker (<u>00:16</u>):

Welcome and thank you for joining us for this podcast brought to you by the American Heart Association. This podcast is part of a series focused on the 2020 Consensus Conference Report on Professionalism and Ethics, released jointly by the American Heart Association and the American College of Cardiology. The goal of this series is to amplify the report's details and actionable steps for healthcare professionals, researchers, and educators.

### Ivor Benjamin, MD (00:44):

Welcome to this podcast on the 2020 AHA ACC Consensus Conference Report on Professionalism and Ethics with a specific focus on patient autonomy, privacy, social justice in healthcare. I am Dr. Ivor Benjamin. I'am a past President of the American Heart Association, and I'm privileged to be the co-chair of this Consensus Conference with past ACC President Dr. Mike Valentine. I'm also the Director of the Cardiovascular Center at the Medical College of Wisconsin.

## Ivor Benjamin, MD (01:20):

Key biomedical principles governing medical practice and research emphasize the primacy of the principles of respect for individuals, beneficence and justice. This section of the 2020 Consensus Conference Report focused on three specific areas relevant to contemporary biomedicine. First, acknowledging respect for patients and their autonomy, to ensure clinical care or research. Participatory efforts are in alignment with the patient's goals and values, particularly as it relates to clinical decision-making.

### Ivor Benjamin, MD (<u>01:59</u>):

Two, ensuring privacy, data access and transparency, with the expansion of research and proliferation of electronic biomedical data science resources. These electronic platforms have facilitated clinical care, but we need to be mindful of the vast data that they generate coupled with the potential value of these data to create new challenges to patient privacy. And lastly, safeguarding justice requires clinicians and the systems in which they work to provide high quality care to all patients, regardless of any underlying characteristics of their patients.

## Ivor Benjamin, MD (02:44):

Social justice is imperative in medical education curriculum, as well as of course, clinical practice settings. I'm delighted to be joined today by Dr. Willie Lawrence, who was a lead author of the paper. Dr. Lawrence is the Medical Director for Health Equity of Spectrum Health in Lakeland, in St. Joseph and Benton Harbor, Michigan. He's been a volunteer for the American Heart Association for over 30 years, where he's held many positions, including being a member on the National Board of Directors. In 2011, he was named the esteemed National Physician of the Year by the American Heart Association. Thank you, Dr. Lawrence for joining us for the fifth podcast in our series of six podcasts, focusing on the 2020 AHA ACC Consensus Conference Report on Professionalism and Ethics. Please tell our listeners about your role on Task Force Four.

#### Willie Lawrence, MD (03:49):

Thank you, Dr. Benjamin. It's a pleasure to be here with you today and with our listeners. I served on the Writing Group focused on patient autonomy, privacy, and social justice in healthcare.

Ivor Benjamin, MD (04:02):

Explain to our listeners why patient autonomy, privacy, and social justice in healthcare has been included in this Professionalism and Ethics Consensus Report?

# Willie Lawrence, MD (<u>04:15</u>):

The task force intentionally decided to focus on three specific areas relevant to contemporary biomedicine. Importantly, these areas are rooted in what is considered foundational principles of medical practice and research, which are, respect for individuals, beneficence, and justice. As professionals, it is our ethical responsibility to ensure adherence to these principles within the context of today's healthcare delivery approaches.

### Ivor Benjamin, MD (04:44):

Thank you, Willie, for so clearly laying the groundwork for this discussion and the importance for addressing these areas in the Consensus Report. What did the task force see as the contemporary challenges within these principles?

# Willie Lawrence, MD (05:01):

Patient autonomy is the right of patients to make decisions about their medical care. Patient autonomy, particularly as it relates to patient-clinician shared decision-making, which is much more patient value-centric than what occurs in the informed consent process. Number two, the second specific area focused on the principle of respect for individuals related to privacy, data access, and transparency. Respect, as it pertains to the research process, involves the responsibility of investigators to clearly communicate being transparent of the objectives of medical research, to potential study subjects in the consent process, and to inform those enrolled in the studies of research results.

### Willie Lawrence, MD (05:46):

In the electronic age healthcare data have proliferated exponentially. While electronic health records held the capacity to expand patients access to their own information there are barriers that exist, which impact patient access and undermine patient engagement and education. In addition, while these electronic health record platforms facilitate patient care, the vast data that they generate coupled with the potential value of these data, create new challenges to patient privacy.

#### Willie Lawrence, MD (06:18):

The third specific area, social justice, that the belief in and commitment to the realization of access to quality healthcare for all, complicated by this is the reality that as much as 80% of a person's health is determined by social economic conditions of their environment. The commitment of the medical profession to social justice is essential and warrants learning opportunities within medical education.

## Ivor Benjamin, MD (06:44):

Willie, those are quite a number of things to unpack. I wonder if you will just share with our listeners some of the short-term action items that the task force recommend with respect to patient autonomy, privacy, and social justice in healthcare?

### Willie Lawrence, MD (07:02):

First of all, there is a common theme here, paramount importance is the recognition that the individual is at the center of our decision-making. In order for us to achieve this, there's a necessity that we meet

people where they are. That's one of the guiding foundational beliefs of the American Heart Association. Patient autonomy, number one, is the right of patients to make decisions about their own healthcare. In order to achieve this, there must be an alignment of patient care with their goals and their values. We have to understand their values, we have to understand their beliefs, and we have to help define their goals. In so doing, we can know what their preferences are and how they want to proceed with their own care.

### Willie Lawrence, MD (07:48):

This shared decision-making is dependent upon communication. Informed consent is necessary, but alone, it is insufficient to assure autonomy. In terms of achieving short-term goals, clinicians can support patient autonomy by eliciting and documenting patient preferences and values and tailoring treatment to optimize the outcomes and to support the values most important to the individual. As it relates to achieving short-term goals around the data privacy, transparency, and access again, the patient must be at the center of this process. Patients should have access to medical information.

### Willie Lawrence, MD (08:29):

Data privacy includes research and commitment to prospective registration of clinical trial protocols and reporting results in public registries and peer-reviewed journals. Results should be reported in aggregate form and where appropriate, individual findings, it can be reported to research participants. As it relates to social justice in terms of achieving short-term goals, I think it's incumbent upon the individual clinician to better understand their patients. Again, in order for us to achieve social justice, you have to meet people where they are. In order to meet people where they are, you have to understand and you have to know who they are. You have to talk to your patients. You have to understand that the social determinants of health impact your patients as much as what you say and do in the office. The Liaison Committee on Medical Education and ACGME should require a first-year course on social justice, race and racism for every medical student they accredit. Medical schools and graduate medical education programs should expand the experience of their medical students and trainees by helping involve them with surrounding communities.

# Ivor Benjamin, MD (09:40):

As you emphasize the patient-centered approach, I can certainly attest to the fact that in our most recent guidelines, social determinants of health actually, is included in part of the efforts, on the part of clinicians, to really be able to incorporate that with their patients. Now, Willie are there some long-term action items for which healthcare professionals should be working toward?

### Willie Lawrence, MD (10:09):

There are and again, I think these too are guided by changing our attitudes towards the individual's role in their healthcare and putting in place the systems of care that ensure that those things are respected, as it relates to a patient autonomy, tools designed to support formal shared decision-making, should be designed with multi-stakeholder input, including both clinician and patients. Payers and healthcare systems must support policies and infrastructure that facilitate patient-centered care, including formal, shared decision-making when appropriate. As it relates to data privacy, transparency and access, data sharing can be challenging and there are certainly concerns for potential HIPAA violations. But using a data governance board that is patient-elected, including patient representation, may help to overcome some of these concerns.

#### Willie Lawrence, MD (11:08):

Lastly, as it relates to social justice and racism, the process of changing medical school curriculum to achieve social justice and changing providers' attitudes, is certainly a long-term project. In order for us to achieve this and to know that we've achieved this, it must be data-driven. We must be able to track our progress and track our success. It may require mandates on data collection, if we are to track it and understand the impact of social determinants of health on our patients. We must track information and it may be mandated that we track information such as race, zip code, income, but we have to, in the end, influence providers to processes self-examination is incredibly important. We have to answer the question in each of our practices, "How is racism acting here? Does this policy promote health equity? Does it help us to close the health disparity gaps?" Again, in order to influence people and influence providers to understand that these policies are important, it takes education and that education hopefully began in medical school, but it may continue afterwards and as we proceed with our own individual practices of cardiology or practices of medicine.

### Ivor Benjamin, MD (<u>12:29</u>):

So, these are obviously incredibly complex, timely and contemporary issues as not only the individual physician, but healthcare systems, as well as organizations such as the American Heart Association, are actively engaged in striving for health equity. Well, thank you so very much Dr. Lawrence for this truly impactful and insightful recap of the work from you and Task Force Four. We have run out of time for this podcast, but hope our listeners will tell their colleagues about this series and the importance thereof.

### Ivor Benjamin, MD (13:13):

Call to action, all who are in healthcare owe it to themselves as professionals and the communities of patients whom they serve, either in roles of clinician, researcher, educator, payer, or administrator, to review the recommendations in the 2020 AHA ACC Consensus Conference Report on Professionalism and Ethics regarding patient autonomy, privacy, and social justice in healthcare. The recommendations offer practical and contemporary strategies that apply across diverse healthcare organizations to ensure respect for individuals, beneficence and justice for everyone.

# Ivor Benjamin, MD (13:56):

My final comments, thanks to all our listeners for tuning in, we have five more podcasts as part of the series, so please return to the HeartBEATS series for additional podcasts in this series, covering both the introduction and historical perspective for this Consensus Report on Professionalism and Ethics, conflicts of interests, relationships with industry, as well as expert testimony, we've covered a podcast on diversity, equity, inclusion, and belonging. We've even dived into the clinician well-being and of course, the modern healthcare delivery. Also please visit the AHA's Lifelong Learning platform for the webinar recording of the round table discussion of this paper, led by Dr. Bob Harrington, a co-author of the Consensus Statement and past President of the American Heart Association. Thank you so very much for joining us.