



Webinar on Open Data for Racial Equity in Healthcare April 6, 2022: Webinar Transcript

On Wednesday, April 6, 2022, the Center for Open Data Enterprise (CODE) and the IBM Center for the Business of Government hosted a Webinar on Open Data For Racial Equity in Healthcare with additional support from ZeOmega.

A full recording of the Webinar is [available here](#). The following transcript has been edited lightly for clarity and continuity.

CODE welcomes inquiries and opportunities for collaboration at contact@odenterprise.org. For more information about CODE, please visit www.OpenDataEnterprise.org.

Speakers (In order of appearance):

- Daniel Chenok, Executive Director, IBM Center for the Business of Government
- Joel Gurin, President, Center for Open Data Enterprise (CODE)
- LaShawn Mclver, MD, MPH, Director, Office of Minority Health, Centers for Medicare & Medicaid Services
- Aneesh Chopra, President, CareJourney
- Leith States, MD, MPH, Chief Medical Officer, Office of the Assistant Secretary for Health, Department of Health and Human Services
- Gary A. Puckrein, PhD, President and Chief Executive Officer, National Minority Quality Forum
- Monique Outerbridge, HHS Partner at IBM and former HHS IT Leader
- Pravin Pant, Vice President of Project Management, Data Science, and Machine Learning, ZeOmega

Introduction

Daniel Chenok: Hello and welcome to this webinar addressing the impact of open data and to address racial equity in healthcare. I am Dan Chenok, the Executive Director of the IBM Center for the Business of Government.

The IBM Center is a research organization that works with academic and nonprofit experts to do research and find insights for government leaders in the US and around the world on major challenges facing government agencies and their work on behalf of the nations that they serve.

We are honored to be working today with The Center for Open Data Enterprise and its president Joel Gurin and terrific staff on hosting this webinar, and our partner ZeOmega. Together we will be providing you with a platform to hear from a number of leaders in the healthcare sector who have great expertise in the issue of addressing equity through data in providing for greater access to and delivery of healthcare.

We came upon this issue especially because the pandemic really amplified disparities that had been growing for years and even decades in access to delivery of and outcomes from healthcare. Our center has addressed this issue in several reports including a recent report from authors Don Kettl, Richard Greene and Katherine Barrett that talked about trends in this area, and then reports from the field at the county level where King County, Washington talked about their experience in addressing and integrating data to provide for better access to healthcare for their population.

How best to address this issue really involves understanding what the data say about access to and delivery of healthcare across different regions of the country, different geographic groups, different demographic groups, and different communities of color. A lot of that information is in the public domain.

So it's with this spirit that we said, "How can we take open data and use it to provide greater insights about how best to understand the problem, how best to address managing information to provide for greater racial equity, greater access to communities of color to care? Then, how best to understand how to act and manage and provide actionable practical recommendations?"

Those types of questions and issues will be addressed today by our speakers who will then inform the work that we will do with CODE to provide a report with recommendations for government leaders about how best to move forward, to learn from the lessons of the past two years and indeed in the past several decades, and to learn how best to use data to address this very important problem.

We are pleased to provide today's webinar for you to watch and we hope that we will be able to engage with you in a continued dialogue on this critical issue. Thank you.

Joel Gurin: I'm Joel Gurin, President of The Center for Open Data Enterprise or CODE. We are an independent nonprofit organization based here in Washington, DC, founded in 2015 with a mission to maximize the value of open and shared data for the public good. We're happy to be cohosting this webinar with the IBM Center for The Business of Government and we will also be cohosting a roundtable with them tomorrow on data to improve equity and healthcare.

We want to thank the IBM Center for their partnership on this event. We also want to thank the population health management company ZeOmega for their additional support.

This webinar and roundtable are part of CODE's work to promote the use of data to address climate change, criminal justice and other social justice issues. This project is the second in CODE's Open Data for Racial Equity series where we're exploring ways to use data for fair housing, workforce opportunity, environmental justice and improving policing as well as equitable healthcare.

Webinars and roundtables like these bring data users and data providers together to help everyone collaborate to use data to solve public problems. In addition to these convenings, CODE publishes research reports with insights and recommendations on applying data for public good. We also develop online resources for the US and international data communities. You can visit our website at opendataenterprise.org to find more information and read our latest reports.

We're very lucky today to have five excellent speakers who will talk about different aspects of using data to improve racial equity and healthcare. They will share their perspectives as experts in the Federal government, in the private sector and in the nonprofit sector. Please feel free to use the Q and A function on the bottom of the screen to send us any questions you would like to ask them. We will have a Q and A session right after you hear from our speakers. So please stay on Zoom for that.

First you will hear from Dr. LaShawn McIver, Director of the Centers for Medicare and Medicaid Services Office of Minority Health. Dr. McIver is a public health leader with experience in driving successful health initiatives and public policy efforts aimed at promoting health equity, improving health outcomes, increasing access to care and promoting health system reform.

Then you will hear from Aneesh Chopra, President of CareJourney, an open data and analytics platform delivering a trusted, transparent rating system for physicians, networks, facilities and markets on the move to value. He previously served as the first US Chief Technology Officer and is the author of the book *Innovative State: How New Technologies Can Transform Government*.

Next you're going to hear from Dr. Leith States, Chief Medical Officer to the Assistant Secretary for Health at the US Department of Health and Human Services or HHS. In that role, he advises and supports Admiral Rachel Levine and other senior leaders in the Office of the Assistant Secretary for Health regarding issues of national public health importance and works with offices across HHS as well as interagency and external stakeholders.

After Dr. States, you will hear from Dr. Gary Puckrein who is the President and CEO of the National Minority Quality Forum. The National Minority Quality Forum is a nonprofit organization that seeks to strengthen national and local efforts to use evidence-based, data-driven initiatives to eliminate the burden of illness on racial and ethnic minorities and other communities.

Then finally, you will hear from Monique Outerbridge who is the Lead Account Partner for HHS for IBM Consulting. She is a senior health IT executive with more than 25 years' experience and is credited with leading complex program implementations and best in class solutions. She is an IBM executive sponsor of its Access and Accelerate Program which helps minority-owned businesses propel their success in the industry and partner with IBM.

Now I will turn it over to Dr. McIver.

Keynotes

Dr. LaShawn McIver: Hi everyone. My name is Dr. LaShawn McIver and I'm the Director of the Office of Minority Health at the Centers for Medicare and Medicaid Services.

I'm delighted to be here today as a part of this webinar to discuss this important topic and will spend a few minutes sharing some background on the CMS Office of Minority Health and what we've done as an agency to integrate health equity into all that we do at CMS.

CMS OMH serves as the principal advisor and coordinator to the agency for the special needs of minority and underserved populations. We provide leadership, vision and direction to address CMS minority health and health disparities goals. Some of the ways we do this include leading the development of an agency-wide data collection infrastructure for minority health activities, supporting the development of CMS goals, policies, strategies, and legislative proposals, consulting with Federal agencies and external organizations to address health equity, and coordinating the implementation of health equity related executive orders.

I would like to take a moment just to note here that although we are talking today about racial equity and data on race and ethnicity, CMS OMH takes a broad view of equity across many different populations regarding healthcare services, considering both demographic and social determinants of health.

Health equity is a priority across the Federal government and CMS has made great progress to integrate health equity into its various activities, especially over the past year. Here's a snapshot of some of the recent progress that we've made.

We've responded to various health equity related executive orders since early 2021. These executive orders really established equity as a defining part of the Biden administration and gave clear guidance to Federal agencies that equity must be included in all parts of our work.

Two in particular are of direct importance to our work at CMS: Executive Order 13985, which is "Advancing Racial Equity and Support for Underserved Communities Through

the Federal Government,” and Executive Order 13995, “Ensuring an Equitable Pandemic Response and Recovery.”

The first one lays out a systematic approach to address inequities. This includes embedding fairness within the decision making part of all Federal government agencies and it takes a very comprehensive approach to doing so.

The second one focuses on ensuring that COVID-19 pandemic response and recovery activities keep equity at the forefront. We’re leading the way of CMS to align thinking about the key definitions and aspects of health equity that can be commonly applied across all of our programs.

In collaboration with other components in the agency, we engage in planning around CMS’s health equity related strategic pillars. These pillars provide the long term agency-wide vision and our administrator’s priorities for health equity.

One of the ways we have worked to enable cross-agency collaboration is through the Advisory Council on Equity or ACOE. The ACOE is an advisory body comprised of CMS center and office leadership to guide CMS-wide efforts to advance health equity. The ACOE has been meeting since the spring of 2021 to discuss ways to respond to the executive orders and take action on CMS’s various strategic plans.

The ACOE is currently in the process of standing up topic-specific workgroups with component staff or in-depth discussion and decision-making to support the ACOE and CMS’s health equity priorities.

CMS and the Office of Minority Health have also worked to address the impact of COVID-19 in underserved communities. Since the start of the pandemic, CMS has expanded and extended telehealth flexibilities in response to the coronavirus public health emergency.

Some flexibilities are not permanent and we’re putting the finishing touches on provider and patient toolkits to help both groups realize the benefits of telehealth. We’ve developed and curated a wide range of COVID-19 resources on our website, at go.cms.gov/omhccovid19.

To address vaccination issues, we’ve built a webpage focused on both the flu vaccine and the COVID-19 vaccine. The page links to vaccine resources to help ensure consistency in the government’s message about vaccination.

Understanding the importance of health equity data, we established a health equity data work group under the guidance of our advisory council on equity to create agents and an agency-wide forum to improve the collection of health equity data.

The goals of our health equity data work group are to focus on improving current health equity data and new data collection efforts across the program; establish consistent data standards across programs for data collection; and provide a means for ongoing collection and technical assistance to CMS. There is a lot for us to do in the space of data collection and standardization as we continue to move this important work forward.

There are many examples of CMS's ongoing efforts when it comes to health equity data. To improve the quality of our data, we developed an algorithm to improve Medicare race and ethnicity data that we receive from the Social Security Administration. We explored the opportunity to collect race and ethnicity data in new ways. We have finalized regulations to collect social determinants of health data in post-acute care settings.

We have tools that allow for identification of disparities for individuals with Medicare fee for service such as our Medicare Mapping Disparities Tool. And since 2016, we have continued to produce stratified reports that examined race, ethnic, sex, dual eligibility and eligibility for low-income subsidies and rural-urban differences in healthcare experiences in clinical care.

We continue to be creative in this work as there is so much for us to do when it comes to health equity data. With the right data, we will be able to tell the stories of those whom we serve, and work on providing them better access to care and quality equitable care.

With that, I will end by saying thank you so much for the opportunity to share this information.

Aneesh Chopra: Good afternoon everyone. My name is Aneesh Chopra. I had the honor and privilege of serving as Chief Technology Officer in the Obama administration and I'm excited to share with you my perspectives on the role of open data to help shine light on the inequities that we've seen in our healthcare system and to promote racial equity.

In particular, I hope to make the case that as we open up more data, we regulate and make accessible information about our own health and we transform the way we pay for care that will create a market dynamic that will put the power and potential of technology data and innovation into the hands of those who could use full access to high quality affordable healthcare.

If you don't mind, I will take us a bit back in time to the beginnings of the Obama administration during the course of our tenure, starting with the transition team work on the buildup to day one. The Technology Innovation and Government Reform Committee gathered together to recommend that President Obama issue as early as possible his commitment to transparency and openness in government.

The president cared deeply about these issues, and the willingness to make a statement about openness and transparency in the midst of an economic crisis was quite impressive.

President Obama ushered in a change in the default setting from closed to open in how the government would inform the American people of its actions.

We fast forward to the first day of the Biden administration. In keeping with this tradition, President Biden issued the same day one executive order on transparency and openness. But here he did so with a purpose, to advance racial equity and support for underserved communities throughout the federal government, but frankly beyond as we interact with the information and improve various sectors of the economy that desperately need to close these gaps.

This priority on openness and equity as it relates to healthcare has really come to a head as we think about the sobering impacts the pandemic has brought across the economy.

Much has been written about the pandemic inequities, in terms of access to care and the challenges of COVID vaccinations, COVID testing, and COVID impacts disproportionately affecting populations, especially those of color.

I wanted to highlight the work that we do as an example of how more access to granular data can shine a very precise light on ways we can make the system work better.

I have the honor and privilege of working and running a company called CareJourney that has a researcher agreement with CMS through the Virtual Research Data Center, allowing our teams to access the underlying claims information, deidentified and linked at a beneficiary level, for parts A, B and D in the Medicare program.

As a result, we're able to make more granular interpretations of where we're doing well as a society and where we're falling short. Our team right now is taking a look at some of the sobering realities on breast cancer screening.

It turns out that maybe double digit level drops in cancer screening rates took place throughout the economy. But if you zoomed in particularly on African-Americans and Hispanics, you can see that even pre-pandemic levels were not where they needed to be. So we've fallen farther behind but there was already a gap.

However there's a shining light. If we put more and more of the American people into accountable care relationships, ACOs, we find that 1.8 times more individuals get the recommended preventive screenings when a beneficiary is enrolled.

So getting people into accountable care relationships is the work of the day. In my view, the data suggests that we've been going sideways on this subject for communities of

color. While the white population has been enrolled in ACOs, nearly one-third, you can see that that number begins to fall. African-Americans at 22 percent, Hispanics as low as 16 percent.

We need to do a better job outreaching to communities of color and enrolling them in Medicare ACO programs, either directly or through the health networks they currently see.

CMS formalized this in a program called ACO Reach in April of 2022. It called for all physician networks to move to total cost of care responsibility to place particular emphasis on health equity, in developing health equity plans, incentivizing with the form of a benchmark adjustment: All the opportunities to make sure that barriers are knocked down and individuals can be enrolled in programs that will make them healthier and hopefully save taxpayers' resources along the way.

I'm so grateful for the opportunity to share a few words to celebrate the history and to think about the possibilities of the future if we can open up more data and move the system towards value. Best of luck. Thanks for having me.

Dr. Leith States: Good afternoon. It's a pleasure to be with you all today to speak to open data and its potential impact on driving racial equity. Let me start by thanking my colleagues at CODE for the invitation to speak and to express my gratitude to those of you who have decided to share your time viewing this webinar.

My hope is that my remarks advance today's discussion and add to your knowledge of ongoing Federal activities. Briefly, I am fortunate to serve as a Chief Medical Officer to the Assistant Secretary for Health at the Department of Health and Human Services. That position has given me a front row to two priorities for this administration, one of which is environmental justice and the other is climate change.

With that in mind, I was asked to speak to the following prompt: Describe the work of the Office of the Assistant Secretary for Health on efforts to understand cumulative impacts of environmental hazards and climate change on health, especially as they relate to racial inequities.

Now I only have five minutes to speak. So let me set the stage with the following. America is the land of promise and unfortunately, it's a promise that remains unfulfilled for many. So many disadvantaged, low income communities, including communities of color, continue to bear the brunt of pollution from industrial development, agricultural practices, cumulative impacts of land use decisions, transportation and trade corridors.

In January of 2021, President Biden signed Executive Order 14008, entitled "Tackling the Climate Crisis at Home and Abroad". That order directed HHS to make achieving environmental justice part of its mission by developing programs, policies and activities

to address the disproportionately high and adverse human health, environmental and climate-related and other cumulative impacts on disadvantaged communities.

Now in response, over the course of the past year, we have established the Office of Climate Change and Health Equity as well as an environmental justice unit, both of which are housed in the Office of the Assistant Secretary for Health. They serve as a department-wide hub for climate change and environmental justice policy through programming, analytics and the pursuit of equitable health outcomes. While one of the priority actions for this team is meant to develop and implement a revamp to department-wide environmental justice strategy, there have been a variety of other opportunities that the environmental justice team has been given to engage on.

One of those has been an opportunity around the initial prompt, which is to capture cumulative impacts of environmental exposures and their variable and inequitable impacts on communities of color.

Now HHS recognizes the importance of that linkage and has been committed to realizing its potential to have a substantive impact on those at greatest risk but who were suffering from environmental injustices. So with that said, this is an area of active engagement within HHS. I'm sorry I can't say more at this point, but it is an active area that is very exciting.

Stepping back for a moment, I want to clearly convey that climate change and environmental justice are not synonyms. The environmental context and the associated social context of a community tend to inform EJ risk in a smoldered baseline. But drivers of climate change are added like gasoline onto those already smoldering embers.

Think of a low-lying area in the South with high levels of baseline poverty, low access to care, located along the transportation corridor potentially with high levels of air pollution and poor sewage infrastructure. If we add on to that sea level change, high annual temperatures and changing migration patterns of insects that are serving as disease vectors, EJ and climate change come together in a way that affects those that frequently are already suffering from higher baseline injustices.

But that's not to discount the role climate change plays and its increasing role as an independent risk factor for worsened health outcomes. Now HHS has historically participated in the U.S. Global Change Research Program. The Interim Director of the HHS Office of Climate Change and Health Equity is Dr. John Balbus. He has been a co-author on the USGCRP National Climate Assessment Chapter which introduced the idea of climate change and health at the Federal level.

Now under his leadership and through continued collaboration with our HHS partners, we're working on leveraging those disparate data sets from public health, from weather, from transportation, from healthcare organizations to name a few and how central they

are to developing better predictive models to allocate resources, pursue policy efforts, facilitate behavior change in the context of equity, a slew of opportunities.

So to conclude, here's my hope for this chat today. To quote the Father of Environmental Justice, Dr. Bob Bullard, "One of the key components in environmental justice is getting people to the table to speak for themselves. They need to be in the room where policy is being made."

So for those of you on the line that are working at the community level or from communities that are at risk yourselves, thank you for being here. Data solutions to drive equity need to be community-informed or led and adaptive to the unique needs of communities that we're all striving to serve.

With that, I hope I've been a good steward of your time today. Thank you very much for your attention.

Gary A. Puckrein: I'm Gary Puckrein. I'm President of the National Minority Quality Forum. We are a research and educational organization based here in Washington DC.

We've been collecting health data now for about 20 years. We have a database of over 5 billion patient records. We collect data on about 160 million lives a year covering well over 100,000 different conditions. We collect a lot of claims data but we also collect environmental data. We collect social determinants data. We even collect voting data, and we collect all that data with a purpose.

To understand our purpose, I want to share with you a timeline that tells you a lot about the African-American experience and what we're doing with that data that we are collecting. For most of the history of African-Americans in this country, they were either slaves or fighting for civil rights.

It has only really been over the last 56 years that African-Americans have had the vote. This period means that we have a chance to define our community, how we want to live in America and how we want to interact with the broader community.

We think that the conversation of the 21st century is really about sustainability and we see sustainability as a data-driven exercise. So all of that data that we are collecting is really focused on sustainability.

When you look hard at sustainability, what you understand is it's about risk mitigation. How do we lower the risk for hospitalizations, emergency room visits, disability, mortality while improving the quality of life? In order to do that risk mitigation, you have to have data and so what we have been building is a community data lake. We have been assembling data from all over the place so that when someone has a question that they want to get answered, we have some data that will at least get them started towards that answer. But even more importantly, what we're trying to do is to help build

sustainable communities certainly in the African-American community but the broader society as well.

Our communities and our societies have matured and that maturity means that we have to use data and data analytics to provide for our economy, for our health and so we assemble all of that data to try to get there.

Most of our data has come from the Federal government which quite honestly is an enterprise because collecting data from the government is much harder than it should be.

So we spend our time writing forms and paperwork and all of that, to get that data into a community data lake and the idea is that we will build applications on top of that community data lake. That will help people who are doing health in the broader sense of the word, environmental health, social determinants of health, transportation for example, housing as well as health in terms of clinical data.

We also love to partner. So I will extend that invitation to anyone who wants to partner both in terms of partnering to aggregate and collect data as well as building applications to make that data more available to the general public.

So we're pleased to be part of this conversation. I hope I've given you a general sense of the National Minority Quality Forum and the way in which we think about data and why we collect the data that we collect. Thank you very much.

Monique Outerbridge: Hi. I'm Monique Outerbridge with IBM and what a wonderful event we've had so far today. CODE has brought us a number of speakers that have been able to address a variety of dimensions for us to tackle and really look at health and equitable outcomes.

Dr. McIver and Dr. States with the US government are really showing us the power the government has to be able to move this needle. CMS is using emergent technologies and voluntary reporting on race and ethnicity. While these are great starts, they both recognize that there's a lot more work to be done.

Aneesh Chopra talked about companies working with the government and how that collaboration is able to gain access to open public data and drive to more granular information needed to address these health outcomes. One example is that they're doing this in breast cancer screenings as we are seeing that there is a difference amongst demographic groups on what those outcomes look like.

Lastly, Dr. Gary Puckrein with the National Minority of Quality Forum is gathering patient data in order to identify risk and this data is coming from a number of different sources.

In each of these areas, they all fall under a topic that I'm personally passionate about and that's social determinants of health. We have been discussing social determinants of health for a number of years now and what we have discovered over these past several years is the need to broaden the definition of what that is and what it looks like.

We can no longer stay in a lane of just discussing safe housing and transportation or even education, education that we know leads to job opportunities, providing income needed to gain healthcare. But we also need to address the tough topics of racism and discrimination and the impact that it has on an individual's health and physical well-being.

Here at IBM, we are also focusing on continuing to help push the need of driving closer to data, gaining more access to different data resources and being able to link those data together.

We have to do it as a global community together in order to address these outcomes and I think we can. So I look forward to our continued conversations and collaborations in order to collectively move this needle forward, so we are no longer just having conversations but seeing the realization of these great ideas coming together and closing the gap on disparities. I hope you all have a great day.

Panel Discussion and Q+A

Monique Outerbridge: Thank you so much everyone for joining our live portion of the webinar. We really heard a lot of great information from our speakers earlier this morning or this afternoon depending on where you are. Most of our speakers will join us for this live Q and A session, sans Aneesh Chopra. Unfortunately he cannot make it today. But we do have an additional guest that will be helping us out with some Q and As. Again, as a reminder, feel free to drop some questions in the chat and hopefully we will have time towards the end to take one or two of those questions and respond to them.

It's definitely wonderful meeting all of you today. Thank you for taking the time to join us.

Our guests watching us today know everyone on the panel except Mr. Pravin Pant, so I would like to start with you. You're representing a population health management company called ZeOmega and are a vice president there. If you could, just tell us a little bit more about yourself and your company and how your technology solutions are being used to help address health solutions across different demographic groups.

Pravin Pant: Absolutely My name is Pravin Pant. I'm the Vice President of Advanced Analytics including social determinants of health for a population health management company called ZeOmega. We're headquartered here in Dallas, Texas and we actually just got recognized by KLAS as the number one care management solution out in the industry. So that was a very proud moment for us and we work very closely with

providers and peers both and from population health management all the way to individual care management.

We have about 38 plus million lives in our platform, which is about 12 percent of the U.S. population. It even has Medicare, Medicaid, as well as commercial lives and in the past two years, we have focused on helping our clients identify the SDOH, social determinants of health barriers. When we are talking with our clients, when we're interacting with them, we find out that there is a huge need with them trying to understand their population across their state or across the area that they're serving.

Right now we work very closely with them and we help them understand from the heat map perspective, like interactive maps perspective, what the different SDOH needs are from populations at the community level.

We go down to the Census tract and this data is more focused on the community so that our clients have a pretty good understanding of what the hot spots are. What areas have housing, food, income issues or what areas have what other kinds of issues?

From that perspective, they have a pretty good visibility which really helps them understand what is causing the health disparities. Then what they really will also do is they will help actually build programs to act, mitigate those disparities and assure health equity for the population.

So we look at the community, the population level. Then we're also able to drill down to the individual level to mitigate that disparity and the best asset for that particular case where they can close the loop and understand that what they're trying to do is really helping.

We're also helping them on a day to day basis to track the outcome. Like certain things they did: How did that really work? Did that really help solve this problem that we're seeing? Are you getting now – is health equity there for the population we are trying to serve?

So it's a combination of understanding the community and understanding the individual level. We're looking at all the different public data pieces to the US government. We're also looking at the assessment data. We're looking at the claims data. So it's a combination of various data as well as learning all the chronic conditions that may be existing in that population just to give them a very holistic view of what are the different issues causing these disparities. How do you mitigate them?

We're also automating that from them so right there and right then, at the point of care, they know how to mitigate that, and then trying to measure how that resulted in equity down the road.

Monique Outerbridge: Great, great. It sounds like you're doing a lot down there. So I will send my next question to Dr. McIver. CMS is growing this internal collaboration with this health equity data work group which is really cool to hear. You're promoting better data collection, data standards and creating a lot of ongoing collaboration across a number of organizations. So what recommendations would you have for other groups that are trying to set up very similar work groups?

Dr. LaShawn McIver: Well, thank you so much for that question and it is a delight to be here with a lot of the other panelists today. I will start by actually backing up and referencing the executive order that I talked about with addressing the needs of racial and ethnic communities across the Federal government. What that has sparked within agencies such as CMS is a conversation of how we operationalize equity as an entire agency.

CMS is a very large Federal agency. We touch many aspects of the healthcare system including data-related activities. It became very clear that we have to do it in a systematic way that allows us to work synergistically on these areas and we had not had a health equity data workgroup before within the agency with this specific purpose: How do we drive policies and strategies collectively?

I would encourage other organizations that are looking to address health equity related data needs for their respective populations to start by taking an assessment of who are the stakeholders within your organization that should be at the table. Within CMS, we have many different data groups across our agency. So we brought all of those people into the same room and we did an assessment and are still doing an ongoing assessment of the types of activities that are underway and prioritizing how we would address them as a selective.

For example, in our programs, we're thinking about collecting certain social demographics or social determinants of health, different data elements. We're making sure we're thinking about what should be our baseline for this as an entire agency across the different programs, recognizing we have different authorities within our programs as to what we can and can't collect. We're starting by asking those key questions, getting the right people in the room and sort of assessing what is the path forward based on our respective priorities. We have 26 centers and offices within CMS but it has created a really rich opportunity for collaboration and certainly dialogue to help drive this as a collective.

So, identifying those who need to be at the table, understanding what activities are happening and creating a strategy as a collective is very important. Thank you for that question.

Monique Outerbridge: Well, thank you so much for answering that. I should probably be transparent and let everyone know I used to be a CMS Federal employee for a number of years. But there's no bias here because Dr. States, next question for you, I

actually had spent some time as a fed at HHS as well. Not specifically at OASH but I'm not playing any favorites here.

So Dr. States, you helpfully described the cumulative impacts of climate change as a threat multiplier and how it plays out with different impacts on the different communities.

What is your hope for how we can use different kinds of data to address some of the climate-related issues that you spoke about earlier?

Dr. Leith States: Thank you for the question Monique and I appreciate you being forthright and transparent about your allegiances to CMS but that's OK. I accept you as an HHS alum. Let me step back for a moment as well and just put some thoughts around how critical it is to look at the development of these data-driven tools from the perspective of the end user. If I look at a community that has experienced environmental injustice and is now experiencing an increased risk due to climate change, the first response I will probably hear from that community is that we don't need another tool telling us what the problem is. We have our own data visualization. We have community-driven epidemiology or from some that we've had discussions with in the past, they will say we documented this. We published this in peer review for decades. How is what you're doing now going to change anything?

This applies to Federal efforts, state efforts, open data efforts, private efforts, consortia, whatever the case may be. All right? So now I will put a pin right there as kind of the foundational element. I've had a discussion with Dr. Puckrein on this previously, so I think I can echo some of his sentiments and I've tried to be informed from folks that know about these things and these spaces since I'm a little bit on the younger side of folks playing in this pool.

But at the same time, looking at this through the HHS lens, how is this going to impact what we're doing within our own backyard? For HHS, for the staff divisions, for the operating divisions? I think this data or disparate data sets that are starting to be able to interoperate, to talk to each other, to have an amplified effect, I think they can start to be used in an actionable way to drive Federal action and following through on promises of addressing equity in a greater degree with how we use our Federal funding.

There have been overtures in the past around how we will focus on X, Y, Z. Environmental justice isn't new. Social determinants aren't new. Terminology may have changed but there's always a population at risk with a certain problem set that requires some type of allocation or resources that doesn't happen for a number of reasons. I think that has to start with the cadence of the culture, of prioritizing equity and actually having the tool to do it, that allows that to be built in over time.

So the bottom line is the hope that I want these tools to drive toward relevance and utility. The idea that equity is something tangible, more than just a political byline, and something to help people get into and maintain power.

It's one thing to have a nice screening tool. It's another thing to have a risk assessment or something that can actually drive action. That's what my bottom line and takeaway hope is for this.

So I will stop there. But hopefully we get to have some more discussion.

Monique Outerbridge: Absolutely. When listening to you earlier, I heard you talk about community-driven data, where it actually needs to come from. And I did have a question for Dr. Puckrein who appears to be working with a lot of community data that he's pulling in.

So Dr. Puckrein, very nice to meet you. And thank you for that overview that you did for the National Minority Quality Forum. When you're gathering your patient data, to understand the very risk that Dr. States just mentioned, can you describe the patient data lake that you stood up in order to use this data from many disparate sources that you're gaining this data from? It sounds like you're pulling it in from a number of different aspects - not just social determinants of health but environmental as well.

Dr. Gary Puckrein: Yes, thank you so much. You know, I think one of the most important things is that we need communities to have access to data. So much of our data now is captured in large organizations that don't necessarily make their data available. But even more importantly from minority communities, they don't want to get left behind. Part of that digital divide, if you will, is also data, right?

So we're trying to build a community data lake that allows community-based organizations to place applications, to build applications off of the data that they can use to answer questions and make progress in the communities that they serve.

It's a challenge because there are all kinds of walls out there to access data to make it available. One of the greatest data collections that we have is the Federal government. I think it's marvelous that our government has so much data. There are a lot of countries out there where that kind of data is not available. But it's a struggle to get it and it's well beyond the capacity of a lot of community-based organizations to be able to assemble that data and then to make use of it.

So we want to make sure that these communities that we describe as underserved, don't become just – we want to teach them how to fish, right? We just don't want to have them be recipients of data that someone else filters for them. It's very important that we take the moment to organize the data, present it in a way that allows them to build applications and use it to address these inequities that we find in community.

Monique Outerbridge: Thank you so much for that. I really appreciate all of our speakers that have come on today and we may be able to grab a couple of questions from the chat. Joel?

Joel Gurin: Thank you to all the panelists and to you for moderating. We are getting some terrific questions from the audience, so I will just share a few. I do want to say unfortunately we are not going to have time to answer all these questions but we will definitely include them in the conversations tomorrow for those who are attending the Roundtable. And if anyone would like to follow up with any of the panelists after this call, please just let us know. Share your email in the Q and A and we will be happy to connect you for follow-up.

The first question is from Dr. David Mann at the Maryland Department of Health is will open – and this is for anyone who would like to answer. The question is, “Will open data approaches be able to tell us one, the effect size of a determinant in a particular community and the prevalence of the determinant in a particular community?” because those ingredients would allow us to know what determinants to target in particular communities. Anyone who would like to address that question?

Dr. Gary Puckrein: I will try to take it on because those are part of what we’ve been talking about. So we have to assemble a massive amount of data. You know, we’ve paid a lot of attention to clinical data but the social determinants of data, environmental data, all of those things impinge on life. And the way we understand what we’re doing in data is that we’re trying to use it to support our biology, to make sure that the inequities that we see in our society are taken care of.

So when we look at the data, right now you could predict how many people are going to go to a hospital with a cardiovascular event in a Zip code. You could predict how many are going to go into dialysis. It isn’t that we don’t have that data and that the prevalence and incidence are mysteries, the fact is we’re not doing anything about them. That’s the point.

So that is what we have to do. We have to assemble the data but not just for the purpose of assembling data. It’s to put it to work and that’s I think where we’re falling now.

Joel Gurin: Great. Thank you. Another question I think Dr. McIver may be for you. Dr. Jade Berry-James asks, “What are the legal parameters that prevent the federal government from requiring race and ethnicity data to be collected in the evidence building practices or evaluation of Federally-supportive programs and services?” We’ve actually had a few questions about the fact that that data would be valuable. So this question is about what are the legal parameters that prevent that from being collected.

Dr. LaShawn McIver: Well, thank you for that question and it’s a really important one. I think generally that there are some concerns about whether it’s appropriate to risk adjust based on race and ethnicity and there are certainly many ongoing conversations about that.

I know that the National Quality Forum has released a couple of reports discussing this point. So if others are interested in that, that might be a resource that we can point to. But with any data analysis, we certainly want to make sure that what data we use for analysis are appropriate and all aspects and concerns are taken into consideration to avoid any bias or inappropriate conclusions. So thank you for that question and certainly noted.

Joel Gurin: Great, thank you. And then Dr. States, maybe you would like to begin on this next one and anyone who would like to can join. We've had several questions around community engagement. One person asked, "How are each of your organizations working with communities and people with lived experiences as you work to address racial equity and healthcare?"

Others have asked similar questions about engaging with communities around both validating data and also building trust around the use of data. So I wonder Dr. States, if you might like to begin and then anyone else who would like to join and then I think we will be wrapping up.

Dr. Leith States: No, that's excellent. That whole constellation of questions, the primary term I hear there is trust, right? I mean without that, there really is a hampered ability to successfully achieve any of the desired outcomes, whether that's at the Federal, state, local, tribal level.

The example I would like to provide around HHS is the reintegration of environmental justice into our agency approaches to developing ties with communities. Up until 2016, there was a very robust community that did engage on a regular basis at the community level, at the individual level where we had some more latitude to engage openly. That has now reestablished under the umbrella of the higher visibility from the White House with regards to climate change and the intersection it has with health.

So what I will say there is that as we've gotten to the point where data development has become more individual or community-centered in terms of not just consumers but generators of content, that has facilitated greater numbers of discussions and a more substantive basis for trust. Do I feel that we've executed on that well? No, not yet.

Part of that I will say is at points, the proof is where the money is. I look at our recent omnibus approval and some of our funding that we hoped for in the spaces that would address social determinants and social needs and as a byproduct, climate change and environmental justice were not addressed in – I won't say in a good faith manner but in a way that didn't really reflect what I think is the true intent of going the extra mile to correct a series of injustices that Dr. Puckrein alluded to.

If I could take one quick moment, I just want to allude to something that Dr. Mann brought up and that was to the point of whether we have been able to tease out this causal relationship with this multiplicity of social determinant input. I think that it gets

back to what I initially mentioned with my reply around you don't need to tell me a new way to characterize the problem that I already have experienced in my own shoes.

For folks that have been or are living in poverty, it's not your healthcare absence or presence that's the issue, right? It's the external stressors of life. It's what you find yourself surrounded by on a daily basis that is driving that.

So I think that we don't need fancy tools to be able to tease that out, right? If we go to the community, it could be as simple as just we're going to prioritize the factors of life and pick one. It does not need to be a knock-down drag out process. We need to innovate in the space to make things happen. It does mean we need the right resources directed at the right time at the right space and that would be at the infrastructure, at the individual, at the beginnings of life in that family unit inside the home. Hopefully that's a helpful characterization.

Joel Gurin: Great, thank you. We are a little bit over time. Monique, would you like to close out the panel?

Monique Outerbridge: I just thought this was amazing. All of you are in my eyes kind of titans in your own manner and you each are carrying a very heavy burden. But I think that burden becomes lighter when you do it all collectively and it sounds like a spirit of collaboration is absolutely here. I look forward to running into your circles in the future. This is something that we definitely plan to stay committed to. It's not just something of the moment. So we look forward to continued conversations.

Joel Gurin: Thank you and Monique, thank you for moderating and pulling this panel together. This concludes the public part of the webinar.