Christie - 00:00:05:

Welcome to AIM for Safer Birth. I'm Christie Allen.

Veronica - 00:00:08:

And I'm Veronica Gillispie-Bell. On this podcast, we dive deeper into the rising severe maternal morbidity and maternal mortality rates in the United States through a data-driven quality improvement lens.

Christie - 00:00:21:

And in this episode, we're talking about measurement again, as we did in the previous episode. This time we'd like to talk about measurement and what the levers are. We talked a lot about what the barriers are and it's plentiful. There are a lot of barriers, but there are things that we're learning and there's things that are growing and developing and we're learning how to do measurement better around equity. Specifically, we're talking about equity and quality improvement in that integrated way. So I think one piece we talked about a little bit that I'd love to dive into more is the disaggregation of data by race and ethnicity. Can you talk to me about your experience of that a little bit?

Veronica - 00:00:59:

Yeah, I think i've mentioned when we first started our quality collaborative and decided that we were going to work on equity, that was one of the first things that we realized we needed to do. Now, we did it mainly with our outcome measures. We learned later, no, we need to do it for all of our measures, but being able to disaggregate by race and ethnicity. And I think it's hugely important because you see where your disparities are. That tells you where you need to do more work. And then from a process measure standpoint, it helps to tell you where you're given equitable or maybe not giving equitable care. And again, where you need to do more work. I will say it is not an easy process, but it's a necessary process to disaggregate.

Christie - 00:01:38:

I think, again, we're back to people don't believe it's possible unless they see it done. And i've definitely seen a shift in the AIM program. I think in around 2019, it wasn't an expectation of the program. And I think as we began to integrate equity concepts, the biggest question we get again is how do you measure equity? And I think this is a first step, a little bit like implicit bias training or the beginning of anti-racism training. It's a first step in the process. I think maybe we're still building the other steps. And I think that as you disaggregate data, sometimes we get unfortunate news. And sometimes we get validation. Actually, we do have pretty comparable outcomes, actually. And I think, again, we talked a little about C-section in the context of measurement, NTSV C-section. And the measurement of that is often a good place for people to start.

Veronica - 00:02:25:

Yeah, it's a little bit easier to, again, to look at that as an outcome measure, just because you had a C-section or you didn't, we're not relying on these ICD-10 codes, and then to be able to disaggregate by race and ethnicity. I will say we have some, I think, reinforcing agencies and agents that are requiring data to be reported in disaggregated ways from a national standpoint. And so it's helping us to have that conversation with our hospital teams as a perinatal quality collaborative. They understand the why, because we've talked about that for so long, but this gives us just another lever as to, you have to do this, let us help you do it. And so we're partnering with our birthing facilities, and we have been for a while to come up with the best ways to actually disaggregate the data. We now require in our latest set of measurements, which is actually going to be going live on Monday, our latest set of quality improvement measurements for our PQC, everything has to be disaggregated.

Christie - 00:03:27:

I think it's incredibly important. I think it can feel burdensome, just to acknowledge. I also am seeing a shift just sort of nationally from a quality standpoint. I may not be boots on the ground, but I talk to so many people in so many areas. And I do believe that it's going to be built more and more into state monitoring to regulatory bodies, some bills. I think
that there’s a real focus as appropriately we focus in on the inequities and disparities. I think that there’s going to be more requirements. So I do think exercising that muscle now to build that is incredibly important. I think everybody’s here with really important data too. I mean, look, relatively recently we were using race as a biological risk factor. It was included in caesarian calculators. It was included in, and I want to assume that people are doing the best they could with the information they had at the time. Although sometimes that is not the case. There’s shifts in how we view things and that by virtue of race or ethnicity, which may or may not be accurate, people do ascribe risks. So I do think it’s another way to validate or even invalidate some preconceived ideas.

Veronica - 00:04:35:

I think that's very true. And we definitely in medicine need to invalidate some of those preconceived ideas. We know it’s written into the textbooks that informed our medical knowledge very early on, soon after slavery, where race was described as a biological condition, where black people were described as having smaller brains, where they were described as having a condition that, and I’m going to mispronounce it so I’m not going to even try, dystopian mania that would make us as black people fight against being enslaved. Just all of these fallacies, and those fallacies though have gone into our bias and it has affected how we deliver care. I mean, there’s countless number of reports and again, these biases that black people have thicker skin, that we don't feel pain in the same way, that as women we are loud and we complain. And just all of these things that then go into effect how we as healthcare providers deliver care, because again, we’re not absorbed from having biases because of these different, and quite honestly, not just social, but these are things that have been described to us in a medical way. Even thinking about as a medical student, you are taught when you're doing your USMLE exams, the first thing that they tell you, this was a blank black or white woman that comes in this with a condition or with symptoms and you're in your head are supposed to think if they, if they're this race, they have this symptom, they have this condition. And so we have a lot of fallacies and a lot of unfounded biases that are based in just stuff that people have made up that we have to combat against and having the data helps with that.

Christie - 00:06:33:

Yeah, absolutely. I think it deserves a deeper dive to talk about some of the myth busting around equity and quality improvement in the future. But I want to shift from those systemic issues that good data and that disaggregated data by race and ethnicity can really inform to some of the complexity of that, that is something that is an opportunity for improvement. So I want to introduce the concept of real data, which is race and ethnicity data that the United States collects. And I want to first acknowledge that we may use terms that are not the accepted terms of the communities they represent, because that is how data is collected. And some of that won’t change. Sometimes when you read an AIM resource or even sometimes a publication, you’re going to hear us say Latina, you’re going to hear us say Hispanic. We are using the terms of the research being cited. And that is what we do right now. We’re trying to find ways to make sure that the ways folks identify are reflected. We're not there yet. So these categories may or may not be aligned with the values of the listener or the communities we're discussing. And I just want to really acknowledge that before we do it. How do we do at capturing folks’ race and ethnicity in the data?

Veronica - 00:07:45:

Well, not so hot. This really goes back to creating that culture, right? That culture around diversity, around inclusivity, where we feel comfortable talking about race. We have not done a very good job of allowing for self-identified race. We have patients that come into the healthcare system. We look at them because we don't want to ask the question because, oh my gosh, I want to talk about race. We assign them a race. This is just anecdotal story, just one. I had a patient, she was sitting in my office, i’m looking at her, i’m looking at the medical record, i’m looking at her again. And I said, i’m doing a lot of work around equity, and so it’s very important for me to make sure that we capture race and ethnicity correctly. Now this patient that's sitting in front of me looks like me. And so I said, i’m looking at the medical record, do you identify as white? So I can make sure I have this correct. And she's like, absolutely not. So, and I was like, I know exactly what happened when she called to make the appointment. She had a certain voice, she has a name, she's not from the south, and they assumed that she was white. Nowhere in her course of getting back to see me did anybody say, wait a minute, this is the right and change it. And so we do have some work to do around advocating with and not advocating maybe educating our registration staff in the hospital to be able to allow patients to self-identify as their race and ethnicity. We’ve worked a lot around this with our PQC. We actually just did a topic call with our PQC where we’ve given out some tools to help our nursing team on our labor and delivery units to have those conversations as well as them to be the ones to have the conversation with the patients. If they make it through registration and nobody asks the patients race and ethnicity, but now the patients on labor and delivery and they're presenting to empower our nurses to have those conversations as well as to handle those uncomfortable responses.
where again, we are all whether we are providers or we’re patients, we are all on a different place in our equity journey. And so some patients, if you ask them their race and ethnicity, their response may be, well, why do you want to know? What are you going to do with that information? And so we have to also be prepared as healthcare providers asking those questions to have a response and we have to equip our teams to feel comfortable to answer those questions as well.

Christie - 00:10:25:

Absolutely. I think as you're talking, i'm listening and i'm thinking about instances where there's a safety concern. We're back to safety again. There is a safety concern with disclosing your race and ethnicity. There's a privacy issue. The why are you asking? Are you going to harm me, not treat me the same? Do you know, is this relevant to my care? Yes and also no. And I think that sometimes we make assumptions and as we talk about this data, it's generally not being collected by clinicians. It may not be understood by front desk, front office staff, the hospital registration staff. And I do think that's where we really have to lean into the quality improvement of bringing in the full team. And sometimes we fully miss team members. We've done a pretty good job, I feel, in OB care with drills and simulations, for instance. A lot of hospitals pull in anesthesia and pediatrics and even the blood bank or x-ray or folks that they know are going to need to be present in an emergency. If that person's data was captured incorrectly, you might have an incorrect data down the road, right? And so i'm not saying they need to attend drills and simulations, but I think we really need to think more broadly about the care team because there is impact, whether we are seeing it in the short term or not, there's definitely impact.

Veronica - 00:11:47:

And that's actually the first step in our health equity plan that we've designed for our teams is to first identify what are all the ways and the avenues that the patients are coming into the healthcare system? Is it registration? Is there a phone service that happens that's off campus somewhere? Is it the emergency room and there's a triage nurse? What are the different ways that patients can enter into the healthcare system? Because those are all the individuals that need to have this education.

Christie - 00:12:16:

And we've talked about the fragmentation of EMRs, them, you know, you come into an ED, they may not have your stuff, you're at a different hospital, your records are there. It's complicated, right? I also think that there is the element of creating a space where people can disclose the information. I love what you're saying about having nurses ask, but I think having someone ask me my details at a front desk, I've had that experience as a patient, been like, really, we're going to talk about this right here? And it isn't about even my physiological, but about payment and about insurance and about, those are touchy subjects that for some folks, with very good reason are triggering in a different way. I think we think about mother-infant separation with marginalized communities. We think about, you know, the involvement of child protective services. There is a lot of history there. Just to highlight one population, I have a colleague whose partner is native indigenous, who actually grew up on a reservation and moved out of that area. And their big joke is that no matter what they do, they are identified as Hispanic in all of their medical records. Nobody has once asked, they have identified based on visual cues. They're offended by that, but they don't say anything because they don't think it's worth it. And i'm fortunate enough to work with colleagues who provide care in IHS facilities and do health services as well as tribal communities. And we know actually that only about 20% of births in the country to native and indigenous folks take place in the IHS system. I think there's a common misconception that you're not going to see native or indigenous delivering people outside of IHS. That's patently false. So we need better information so that we do a better job caring for folks and so that we can look at our true outcomes as honestly and openly as possible.

Veronica - 00:14:07:

I think that, and we talk about culturally sensitive care, how can you provide that if you don't know what culture this patient identifies with? And so, just one more reason that we need to ask those questions.

Christie - 00:14:19:
And maybe asking better about culturally responsive care or to provide culturally responsive care. I think of the questions, we have some really well-intended questions in our EMRs. I remember in practice asking, are there any cultural things I should be aware of around birth? People don't know it's cultural, it's just their life and it's what they want. So I think it's the shift, you know, how can I make sure we honor any of your traditions or things that are important to you? I mean, there's a shift about making it patient-centered instead of what I'm doing, what is it you need? You know, I think it goes back to, again, meeting people where they're at, treating them as individuals while providing a high standard of care.

Veronica - 00:14:54:

And as we said in the first episode, words matter. And the way that you phrase and ask those questions, it matters.

Christie - 00:15:01:

I recently was filling out intake form myself and I saw that they were asking about language. And at first I didn't even catch it, again, my white-centric, English-centric self, but they said, do you receive care in English? That's strength-based. You're receiving care. You're not being given care. It's like, do you need an interpreter or a translator? Is a very different way to ask that than do you receive care in English or does the patient receive care in English. That was a really interesting twist. And it's, you're going to get likely the same outcome. Or at least the express preference. But you're asking it in a really thoughtful way. I don't think we can fix all the questions, but at minimum we need to be collecting accurate information.

Veronica - 00:15:43:

Yeah, and if we're not, well, for the reasons that we've already said, we have to collect it and there's data that shows that when they've looked at the medical record and they've done data to see how patients identify, it's not the same. And that, you know, not saying that it's 100% wrong, but we have room for improvement.

Christie - 00:16:03:

Yeah, I think that's the bottom line in measuring equity. We already have things that we can do, that we can continue to improve on. I think it's so essential as we want to work on equity, you literally, I've said this before already, you can't do better unless you know better. And I think often the perception is, I provide equitable care, I'm doing the right things, I'm learning about my own equity journey, my anti-racism, I'm learning how to de-center that. But to your points earlier about medical training and the other pieces, there are pieces we don't even know our mythology built into the practice. There were things I was told in nursing school that are just very clearly made up based on white supremacy and based on other factors that came out of slavery and the medical perpetuation of slavery. We will have some associated resources with these podcasts where folks would like to read more about that, their hard reads, their important reads, and they really have helped inform how I see the culture because it isn't that you have all bad actors caring for people, and it isn't that patients aren't doing all the right things, right? We're going to talk a little bit about myth busting around that in future episodes, but to me, it's really centering understanding the history so that we continue to improve as we move forward.

Veronica - 00:17:22:

Yeah, I 100% agree. And again, just rethinking about how we meet patients where they are and think of them as individual patients. As you were talking, I was reflecting on being at the annual clinical meeting as a resident, as a junior fellow, and they, I'm assuming they still do this, but they used to do stump the professor for the junior fellows. And the stump the professor was they described someone that came in, it was a black female who was having shortness of breath and she was having cough and she kept getting ill. And I don't remember all the details, this is a long time ago, I was not a junior fellow like recently, that was a long time ago. I can't remember all the details with the clinical situation, but what the reason it was a stump the professor is this patient has cystic fibrosis. And nobody ever thinks about black people having cystic fibrosis because again, we have been, it's been ingrained in our head, white women. Cystic fibrosis, screen them in pregnancy, cystic fibrosis. No black people have cystic fibrosis too. That's why it became the stump the professor because nobody, nobody got it. Nobody figured out that this patient had, well, the, her, thank god her treating doctor realized that she has cystic fibrosis, but no one in the audience got it. No one in the audience figured it out.
I think that really speaks to something that data can help with, which is sort of the, I don't want to call it like situational blinders maybe. I've been guilty of this in care. I think it's a thing and then I don't see the other things if that makes sense. And I know it's a recognized phenomenon in misdiagnosis and in the way I read a really fantastic book that was interesting to me by Jerome Groopman called How Doctors Think. It was fun to leave out on my desk and let doctors see I was reading it. And it got lots of laughs. But the ideas about cognitive processing and when you're latched on to a very specific idea based on evidence. For what that evidence is worth. Skin color, race and ethnicity, for some, like basically it's bias and you have these blinders on and you're incapable of seeing the other important pieces. And I think that's one thing that data can actively combat. It isn't this problem, it's this problem. It isn't your presumption of the main issue. It's a lot simpler than that and it's this. It helps us pinpoint where we can improve processes. Data is not to get the provider in trouble. Data is not to call out a healthcare team. Data is not to try to get a hospital in trouble. Data is so we know where the gaps are and we can process improve them. And really data also has to be approached fully through a just culture lens of systemic impacts.

Yeah, it's just what you're saying. And again, thinking about it's not an individual problem, it's a system problem. Our system is ingrained in us because it is really, quite honestly, based in racism and it's based in slavery. And so it is a system that we have to undo, but you don't know what you don't know if you don't measure, right?

Right. No, I couldn't agree more. I also think that as we work with data, i'm hopeful about some of the integrations and the technology platforms that are happening. I don't think they're well actualized yet, just in my experience, admittedly limited, i'm not an informaticist. We're slowly getting to the point where we can measure things better in EMRs and in different clinical care settings. I think there's more knowledge about the operability of those. And I think that it would be helpful to have more data type folks and QI folks engaged in informatics work. Maybe if you're listening to this podcast, you already are and that's why you're listening. But I do think we need to acknowledge that often those are not the folks at the table when decisions are being made about EMR, when we make the decision about how we want to build a platform, because all EMRs, you've seen one, you've seen one, even if they're the same brand, because they have add-ons, they have different packages and they're sort of hybrids. And I think that not having the right qi folks at the table for that, we have a lot of missed opportunities for data collection.

Yeah, and it really makes me think about something that's been very much in the news recently, and that's about artificial intelligence and ChatGPT, and how that's making its way into medicine as well. And I haven't really heard, I'll be honest, I've not done like. Well, I'm not, I was going to say I haven't done a ton of research. I'm going to go back and say I hadn't done any research on this, but I don't know from how much, um, equity is being put into that lens of ChatGPT and AI, or maybe perhaps because it is AI and ChatGPT, maybe race is removed altogether and it's not put into the equation. I have to say that I would be, I think that would be naive to think, I would love for that to be the case, but I would say that would be naive to think that's going to be the case considering we already have algorithms that have been in the healthcare system. You mentioned one, the vbat calculator, and there are others where race has been a factor for these algorithms, um, that have used race as a biological condition and, and, uh, so I, I, like I said, would love to think that race is not involved in AI and ChatGPT, but that hasn't been what we've seen, you know, traditionally.

Yeah, correct. Absolutely. I have a colleague who I was just talking to recently about another type of system at a hospital. It's an emergency call system that I will not mention the name of, and it's a wearable device. And their biggest issue with it is it does not recognize names that are not very westernized, very, you would associate with the United States or the UK. If there were folks from other countries that had what could be traditionally thought of as harder to pronounce names, it won't recognize them. It leads to major inaccuracies when trying to call for help. It also has a very difficult time reading accents of any kind. So even a stronger southern accent, it wasn't picking up the
words correctly. And it's actually in some facilities we were talking about has risen to the level of a safety concern. So I want to be optimistic about AI and some of these things that are coming up, but I think we have to take an incredibly intentional equity approach to them. And as we're bringing new technology and data measurement tools into the facilities that we work with and into the settings of care, there needs to be an equity lens in that space. Thank you for tuning in to AIM for Safer Birth. If you like the show, be sure to follow wherever you get your podcasts so you don't miss an episode.

Veronica - 00:23:53:
And to learn more about the Alliance for Innovation on Maternal Health, visit saferbirth.org. I'm Veronica Gillispie-Bell.

Christie - 00:24:02:
And I'm Christie Allen. And we'll talk with you next time on Aim for Safer Birth. This podcast is supported by the Health Resources and Services Administration, or HRSA, of the United States Department of Health and Human Services, or HHS, as part of an award totaling $3 million annually and is 100% funded by HRSA. The views are those of the hosts and do not necessarily represent the official views of nor endorsement by HRSA, HHS, or the US government.